The Metaphorical Prison

Nurses, adolescents with anorexia nervosa and the formation of therapeutic relationships within a 'behaviour-modification' program

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Doctor of Philosophy
University of Western Sydney
Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

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ABSTRACT

The increasing prevalence and severity of anorexia nervosa among the young has led to an increase in the number of paediatric hospital admissions and readmissions over the years. Moreover, there has been a significant drop in the age of patients being admitted to hospital for treatment. Within these settings, ward nurses fulfil a pivotal role in the care, treatment and, ultimately, the recovery of these young people, undertaking the role of primary care-giver twenty-four hours a day, seven days a week. The nursing literature strongly emphasises the potential of therapeutic nurse-patient relationships in assisting patients towards a sense of healing or recovery. Recognising the importance of the nursing role and the therapeutic relationship, this thesis reports specific, detailed insights into the daily routine of nurses and adolescents with anorexia on a ward, which bases its re-feeding program on behaviour-modification principles (‘The Level System’), and the impact of this program on nurse-patient relationships. Utilising a naturalistic framework, this study explores the experiences of ten paediatric nurses and ten adolescent patients with anorexia nervosa (six current inpatients and four discharged patients) and compares their experiences within this particular behaviour-modification program. The study illuminates the struggles nurses and patients encounter in forming therapeutic relationships within this contextual environment and the “inherent conflict between the opposing logics of treatment based on behaviour-modification, on the one hand, and a therapeutic relationship, on the other” (Shoebridge, 2002, p. 3). In many ways, life for an adolescent with anorexia on the ward mirrored life for a prison inmate. Within ‘The Level System’ program, nurses and doctors became analogous to prison officers. The subsequent themes reflect these similarities. The four major themes that emerged were: (1) ‘Entering the System’, (2) ‘Life within the System’, (3) ‘On Parole or Release’ and (4) ‘Reforming the System’. The study provides positive recommendations for constructive change to improve the lives of both nurses and patients and further enhances lay and professional understandings of the nursing care for adolescents with anorexia within a behaviour-modification treatment program.
Chapter One

INTRODUCTION

“As we grow older we are apt to forget that the despair of the young is even more gigantic and immediately overwhelming than their hopefulness: we never again face such towering walls of misery”

There have been relatively few advances in the treatment of anorexia nervosa over the past fifty years. There remains little consensus among eating disorder experts on best treatment and little predictability on likely outcome. Disconcertingly, the incidence among the child and adolescent population is on the rise and many young people are requiring multiple admissions and intensive treatment within paediatric hospitals. Within these settings, ward nurses fulfil a pivotal role in the care, treatment and, ultimately, the recovery of these young people, undertaking the role of primary care-giver twenty four hours a day, seven days a week (Anderson, 1996, 1997; Newell, 2004). As part of this role, the formation of a therapeutic relationship between nurse and patient can be instrumental in assisting healing or recovery (Anderson, 1996; Geanelllos, 2005; Halek, 1997; McCann & Baker, 2001). Recognising the importance of the nursing role, this naturalistic study set out to investigate whether the formation of therapeutic relationships, between nurses and adolescents with anorexia, were possible within an inpatient behaviour-modification treatment program in Sydney, Australia.

The majority of Australian paediatric inpatient ward programs are based on behaviour-modification principles that focus on supporting the young adolescent to achieve nutritional and medical stability through re-feeding. A study conducted in The Princess Margaret Hospital for Children in Perth, Western Australia, reported that “97% of all inpatient admissions [with a diagnosis of anorexia nervosa] are now for nutritional resuscitation or other physical complications” (McDermott, Gullick & Forbes, 2001, p. 154). Additional motivational or family-oriented therapies and psychological interventions may be initiated while the adolescent is in hospital but are primarily conducted as an outpatient service once the young person is discharged from hospital1 (McDermott et al., 2001; Simonds, Nolan, Madden, Kohn & English, 2000).

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1 One such therapy, the Maudsley model of family therapy, has recently shown much promise in reducing the readmission rates to hospital for children and adolescents with anorexia nervosa and has assisted with recovery in the home setting (le Grange & Lock, 2005a; Rhodes & Madden, 2005). Incidentally, since November 2002, the children’s hospital in this study began to offer the Maudsley model of family therapy as an outpatient service (i.e post-discharge), to all patients and families with anorexia nervosa (P. Rhodes, personal communication, 2004). Research has shown this therapy to be most effective for those who have a short duration of illness and who are under the age of eighteen (Eisler, Russell, Szmukler, le Grange & Dodge, 1997; le Grange, Eisler, Dare & Hodes, 1992; Mitchell & Carr, 2000; Russell, Szmukler, Dare & Eisler, 1987).
Nurses are generally not directly involved in providing family therapy and other psychological therapies and interventions to patients. Instead nurses play a crucial role in the inpatient acute care setting. They support, encourage and guide adolescents with anorexia to progress through the stages inherent within the ward’s behaviour-modification program. Therefore this study will focus on an exploration of therapeutic relationship formation ‘within’ the context of the inpatient ward treatment only (i.e the behaviour-modification re-feeding program). Anderson (1996) stated that inpatient nursing care and management of adolescents with anorexia should be holistic and should focus on the patient’s physical, psychological and emotional needs. First and foremost nurses need to ensure medical stability through adequate nutrition and re-hydration. They are also a role model and teacher in emphasising the deleterious effects, in the short and long term, of malnutrition on both physical and cognitive development. Anderson (1996) claimed, for these adolescents to begin to feel a sense of healing, the maturation of a therapeutic relationship based on trust between nurses and patients with anorexia, is extremely advantageous.

A plethora of nursing literature also strongly emphasises the potential of therapeutic nurse-patient relationships in assisting patients towards a sense of healing or recovery (Geanellos, 2005; Halek, 1997; Stickley & Freshwater, 2002; Stockmann, 2005; Taylor, 1995; Whittemore, 2000; Williams & Irurita, 1998). Within mental health circles, this relationship is seen as the cornerstone of nursing or “the essence of nursing practice” (Moyle, 2003, p. 103). This dyadic relationship is aptly described by McKlindon and Barnsteiner (1999, p. 238) as being “caring, clear, boundaried, positive and professional”.

Many elements are required for the success of therapeutic relationships. The most important element is trust (Martin, 1987; Morse, 1991). Williams and Irurita’s (1998) Western Australian study on the importance of the nurse-patient relationship, demonstrated that a positive connection and a rapport generally needed to be established before trust could be gained within the relationship. However once trust was procured the relationship flourished as the patient opened themselves up to the nurse and felt greater comfort in sharing information. A nurse with good communication skills, a positive attitude and the ability to listen to the patient’s needs and respond in turn, was better equipped to provide optimal patient care and nurturance. The nursing literature asserts that this relationship does take time to develop but is pivotal in promoting well being and recovery.
(Moyle, 2003; Williams & Irurita, 1998). In addition, an American study by Dearing (2004), reported that a solid relationship between patients with schizophrenia and their case manager nurses, assisted these patients with treatment compliance within the community.

Nevertheless, for all the strong support for and emphasis on the importance of nurse-patient relationships, there is also an admission that the task of forming these relationships with adolescents with anorexia is an extremely complex one for nurses (Garrett, 1991; King & Turner, 2000; Ramjan, 2002, 2004), yet very few studies have examined these difficulties in great depth (Ramjan, 2004; Williams & Irurita, 1998). There are several research studies within the nursing sphere that have examined the nurse’s perspective on the positive and negative factors influencing the maturation of nurse-patient relationships within psychiatric settings or community psychiatric settings (Cleary, Edwards & Meehan, 1999; Dearing, 2004; Forchuk, Westwell, Martin, Bamber-Azzapardi, Kosterewa-Tolman & Hux, 2000; O’Brien, 2000), within acute care or generalist settings (King & Turner, 2000; Micevski & McCann, 2005; Morse, 1991; Ramjan, 2002, 2004; Williams & Irurita, 1998) and a limited number of studies have examined the patient’s perspective (Forchuk, Westwell, Martin, Bamber-Azzapardi, Kosterewa-Tolman & Hux, 1998; Moyle, 2003; L. O’Brien, 2001; Williams & Irurita, 1998). No research to date has compared and contrasted insights, from both adolescents with anorexia and their paediatric nurses, into how hospitalisation and day to day nursing practice, within an inpatient behaviour-modification program, impacts on the development of nurse-patient relationships and the significance of this for patient healing and recovery. This thesis ‘bridges this gap’ and addresses this deficit by exploring the insights of paediatric nurses and adolescents with anorexia, who are working and being cared for respectively, within an inpatient behaviour-modification program in Sydney, Australia.

1.1 AIM

This study extended the research I undertook as part of an undergraduate Honours program, in which I examined the formation of therapeutic relationships with adolescents with anorexia from the nurses’ perspective only. My previous research revealed that paediatric nurses working on two separate wards, a medical ward and an adolescent ward, were ‘struggling to develop therapeutic relationships’ with adolescents with anorexia (Ramjan, 2002, 2004). This present study gains specific, detailed insights into the daily
routine of nurses and adolescents with anorexia on a ward, which bases its re-feeding program on behaviour-modification principles (‘The Level System’), and the impact of this program on nurse-patient relationships. Through an in-depth analysis of both the nurses’ and the patients’ perceptions of the ward environment, ‘The Level System’ program and the daily nursing practice within that program, a deeper understanding of the impact of these contextual factors on the formation of therapeutic relationships was elucidated. This study compares and contrasts insights from both nurses and patients so as to obtain an ‘insider’s view’ of the lived experience of ‘working’ and ‘being cared for’ within ‘The Level System’ program. This study also further enhances lay understandings of the nursing care for adolescents with anorexia within a behaviour-modification treatment program. A critique of behaviour therapy and behaviour-modification was not an aim of this study.

As a consequence of this study, recommendations are proposed, which suggest ways in which current nursing practice can be improved to enhance the formation of therapeutic relationships between nurses and patients, within a behaviour-modification re-feeding program. This may well lead to greater nurse satisfaction and fulfilment and could potentially reduce the ‘revolving door syndrome’ for patients. The study also identifies future research needs in the area of adolescent anorexia nervosa.

1.2 BACKGROUND

The increasing prevalence and severity of anorexia nervosa among the young has led to an increase in the number of paediatric hospital admissions and readmissions over the years (Marcus, 2006; McDermott et al., 2001; Rhodes & Madden, 2005). There has also been a significant drop in the age of patients being admitted to hospital for treatment over the years (Anderson, 1997). As a nurse, working part-time on the adolescent ward under study, these facts are extremely worrying for me. It saddens me to see bright young people struggling to overcome the hold this disorder has on them and the toll this then takes on their family members. It concerns me to see nurses’ altruistic attempts eventually turning into heartache when things do not go as planned. I have also directly witnessed the frustration that nurses, patients and family members have experienced with this behaviour-modification inpatient treatment program. Thereby this study was in part stimulated by a desire to reduce this frustration. Through my research I wanted to make a positive difference to the nurses’ and adolescents’ lives. In particular, I wanted the
adolescents with anorexia to have a ‘voice’ and to be heard rather than their ‘voice’ being suppressed as is generally the case with many vulnerable individuals.

The methodology chosen for this study was the ‘naturalistic’ paradigm (Guba, 1981; Guba & Lincoln, 1981, 1994; Lincoln & Guba, 1985). This inquiry is useful in reconstructing and understanding “real-world situations” as they are ‘brought to life’ by the participants within the natural context (Patton, 2002, p. 40). This methodology not only ‘brought to life’ the nurses’ ‘voices’ but also increased the status of adolescents with anorexia by listening to and acknowledging their ‘voices’ as well. The researcher also plays a fundamental part in the research process and in the shaping of ‘human’ constructions (Ford-Gilboe, Campbell & Berman, 1995). Moreover the data obtained from a naturalistic study is ‘context-dependent’ thereby generalisations to other settings are impossible (Guba & Lincoln, 1989; Lincoln & Guba, 1985). As Erlandson, Harris, Skipper and Allen (1993) have pointed out; all aspects of reality are interconnected in some way, “[t]o isolate one aspect from its context destroys much of its meaning” (p. 11). Needless to say, the nurses’ and patients’ perceptions of nursing practice in this study varied within and across participants and were situation and context specific for that point in time. Thus the naturalistic approach was deemed the most appropriate for this study as context was central to understanding the participants’ constructions and the researcher’s interaction with the participants was similarly crucial for uncovering the meanings of participants’ personal experiences (Ford-Gilboe et al., 1995). As I was an active participant, part of the context, this methodology was the most appropriate for this study.

The following chapter (Chapter Two) discusses the context of this study including ‘The Level System’ which is the primary form of treatment provided to adolescent patients with anorexia. Additionally, a brief overview of behaviour-modification therapy and its evolution is provided in Chapter Three as part of the literature review. This overview is provided as part of describing and establishing ‘the context’ for the study (i.e the basis on which ‘The Level System’ was developed and evolved). The purpose is to assist the reader in obtaining a holistic understanding and appreciation of the context of this study within which the participants ‘live’ and ‘work’. This understanding is fundamental within a naturalistic paradigm. As stated earlier, an in-depth evaluation or critique of behaviour therapy or ‘The Level System’ itself was not an aim of this study. Chapter Four: Methodology examines the naturalistic approach in greater depth and detail.

Chapter One: Introduction
All in all this naturalistic study explores the experiences of ten paediatric nurses and ten adolescent patients with anorexia nervosa (six current inpatients and four discharged patients) and compares their experiences within an acute care setting where the principle form of treatment consists of a behaviour-modification program (‘The Level System’). Nurses (who, among all health professionals, spend the greatest amount of time implementing ward programs) and the adolescents themselves, appeared the most qualified to provide knowledge and expertise in this area. The study gains an appreciation of the impact of these contextual factors on forming therapeutic relationships within a program such as ‘The Level System’. A thorough understanding of the complexities can lead to the identification of strategies to improve relationships between nurses and patients. This ultimately will improve the quality of life for young people admitted to the ward with anorexia nervosa.

1.3 SIGNIFICANCE

There continues to be a paucity of research in the area of adolescent anorexia nervosa (Ha, Marsh & Halse, 2003). Much of the literature in the area centres on adult females (Ha et al., 2003) and much of the scientific research that attempts to examine the adolescent population is flawed by the inclusion of adult participants within samples (Kreipe et al., 1995). The majority of research and literature in the area of anorexia nervosa is quantitative in nature and explores issues such as the aetiology of anorexia (Polivy & Herman, 2002), prevalence (Ben-Tovim & Morton, 1990; Wade, Heath, Abraham, Treloar, Martin & Tiggemann, 1996; Wade, Bergin, Tiggemann, Bulik & Fairburn, 2006), the risk factors (Garner, 1993; Kraemer, Kazdin, Offord, Kessler, Jensen & Kupfer, 1997) and the psychological and physical consequences of the disorder (Brown, Mehler & Harris, 2000). Some randomised controlled trials evaluate the effectiveness of certain treatment modalities (Bergh, Brodin, Lindberg & Södersten, 2002; McIntosh et al., 2005) while others examine prevention and screening programs for eating disorders (Chally, 1998; Pratt & Woolfenden, 2002). Some research studies focus on recovery and outcome (Beresin, Gordon & Herzog, 1989; Garrett, 1998; Tozzi, Sullivan, Fear, McKenzie & Bulik, 2003) and there is an abundance of self-help books and personal recovery stories on the market (Hornbacher, 1998; Hutchings & Thornton, 2001; Keeley, 2005).
However the literature continues to assert a strong need for greater qualitative research in the area of adolescent anorexia and adolescent mental health (Buston, 2002; Cameron, Willis & Richter, 1997; Chan & Ma, 2002). Whilst the need for further research is recognised, the response has been limited. Frost, Murphy, Webster and Schmidt (2003) found that leading medical journals, from the disciplines of psychiatry, psychology and medicine, published twice as many articles about anxiety disorders than eating disorders despite these two disorders having similar burdens on health and lifestyle. The authors believed that possibilities for this discrepancy and what they assert is a prejudice, were two fold. They argued that there is a persistent stigma associated with eating disorders which appears deeply entrenched and is compounded by a prevailing notion among health professionals that eating disorders are “self-inflicted” and “not genuine illnesses” (Frost et al., 2003, p. 363). This second issue is explored in Chapter Five: Results.

Gowers, Weetman, Shore, Hossain and Elvins (2000, p. 141) reported, “[a]ll effective treatments are likely to have the potential to cause negative (side-) effects as well as positive benefits. The possible negative consequences of inpatient treatment are under-researched. They may be particularly important for younger subjects”. Negative effects that have been identified include the intensification of a patient’s sense of personal inadequacy and lack of autonomy as a hospitalised patient with anorexia (Gowers et al., 2000). Thus an additional impetus and rationale for this study came from the above findings that inpatient treatment is under-researched within the younger population and that unfortunately there remains a dearth of qualitative research in the area of adolescent anorexia nervosa.

An examination of the daily ward routine and the nursing practice within this behaviour-modification program (‘The Level System’), through the eyes of both its nurses and patients, shed light on ways to enhance therapeutic relationships and resolve the conflict between nurses and their adolescent patients. Consequently this study contributes to our understanding of adolescent anorexia and the establishment of therapeutic nurse-patient relationships.

Chapter One: Introduction

8
1.4 GLOSSARY OF TERMS

Within this thesis the terms ‘adolescents with anorexia’, ‘young people with anorexia’ or ‘patients with anorexia’ refer to adolescents diagnosed with anorexia nervosa. Other terms are defined below:

**The Level System**

The name allocated to the treatment program based on behaviour-modification principles for adolescents with anorexia. The elements of this program are discussed in Chapter Two: Context.

**Behaviour-Modification**

The term stems from behaviour therapy and behavioural psychology and originates back to the early work of psychologist B. F Skinner and his animal studies. Skinner designed a box, known as the ‘Skinner Box’ and animals placed inside this box learned to manipulate their environment to receive food (i.e. press a lever or peck at a key). This learnt behaviour was called ‘operant-conditioning’. It is from Skinner’s original work in ‘operant-conditioning’ that the belief arose, that all behaviour is learned and is both controlled by and a response to the external environment. It is therefore believed that if behaviour is learned it can consequently be ‘unlearned’ (Feldman, 1996, 2002). Behaviour-modification is "a technique for promoting the frequency of desirable behaviours and decreasing the incidence of unwanted ones" (Feldman, 1996, p. 212; Feldman, 2002). Positive reinforcement, negative reinforcement and punishment can be used to elicit ‘behaviour change’.

**Maudsley model of Family Therapy**

The Maudsley model of family therapy was developed in London as an outpatient treatment. The therapy has three phases and is of a year’s duration. In brief during the first phase, the therapy includes parents re-feeding their child in the home with the support of the therapist. Siblings act as emotional supports for the adolescent with anorexia. In the
second phase a transition is made for the adolescent to take control and eat by themselves. In the third and final phase the family as a whole is assisted to resume and progress through the development stage of ‘normal’ adolescence. The main belief of the therapy is that the family is a resource for recovery of the adolescent with anorexia. Unlike earlier forms of family therapy, the Maudsley model rejects that there is some dysfunction within the family which is consequently the root cause of the illness in the child (Lock, le Grange, Agras & Dare, 2001; Rhodes, 2003; Rhodes & Madden, 2005).

There is a separation of the child from the illness as well (Lock, le Grange, Agras & Dare, 2001; Rhodes, 2003; Rhodes & Madden, 2005).

**Rapport**

Rapport is an emotional bond and common understanding that has developed between people as a result of a close and harmonious relationship (Soanes & Hawker, 2005).

**Empathy**

Empathy is the ability to recognise and understand the feelings and emotions of another and to accurately communicate those feelings and their meanings back (Baillie, 1995). Deering and Frederick (2003, p. 53) described empathy as “[t]he emotional knowing of another person”. According to Alligood (1992) empathy can be a natural inherent trait or a trained or learnt skill.

**Trust**

Trust is a complex term to define but generally it is having a strong belief in someone to be reliable, honest and capable in both their words and their actions (Soanes & Hawker, 2005). Deering and Frederick (2003, p. 53) defined trust as “[t]he risk of sharing oneself with another, knowing that one is opening himself or herself to the possibility of hurt, embarrassment, judgment, and disappointment”.

*Chapter One: Introduction*
The therapeutic relationship is a multifaceted and elusive term to define (Welch, 2005). The literature describes many significant elements for a therapeutic nurse-patient relationship. Some of these factors include rapport, trust, respect, empathy, an unconditional positive regard, limit and boundary setting. McKlindon and Barnsteiner (1999, p. 238) described this dyadic relationship between nurse and patient as being “caring, clear, boundaried, positive and professional”. These factors are discussed in detail in Chapter Three: Literature Review.

1.5 OVERVIEW OF THE THESIS

Chapter One has provided an overview of the thesis including the aim, background and significance of this study.

Chapter Two sets the scene for this naturalistic study. It provides the reader with an overview of the ward environment and layout as well as an overview of the elements involved in ‘The Level System’ program. As described earlier, context is central to meaning in naturalistic inquiry. Consequently, the intention is to provide the reader with a holistic understanding of the context in order to make sense of the context-specific interrelationships that are presented in Chapter Five: Results. Chapter Two does not intend to provide the reader with a thorough explanation of the complexities of behaviour-modification principles and theory, as this is outside the scope of this thesis. The thesis is in no way evaluating or critiquing the success of ‘The Level System’ program as a treatment approach.

Chapter Three will briefly examine the history of anorexia followed by a general examination of the condition including its definition, incidence, outcomes, diagnostic criteria, signs and symptoms, aetiology and treatment. The literature review will then focus on a discussion of behaviour-modification programs and the nurse’s role within these programs, paying particular attention to the literature relating to the importance of therapeutic nurse-patient relationships. Finally studies examining the nurse-patient relationship will be explored as well as the patient’s perspective on hospitalisation.
Chapter Four discusses the research approach and the methods employed within this naturalistic study. An examination of the naturalistic paradigm is provided followed by a discussion of how this approach has been applied within this study and how methodological rigour was maintained. This chapter is written from the stance of the 'first person' rather than the 'third person' to be true to the elements of naturalistic inquiry. Similarly parts of Chapter One have been written in the ‘first person’ for the same reason.

Chapter Five discusses the findings of the study. It reveals the adolescents with anorexia and the paediatric nurses', experiential knowledge on how hospitalisation and the nursing practice within an inpatient behaviour-modification program, impact on the formation of nurse-patient relationships. In particular, it illuminates the struggles nurses and patients encounter with forming relationships in this particular environment and provides some positive suggestions for constructive change. Verbatim excerpts from interviews are utilised throughout this chapter to support the interpretation of themes. The themes chosen reflect clear parallels between 'life on the ward' to that of ‘prison life’.

Chapter Six is a further reflection and discussion of the participants' experiences as described in Chapter Five. The major findings of this study are discussed in relation to the literature.

Chapter Seven provides a final re-cap and overview of the study. Some key strategies to improve the establishment of relationships on inpatient wards with programs such as this are offered. It discusses the implications of this study for nursing practice in paediatric hospitals, the directions for future research and the limitations of this study.
Chapter Two

CONTEXT

“Meanings cannot be disconnected from their context...”

*Nagy & Viney, 1994, p. 2.*
2. CONTEXT

In a naturalistic study it is important for the reader to understand and appreciate the context within which the study took place and within which the participants ‘live’ and ‘work’. This chapter is designed primarily to ‘set the scene’ for the study and describes the ward and hospital environment followed by a discussion of the specific aspects of the behaviour-modification program for adolescents with anorexia (‘The Level System’). An understanding of the context will help the reader to interpret the similarities and differences between the nurses’ and patients’ viewpoints of life on the ward, as discussed in Chapter Five: Results.

2.1 THE HOSPITAL

The hospital where the study was undertaken is a large tertiary paediatric hospital in Sydney, Australia. There are, on average, fifty cases of children and adolescents with anorexia nervosa admitted as inpatients each year to this hospital (Marcus, 2006; Rhodes & Madden, 2005). There are approximately one hundred outpatient cases of children and adolescents with anorexia nervosa being treated each year at this same hospital (Madden, 2004). There appears to be an increasing incidence of anorexia nervosa among the young and the average age at onset has fallen below fourteen years (Kohn, 2004; Madden, Kohn, Clarke, Morris & Elliot, in press). Many adolescents are frequently re-admitted for treatment leading to a considerably high readmission rate for anorexia nervosa among the adolescent population. The ages of patients presenting to this children’s hospital with anorexia nervosa have varied from seven years to sixteen years of age\(^1\). One in twenty patients, within this cohort, is male (Madden, 2004).

2.1.1 THE ADOLESCENT WARD

This study was undertaken on a 20 bed adolescent ward. The adolescent ward specifically caters for young people over the age of twelve with a variety of medical and surgical conditions. At any one time four of these beds are allocated to adolescents with

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\(^1\) Two cases of children aged 7 years have presented for treatment at this hospital (Madden, 2004). Predominant mean age of patients presenting to the adolescent ward is 13 years to 14 years.
anorexia. During write-up for this study the number of beds allocated for adolescents with anorexia on this ward was increased to six. Those patients with anorexia under the age of twelve are cared for on another medical ward within this hospital.

This site (the adolescent ward) was specifically selected as it is the site where the researcher is currently employed part-time and a site where both patients and staff expressed a genuine interest and commitment to the study. The medical and allied health team were also supportive of the researcher’s further studies in this area. The researcher’s previous undergraduate research project had also been conducted in this hospital. Consequently, the researcher aimed to extend and further her work on therapeutic relationships by examining what effect the program, the environment and the way nurses practised, had on the formation of relationships with adolescents with anorexia. However a full understanding of this study is not possible without insights into the surroundings in which nurses ‘work’ and adolescents ‘live’.

2.1.1.1 The Ward Layout

Observation is an important element in naturalistic inquiry for “capturing the life” on the ward for the outside observer (Erlandson et al., 1993, p. 96). This feature and its importance in relation to naturalistic inquiry will be discussed in further detail in Chapter Four: Methodology. Below is an example of some of the researcher’s observations in relation to the ward layout. These observations provide the reader with a ‘glimpse into’ or ‘entry into the world’, of both nurses and patients with anorexia nervosa, on an adolescent ward. A floor map will assist the reader on their journey through the adolescent ward (see Appendix A: Floor Map).

2.1.1.1.1 OBSERVATIONS

As you walk down the green carpeted hallway towards the adolescent ward, you will notice that the walls and ceiling are decorated with numerous colourful cardboard butterflies. Some of these butterflies are painted with paints. Others are coloured with crayons, coloured pencils or decorated with glitter, stickers and tinsel. Some butterflies have mottos. Others have poems or sayings on them. For example one particular butterfly has written across its wings: ‘Live Life to the Fullest’. Each butterfly has been uniquely
decorated by the adolescents with anorexia, other ward patients and their siblings. It is an interesting and colourful display that has been produced by the young people from the adolescent ward (see Appendix B: Photograph 1).

As you enter the ward’s main doors, to your left is the nursing station desk. A large semi-circular desk complete with two computers, three phones and a clutter of clipboards containing patients’ observation and medication charts. The butterfly theme pervades the walls and covers a large fire-engine red column that sits midway along the nurses’ desk and extends up towards the ceiling. This area is the main hub of activity for nursing staff. Behind the main nursing station desk is the nurses’ tea room, the Nursing Unit Manager’s office and the medication room.

To your right of the nursing station desk is the informal waiting area known affectionately as ‘The Moroccan Area’. This area was designed by the adolescents with anorexia and other patients on the ward with an artist from the Adolescent Medicine Unit. The main terracotta brown wall has been painted with a sketch of ‘Moroccan city life’. In front of this backdrop are six lounge chairs (see Appendix B: Photograph 2). The adolescents with anorexia sit here when they are having post meal ‘bed rest’, which is an element of their program.

As you pass ‘The Moroccan Area’ there is a corridor to your right. Down this corridor are four rooms with seven beds in total. There are three single rooms and one four-bedded room. There is also an area with a large bathtub, washing machine and dryer facilities. A small office, an interview room, a linen cupboard and the weigh room are also found down this hallway.

Making your way back to the nurses’ desk, opposite the desk and to the right a little, there is a staff board on a wall. This staff board has the names and photographs of nursing staff who work on the ward. Moving around to the left and centre of the nurses’ desk there are three rooms. One is a store-room for supplies and equipment. The middle is the treatment room where procedures are done; such as inserting a nasogastric tube or intravenous cannula and the third room is a dirty utility room where bedpans and urine bottles are stored and cleaned and where large contaminated waste bins are found. On the wall, near the dirty utility room, is a white-board where patients communicate their whereabouts to
staff, if they are leaving the ward at any time. To the left of the nurses’ desk is a small kitchen for parents and staff to use. Two fridges are found in this kitchen. One fridge has general drinks and food for all patients while the other fridge is for special high calorie supplement drinks. These supplement drinks or ‘feeds’ as they are generally called, are sent up primarily for the adolescents with anorexia. Beside the entry to the kitchen there is a small area, visible from the nurses’ desk, where a snack trolley resides and where all the meals are placed when they arrive from the hospital’s main kitchen.

Walking past the food area, you are confronted with a second, longer corridor. As you walk down this hallway, to your immediate left is another interview room. As you continue your way down there are a further seven rooms with thirteen beds in total on both your left and right hand sides. There are three single rooms, three twin bed rooms and one four-bedded room. As you pass the interview room, the first room to your right is the four-bedded room. This room is normally designated for the adolescents with anorexia. This room has one combined shower and toilet. Each of the four bedsides in this room is individually decorated by each current incumbent with posters or photos of their family, friends and pets. The beds in this room are usually covered with eiderdowns from home rather than hospital linen. There are stuffed toys on beds, flowers by bedsides and ‘Get Well’ cards on bed boards. Each bedside has its own television set (connected to the hospital’s Starlight Channel and Radio Bedrock), nurse call buzzer and reading light. This room is chosen for the adolescents with anorexia because it is in close proximity to the nurses’ station. The patients with anorexia nervosa that require ‘specialling’ or to be nursed ‘one-to-one’ are usually placed in one of the single rooms on the ward. ‘Specialling’ or ‘one-to-one’ nursing means a single nurse remains with this patient twenty-four hours a day. The patient is never out of the nurse’s sight. Whilst ‘specialling’ is not presently a routine part of the program and now seldom occurs on the ward, a couple of the discharged adolescents in this study described earlier admissions when they had been placed on ‘specialling’ orders because of non-compliance with the program.

As you continue down this longer corridor, half-way down you will see a framed set of photographs on the wall of some of the adolescents with anorexia with staff and patients from the ward. Opposite this you will see a large glass cabinet filled with photographs of staff and patients both past and present. Strategically placed on the walls around the ward will also be the weekly schedule, designed by patients, of the activities for the afternoon

Chapter Two: Context
Group sessions. Group takes place each weekday and all adolescents that are medically stable must attend. It is an opportunity to spend an hour off the ward doing art, craft or discussing adolescent issues with the artists, social workers and occupational therapists from the hospital.

At the very end of this corridor there is a large room which is a combined more spacious kitchen and games room. There is a dining table covered in a tablecloth that was designed by patients, mainly the adolescents with anorexia, from the ward. The adolescents with anorexia sit with a nurse in this larger kitchen and at this dining table for all their meals and snacks.

The games room is complete with video-players, a funcentre (a mobile machine that plays DVD’s and houses a variety of movies and computer games), Playstation and X-Box machines and games, a pool table and air hockey table. The patients may take the mobile video-players and games machines to their room if they like. Within the games room, there is a small adjoining room that houses a selection of art and craft supplies for the adolescents and in the courtyard outside the games room there is a basketball ring. Finally, every Saturday morning, without fail, a volunteer arrives to the ward and spends time making balloon animals, doing magic tricks or card tricks for those adolescents who remain on the ward.

These are but a few of the researcher’s mental observations of the ward and its layout. These observations are an attempt to enrich the reader’s understanding of the ward environment under study. What now follows is a description of the inpatient program for adolescents with anorexia.

2.2 THE INPATIENT PROGRAM

Two main departments within the hospital (The Department of Psychological Medicine and the Adolescent Medicine Department) are involved in the care of adolescents with anorexia. A large multidisciplinary team consisting of nurses, physicians, psychiatrists, psychologists, dieticians, social workers, occupational therapists, physiotherapists, school teachers, artists and chaplains all play an important role in providing services to patients with anorexia nervosa while an inpatient (Simonds et al., 2000).
2.2.1 THE PHILOSOPHY

The philosophy of the inpatient program (‘The Level System’) as described in the policy document is as follows:

The philosophy of the inpatient program is to provide a supportive, therapeutic structure, which enhances the opportunity for children and adolescents, with an eating disorder to return to a healthy weight and healthy eating pattern within the context of their families and peers. The aim is to provide an age appropriate ward milieu in which the young person will spend time with peers from a variety of backgrounds with varying medical conditions where the sense of recovery and wellness is fostered. This developmentally appropriate environment supports the medical and nursing management of the disorder while facilitating psychosocial interventions.

(Simonds et al., 2000, p. 2).

Of particular interest is the fact that the current program document (‘The Level System’) does not explicitly make mention of the therapeutic relationship. The therapeutic relationship is cited only once throughout the entire 13 page document².

2.2.2 DESCRIPTION OF THE PROGRAM

The program is ‘loosely’ based on behaviour-modification techniques and is known as ‘The Level System’ by both patients and staff. There are four levels currently in place (see Appendix C: The Levels). Patients are either admitted to the ward on Level One or Level Two depending on their medical and psychological state on arrival. Progression up the levels occurs as a patient improves both from a medical and psychological standpoint. The program aims for a kilogram of weight gain each week (Simonds et al., 2000).

Most major decisions are made by the treating doctor in collaboration with the multidisciplinary team members at the Tuesday and Friday meetings. Any outcomes from the meeting are passed on to the patient and their family. The program intends to offer “clarity, medical safety and consistency” for the patient and family and attempts to provide

² Nurses, in collaboration with medical professionals, were involved with the development of the program guidelines. Perhaps these nurses and doctors were not cognizant of the value of therapeutic relationships for a patient’s healing and recovery as evidenced by the disregard they show for this concept within the policy document.
personalised activity and meal plans to accommodate the individual patient’s needs (Simonds et al., 2000, p. 2).

Adolescents with anorexia admitted to the program are expected to follow the ‘Anorexia Program Ward Timetable’ which schedules the times for all meals and snacks as well as the times for school, group activities, physiotherapy sessions and free time (see Appendix D: Ward Timetable). Most of the adolescents on this program are also prescribed multivitamin and phosphate supplements. Some patients may also be prescribed antidepressants or anxiolytics if there is evidence of an additional co-morbidity such as depression, anxiety or obsessive-compulsive disorder (Simonds et al., 2000).

During the adolescent’s admission, planning takes place between the treating team, the patient and their parents for discharge back into the home environment. Similarly, the hospital school liaises with the patient’s regular school to assist with a smooth transition back into school life. The treating team discusses with the patient and family the goals and expectations of the program, the estimated length of stay and a pre-determined minimum healthy goal weight is set for discharge (Simonds et al., 2000).

The adolescents with anorexia are generally placed under the care of either one of the main consultants namely, the Adolescent Physician or Child and Adolescent Psychiatrist within the hospital. In most instances, these two doctors work together collaboratively in the management of eating disorder patients (Simonds et al., 2000). However, technically, ward nurses remain the adolescents’ primary care-giver while they are on ‘The Level System’ program as they are available and in contact with the patient twenty four hours a day, seven days a week.

2.2.3 THE ELEMENTS OF THE PROGRAM

Nurses play a critical role in ensuring the adolescents with anorexia adhere to the daily routine and comply with the rules and guidelines of this program. The therapeutic relationship unfortunately is not emphasised within the program. The only time this relationship is mentioned is while discussing the rationale behind the visiting restrictions of the program. The program describes: “[t]o facilitate the development of therapeutic relationships between patient and staff, and to provide respite for both patient and family,
initially visiting is limited to immediate family…” (Simonds et al., 2000, p. 4, italics added). As primary care-givers within a program like ‘The Level System’, nurses would theoretically be in a prime position to form these relationships with adolescents with anorexia. Brief explanations of the most important elements of the program are discussed below so as to further assist the reader with their understanding of the ward’s ‘Level System’ program.

2.2.3.1 ‘Bed Rest’

‘Bed rest’ is used to reduce the exertion of energy by those patients that are medically unstable. ‘Bed rest’ entails sitting or lying on the patient’s own bed. The patient may or may not be able to use the bathroom. If allowed to walk to the bathroom, the patient must first ‘buzz’ for a nurse and will be escorted there and back by a nurse. If not able to use the bathroom, the patient will be provided with a bedpan or urine bottle by the nurse and the cubicle curtains around their bedside will be closed. The patient will ‘buzz’ the nurse when they are finished. Patients on ‘bed rest’ spend their time engaging in activities such as watching television, reading, doing art and craft, journal writing or chatting with peers and family (Simonds et al., 2000).

2.2.3.2 Post Meal ‘Bed Rest’

Following main meals (breakfast, lunch and dinner), patients are required to sit for thirty minutes on lounge chairs near the nurses’ station desk where they can be observed (‘The Moroccan Area’). During this time patients are not to visit the bathroom (Simonds et al., 2000).

2.2.3.3 Leaving the Ward

Nurses are accountable for the adolescent’s well-being and safety whilst on the program. If patients are allowed to leave the ward, they need to inform the nurse looking after them and write their name and any details on the ward’s white-board. Certain levels of the program allow a patient to leave the ward with their parents, a nursing staff member or responsible adult for a prescribed period of time (Simonds et al., 2000).
2.2.3.4 Visitors

The program restricts visiting to enable families to “relinquish” the “responsibility” of care to the ward staff and treating team\(^3\) (Simonds et al., 2000, p.4). The time apart enables the family to have respite from battling with the adolescent over food and eating issues and enables the staff greater time to connect with patients and establish therapeutic relationships. Visiting is initially restricted to immediate family only (parents/guardians and siblings) for a maximum of two hours each weekday and three hours on weekends. The rationale behind the above is to allow families to gradually “reconnect” with the adolescent in a more positive way without focusing solely on food and weight gain (Simonds et al., 2000, p. 4). Families are encouraged to visit together, however if this is not possible, the period of ‘separate’ visits cannot exceed the prescribed total hours. Visiting must occur outside program and activity times, including meal times, and therefore it is usually best that family visit in the evenings. Once on Level Three of the program, visitors can include one other relative and this may be an aunt, uncle or grandparent (Simonds et al., 2000).

2.2.3.5 ‘Gate-Pass’

When a patient reaches Level Three of the program they may be offered ‘gate-passes’ on the weekend. ‘Gate-passes’ are dependent on compliance, weight gain and psychological improvement. A half day ‘gate-pass’ means a patient may have one main meal and one snack off the ward with family. In most instances, patients leave the ward after breakfast and return before afternoon tea. Full day ‘gate-passes’ mean a patient may have two main meals and two snacks off the ward with family. In most cases, patients leave the ward after breakfast and return before supper. ‘Gate-passes’ are also further classified as internal or external. Internal means the patient and family must remain within the hospital grounds at all times. Conversely, external means they may leave the hospital grounds after signing documentation. ‘Gate-passes’ are an opportunity for the young person to re-integrate themselves back into family life and for the family to partake in meals together as a unit. Any difficulties while on ‘gate-pass’ can be discussed with nursing staff on return to

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\(^3\) This restriction could be seen as contradictory and potentially detrimental in a family-centred philosophy. However, in many cases family relationships have become strained to the point that family members feel a consuming sense of duty to ensure the patient eats enough food. The patient, in many cases, reacts negatively to this parental/family pressure and thus a period of respite assists with restoring these relationships (Simonds et al., 2000).
the ward. ‘Gate-passes’ may also be approved for special circumstances such as birthdays or important school events (Simonds et al., 2000).

2.2.3.6 Meals and Supplemental Feeds

Nurses remain in the dining room with patients for all meals and snacks to supervise the meals and encourage normal eating habits. The program requests that family do not bring in food from home so that nurses can accurately monitor the patient’s nutritional and caloric intake (Simonds et al., 2000). At the end of this chapter some of the rules in relation to mealtimes for an adolescent with anorexia on the program are outlined (see Table 1: Mealtime Guidelines).

The dieticians, in consultation with the team, will decide on a meal plan to suit each individual’s energy requirements. The patient will be expected over time to slowly increase the variety and amount of foods eaten. Patients may be on a ‘meal plan’ (food only) or a ‘bolus-exchange’ meal plan (food and supplements) (see Appendixes E & F: Meal Plans). The ‘bolus-exchange’ meal plan designates an equivalent amount of supplemental feed next to each item on the meal plan. Any item that has not been consumed completely by the patient requires the patient to have the ‘full bolus’ amount of feed either orally or down a nasogastric tube (Simonds et al., 2000).

Supplemental feeds are usually given via a nasogastric tube. The feeds are usually high calorie supplements called ‘Ensure’ or ‘Ensure Plus’. Patients on continuous or overnight feeds will be on ‘bed rest’ while feeds are being administered in a bag through a feeding pump. The pump is attached to a non-mobile pole at the head of the patient’s bed. The nurse will disconnect the patient from the feeds if they require the use of the bathroom. For those patients on a ‘bolus-exchange’ meal plan, they may be allowed to drink their supplemental boluses if they do not have a nasogastric tube. Otherwise the supplemental ‘bolus’ feed is either syringed down their nasogastric tube by a nurse (if it is a small amount of feed) or given via a bag using a feeding pump (Simonds et al., 2000).
2.2.3.7 Weights

A patient is weighed by the night staff on duty each Tuesday and Friday morning. Patients will be provided with a gown and a urine bottle or bedpan. Patients are asked to void behind their cubicle curtains prior to the weight being taken. The nurse measures the amount of urine and then tests the urine for its pH and its specific gravity (concentration) using a dipstick. The patient is weighed in their underwear with a hospital gown on. At times spot weighs or random weighs may be attended by staff if there is uncertainty regarding the correct weight of the patient or considerable discrepancies with weight from one week to the next (Simonds et al., 2000).

2.2.3.8 School, Group, Physiotherapy and Other Therapies

Every adolescent is expected to attend the hospital school daily when medically stable. Primary school runs from 9am to 3pm each weekday except Friday when classes finish at 12.30pm. Patients return to the ward for their morning tea and lunch. For secondary students, school runs from 9am till 12.30pm each weekday. Patients return to the ward for their morning tea. The hospital school liaises with the patient’s regular school in order to keep the patient up to date with their work (Simonds et al., 2000).

Group is held each weekday from 2pm to 3.30pm. Again all adolescents are expected to attend if medically stable. These sessions are organised and coordinated by a group of occupational therapists, artists and social workers. Activities may include arts and crafts, discussion and relaxation sessions or activities to encourage socialisation (Simonds et al., 2000).

Once medically stable a physiotherapy program is created to suit each adolescent’s individual needs. The program aims to restore and strengthen muscle tissue through stages of stretching, strengthening and aerobic exercises. Exercise apart from the physiotherapy sessions is to be avoided while on the program. The opportunity to exercise unobserved in the bathroom is minimised by limiting showers to ten minutes only once a day (Simonds et al., 2000).
Lastly, other psychological therapies may be provided to individual patients and families depending on their needs while in hospital (Simonds et al., 2000). Since November 2002, all families with an adolescent with anorexia are offered family therapy as an outpatient service, as discussed earlier in Chapter One.

This chapter has provided the reader with an overview of the ward layout and a description of ‘The Level System’ program. The following chapter provides a review of the literature in the area of anorexia nervosa with particular attention to the therapeutic relationship in nursing.

**Table 1: The Main Mealtime Guidelines for Patients with Anorexia**

<table>
<thead>
<tr>
<th>MEALTIME GUIDELINES</th>
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</thead>
<tbody>
<tr>
<td>• Main meals are thirty minutes and snacks are twenty minutes</td>
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<tr>
<td>• Must be escorted to and from the dining room with your nurse to have your meals</td>
</tr>
<tr>
<td>• Eat and drink only what is on your tray</td>
</tr>
<tr>
<td>• Do not swap items that have been sent to you</td>
</tr>
<tr>
<td>• Everyone needs to remain in the dining room until the end of the mealtime</td>
</tr>
<tr>
<td>• Please eat at a normal pace and be courteous to one another and staff</td>
</tr>
<tr>
<td>• Use appropriate cutlery and utensils for what is being eaten</td>
</tr>
<tr>
<td>• Please remain seated once meals have started. Ask your nurse if you need something</td>
</tr>
<tr>
<td>• After meals let your nurse check your tray before placing them back on the trolley</td>
</tr>
<tr>
<td>• Please do not bring food from home</td>
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<tr>
<td>• One vegetarian meal allowed per week</td>
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<tr>
<td>• No salt allowed with meals</td>
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<tr>
<td>• Vegemite allowed only at morning tea</td>
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<tr>
<td>• Water is not permitted on the meal plan</td>
</tr>
<tr>
<td>• 1/4 packet of margarine per slice of bread or bread equivalent (3 pikelets, 3 jatz, 3 vita-wheat)</td>
</tr>
<tr>
<td>• Additional toppings such as honey and jam must be included as a topping along with the margarine. The exception being, croissants require toppings but do not require butter or margarine</td>
</tr>
<tr>
<td>• Juices are not to be frozen</td>
</tr>
<tr>
<td>• Milk is not to be heated</td>
</tr>
<tr>
<td>• Bread can be toasted under supervision</td>
</tr>
</tbody>
</table>

Adapted from the ‘Anorexia Nervosa Program’ (Simonds et al., 2000)
“To be sure, anorexia is numbing: When you never feel good enough or worry that you could have done more, been more, or tried harder, it’s a way to escape the ache that lingers in the belly. In addition, anorexia is filling: It fills that emptiness in the belly and squeezes out the room for food”

Keeley, 2005, p. 145
3. LITERATURE REVIEW

The literature review provides a brief history of anorexia nervosa and explores its roots within medieval life. This is followed by a formal definition and general overview of the condition including diagnosis, incidence, signs and symptoms as well as a brief look at some aetiology and treatment issues. The literature review then explores in depth the nurse’s role in caring for adolescents with anorexia within an inpatient setting and the significance of the nurse-patient or therapeutic relationship, establishing its theoretical importance for the adolescent’s healing and ultimate recovery. Particular attention will also be given to the literature discussing the impediments to the formation of therapeutic nurse-patient relationships within such a setting.

3.1 HISTORY OF FOOD REFUSAL

Historically prolonged fasting and self-abnegation date back to medieval Europe during the 13th–16th centuries. The ‘food refusal’ generally developed during adolescence and predominantly affected females. Some historians believe this religious practice was a method by which female ascetics attained a sense of personal liberation. Control of the body through fasting and self-flagellation allowed these women to demonstrate their power and control and their ability to rebel against the fervently held family and patriarchal ideologies of the time, regarding women, marriage and childbirth. ‘Holy anorexia’ enabled these women to forge an identity in opposition to the norm (Bell, 1985; Gordon, 2000).

Female mystics were influential women of the time. Religious visions, extreme fasting and the performance of miracles for the sick and needy contributed to this fame. The preoccupation with food and intransigent abstinence was a mode for expressing their suffering and devotion to God whilst denouncing traditional expectations (Brumberg, 1988; Bynum, 1987). Many of these women strove to achieve an unprecedented feat, ‘spiritual authority’ and equality in a male-dominated Church (Gordon, 2000). For mystics like Saint Catherine of Siena, “to yield to food was to yield to sin, to deceive God, to lose all the power that she had laboriously garnered, erasing the sense of identity gained from the victory over her opposition to family regulation” (Reda & Sacco, 2001, p. 44).
Parallels exist between the contemporary experience and motivation of anorexia nervosa sufferers and the medieval mystics’ plight for control and power through suffering. Egan (1999) describes the similarities between medieval mystics and modern day eating disorder sufferers in a media article she wrote for The New York Times Magazine. Egan (1999) commented on how the late Diana, Princess of Wales, publicly exhibited her strong virtues of compassion, kindness and charity through many humanitarian efforts yet these selfless acts disguised her own personal sufferings and demons including her bouts with anorexia, bulimia and self-mutilation.

Religious and moral sentiments continue to pervade the thinking of many people with anorexia who strive to be the thinnest and the most ‘pure’ by restricting their eating. Even though our culture overtly deplores these attitudes, food advertising campaigns continue to endorse the ‘immorality’ of food. For example companies use food connotations such as ‘wicked’ and ‘sinful’ to describe and promote products and unconsciously substantiate this negative thinking.

3.1.1 THE TRANSFORMATION OF ‘FASTING’ OVER TIME

The ‘practice of fasting’ has undergone numerous transformations throughout history and within differing cultural contexts (Brumberg, 1988; Vandereycken & van Deth, 1996). During the Middle Ages it was seen as “saintly” yet by the time of Reformation it was seen as being “inspired by the devil” and then later again these particular women became “objects of wonder and notoriety” (Beumont, 1991, p. 10). It was not until the late 19th century that prolonged fasting was considered a medical condition. A French psychiatrist Louis-Victor Marcé produced the first classical descriptions of anorexia nervosa in 1859. Dr Ernst-Charles Lasègue and Sir William Gull are honoured with publishing the first medically documented accounts of anorexia nervosa as a mental illness in 1873 (Beumont, 1991; Vandereycken & van Deth, 1996).

The medicalisation of anorexia nervosa as an illness has resulted in its treatment within both outpatient and acute care inpatient settings. However over the past fifty years there have been relatively few advances in the management of this chronic life-threatening illness. No single treatment appears to be superior to another with many people recovering without professional involvement (Ben-Tovim, 2003; Ben-Tovim, Walker,
Gilchrist, Freeman, Kalucy & Esterman, 2001; Beumont, Hay & Beumont, 2003; Garrett, 1998). What is concerning is the fact that a growing number of young children and adolescents seem to be plagued with this ‘illusion of control’ expressed through their extreme eating restraint and control over weight and food intake. Because they are medically compromised, many are requiring multiple and intensive acute care admissions in paediatric hospitals where nurses are their primary care-givers twenty-four hours a day (Anderson, 1996, 1997; Newell, 2004). It is because of the significance of nursing care in these instances that this thesis has evolved and is important. The nursing care and the establishment of a relationship of therapeutic value between nurses and the adolescent with anorexia can be a vital element in their progression towards healing or recovery from anorexia nervosa (Swain-Campbell, Surgenor & Snell, 2001), yet often the formation of this relationship is particularly challenging for nurses (Garrett, 1991; King & Turner, 2000; Ramjan, 2002, 2004).

What now follows is a brief overview and introduction to the condition, including a formal definition, the incidence, outcome, diagnosis, signs and symptoms, aetiology and treatment. Then an in-depth exploration of the nursing literature is presented, with particular attention to the nursing care of adolescents with anorexia, the importance of therapeutic nurse-patient relationships for healing, the factors fostering and the obstacles inhibiting this relationship in differing nursing contexts and finally the patient’s perspective on hospitalisation.

### 3.2 DEFINITION

The Latin term ‘anorexia nervosa’ literally means ‘a nervous loss of appetite’; however this is far from the truth (Sobel, 1999). People with anorexia do not have any loss of appetite; sufferers intentionally refuse to eat sufficient amounts to maintain a healthy body-weight for fear of becoming fat (Gilchrist, Ben-Tovim, Hay, Kalucy & Walker, 1998; Perry, 2002). Despite being underweight the person perceives her or himself to be overweight and may persist with engaging in dangerous weight loss practices, such as restricting food, over-exercising, vomiting or misusing laxatives and diuretics (Duker & Slade, 2003). People with anorexia have an intense preoccupation with restricting their eating, controlling body weight and food intake (Mental Health Information Service, 2001).
Anorexia nervosa does not fit neatly into either a ‘physical illness’ category or a ‘deliberate action’ category. It appears to possess characteristics of both categories, “in which a person’s actions are constrained and have progressively become so as a result of physical and psychological changes that are self-induced” (Duker & Slade, 2003, p. 12).

3.3 INCIDENCE

Anorexia nervosa is a potentially life-threatening eating disorder predominately affecting adolescent females. The incidence of anorexia nervosa is on the rise among the adolescent population (American Academy of Pediatrics, 2003; Fisher et al., 1995; Kreipe et al., 1995; Lask & Bryant-Waugh, 2000), with anorexia nervosa being the third most common chronic medical condition among teenage girls after obesity and asthma (Beumont, 2000). Various studies estimate the point prevalence worldwide to be between 0.5%-0.7% of teenage girls (Beumont, 2000; Emans, 2000; Gilchrist et al., 1998; Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for Anorexia Nervosa [RANZCP CPG Team for Anorexia Nervosa], 2004; Fairburn & Harrison, 2003). Statistics indicate 90-95% of sufferers in the general population are female (Beumont, 2000) with males representing the other 5-10% of people with the condition (Andersen & Holman, 1998; Golden, 2003; Hoek, 2002). More males are seeking treatment (Braun, Sunday, Huang & Halmi, 1999), with reported incidence as high as 30% among males in the child and adolescent population (Rees, 2005). However, the incidence of anorexia nervosa in the general population may potentially be even higher as these recorded figures are based only on those that present for treatment.

Anorexia can affect a person of any age, ethnicity or socio-economic background (Rome, 2004), however typically the peak age of onset is between 13 and 15 years (Golden, 2003). Two Australian studies indicate the point prevalence in the community to be 0.1%-0.4% (Ben-Tovim & Morton, 1990; Wade et al., 1996). In New South Wales, Australia approximately 5,000 people are afflicted with anorexia nervosa at any point in time and research indicates there are 400 newly diagnosed cases each year (Beumont, 2000). Mortality and morbidity rates are devastatingly the highest of any psychiatric disorder (Garner, 1997; Palmer, 2003) with two-thirds of all deaths a result of suicide or overdose (Duker & Slade, 2003).
3.4 OUTCOMES

A comprehensive long term outcome study by Steinhausen (2002) estimated mortality rates of 5% among the 5590 patients studied. Steinhausen (2002) had reviewed 119 outcome studies in anorexia, published in English and German, over the period 1953 to 1999 to reach the above conclusion. According to Litt (1995) within the adolescent population mortality rates are greater than 10%. While other studies estimate mortality rates as high as 20% after 20 years (Beumont, 2000; Grothaus, 1998; Walling, 2000).

Overall outcome varies with most research in the area estimating 40% of sufferers recovering in 5 years, 40% remaining symptomatic but able to cope sufficiently with symptoms and 20% remaining chronically unwell (Ben-Tovim, 2003; Ben-Tovim et al., 2001; Gilchrist et al., 1998; Steinhausen, 2002). Outcomes appear comparatively healthier for the adolescent onset sufferers (le Grange & Lock, 2005b) who have better recovery rates and a lower mortality; approximately 0.5% annual mortality (Kohn, 2004). Studies show that a shorter duration of illness and a young age at onset lead to a more promising prognosis following treatment (Fisher et al., 1995; Fisher, 1996; Hsu, 1980; Treasure & Schmidt, 2002). The few long-term follow-up studies in adolescent anorexia nervosa indicate more than two-thirds recovering (Herpertz-Dahlmann, 2002; Strober, Freeman & Morrell, 1997; Theander, 1996).

However, there still remains a paucity of long-term (greater than ten years) outcome studies in the area of adolescent anorexia and unfortunately leading experts believe there are methodological flaws and other limitations within the study designs of these outcome studies thereby deeming results questionable (Ben-Tovim, 2003). According to experts in the field, many sufferers believed to have ‘recovered fully’ have not restored normal eating habits or a completely normal lifestyle (Beumont, Russell & Touyz, 1993). In fact, many young people diagnosed with anorexia during adolescence continue to battle ongoing health problems and difficulties with psychosocial adjustment in adulthood (Striegel-Moore, Seeley & Lewinsohn, 2003).
3.5 DIAGNOSTIC CRITERIA

Like the outcome studies above, limitations are also inherent within the diagnostic criteria for adolescent anorexia nervosa (Bryant-Waugh & Lask, 1995; Nicholls, Chater & Lask, 2000; Walsh & Kahn, 1997). The criteria used to classify anorexia nervosa include the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000) [see Appendix G: DSM-IV-TR] and the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (World Health Organisation, 1992) [see Appendix H: ICD-10].

These criteria overlook children and adolescents with anorexia, as they do not take into account "[t]he wide variability in the rate, timing and magnitude of both height and weight gain during normal puberty, the absence of menstrual periods in early puberty along with the unpredictability of menses soon after menarche" (Golden et al., 2003, p. 496). Child and adolescent cognitive development is also not taken into consideration (Golden et al., 2003), along with the fact that boys will not meet the DSM-IV amenorrhea criteria (Farrow, 1992). Though the ICD-10 does refer to pubertal delay and lowered hormonal levels in boys and men (Watson & Andersen, 2003), its criteria regarding a body mass index (BMI) of 17.5 or below, would be ‘normal’ for a child or adolescent under the age of 15 (Bryant-Waugh & Lask, 1995). Clearly both diagnostic criteria may be unreliable in diagnosing child and adolescent anorexia and revisions are necessary.

3.6 SIGNS AND SYMPTOMS

3.6.1 PHYSICAL EFFECTS

In anorexia nervosa, most organs of the body are affected by malnutrition. However most of the physical effects are reversible with adequate restoration of nutrition. Physical effects include amenorrhea, cyanosis, sensitivity to the cold, 'lanugo' (fine hair growth over the body), hypotension, bradycardia, dry skin, hair loss, fatigue, muscle weakness, gastrointestinal problems, poor concentration, weight loss, urinary tract infections, growth and pubertal retardation, structural brain changes, hyperactivity and impaired peak bone mass (predisposing to osteoporosis and fractures) (Brown et al., 2000; Murphy & Manning,
Cardiac abnormalities, in particular, can be life-threatening for children and adolescents with anorexia (Brown et al., 2000; Kohn, Golden & Shenker, 1998; Rome & Ammerman, 2003).

### 3.6.2 Psychological Effects

The psychological effects of malnutrition include major impairments to intellectual functioning. Normal complex thoughts succumb to the ‘anorexic mindset’. Thinking becomes progressively more ‘black-and-white’ as weight continues to fall (Duker & Slade, 2003). The sufferer in a sense believes “if my weight is right, then I am all right [sic] and if I am thinner then I must be a better person” (Gilchrist et al., 1998, p. 438).

The person with anorexia becomes totally preoccupied with thoughts of food, exercise, body shape and weight. They usually deny the seriousness of low body-weight or deny anything is wrong. They generally have low self-esteem and feelings of inadequacy or ineffectiveness. The quote at the start of this chapter describes the sense of accomplishment the sufferer gains by restricting their eating, which then ‘symbolically’ fills the void they feel inside. Sufferers also experience major difficulties with food activities yet fear the disapproval of others. This may lead them to secrete food, socially withdraw from activities with peers and family, eat alone or miss meals to avoid others detecting their symptoms (Beumont, 2000; National Mental Health Strategy [NMHS], 1998, 2000; NSW Mental Health Information Service, 2000).

Characteristically sufferers are high achievers and perfectionists. They may isolate themselves and become very organised and rigid in their routines. Mood swings, anxiety, depression and thoughts of suicide may be common (NMHS, 1998, 2000; Touyz & Beumont, 1999). Feelings and emotions may progressively become more labile and when weight loss is severe, sufferers may feel a sense of ‘detachment’ from the world (Duker & Slade, 2003). This ‘detachment’ can often invoke in the person a “haughty attitude”, “aloofness” or a “distant superiority” (Duker & Slade, 2003, p. 32). The two most common co-morbidities associated with anorexia nervosa are depression and obsessive-compulsive disorder (OCD) (Beumont et al., 2003). As with the physical effects, the psychological effects of starvation often recede as weight is gained (Plenderleith, 2001).
3.7 AETIOLOGY

There remain no clear answers as to what causes anorexia nervosa. Researchers believe a culmination of biological, psychological, familial and socio-cultural risk factors are involved. It is best described as a ‘multifactorial’ or ‘biopsychosocial’ eating disorder (Garner, 1993; Polivy & Herman, 2002; White, 2000). The list of potential causative risk factors is enormous and an exhaustive discussion of each of these is outside the scope of this thesis. A number of the most commonly cited potential risk factors for developing adolescent anorexia nervosa are described briefly below.

3.7.1 BIOLOGICAL

Researchers have shown that biological factors believed to play a part in the onset for children and adolescents include heredity (Hewitt, 1997; Treasure & Holland, 1995; Walters & Kendler, 1995) and the chemical or hormonal changes associated with puberty (NMHS, 2000). Walter Kaye, an American psychiatrist and researcher, believes strongly in the genetic contribution to vulnerability in eating disorders and reported “genes load the gun by creating behavioural susceptibility factors such as perfectionism or the drive for thinness…[e]nvironment then pulls the trigger” (Lamberg, 2003, p. 1438). Studies also illustrate that a prior history of a physical illness can be a risk factor in the onset of anorexia in children and adolescents (Watkins, Sutton & Lask, 2001).

3.7.2 SOCIO-CULTURAL

Dieting is also considered a major risk factor for the onset of anorexia in young girls and boys (Hsu, 1997; Patton, Carlin, Shao, Hibbert, Rosier, Selzer & Bowes, 1997; White, 2000). This is worrying given that studies show that there is an escalating ‘dieting’ and ‘weight loss culture’ among Australian adolescents (Maude, Wertheim, Paxton, Gibbons & Szmukler, 1993; Nowak, Speare & Crawford, 1996; O’Dea, Abraham & Heard, 1996; Patton et al., 1997; Paxton, Wertheim, Gibbons, Szmukler, Hillier & Petrovich, 1991). Bullying at school, dissatisfaction with pubertal weight gain or comments made by others regarding weight or shape can predispose a young person to diet and exercise (Emans, 2000; Paxton, 2000). The young person’s ability to restrict their eating and maintain
thinness instils for some sufferers a sense of personal achievement, autonomy and a sense of superiority and of being in control, thereby enhancing their own self-esteem and sense of self-worth.

Other socio-cultural risk factors include cultural pressures from Western society regarding weight and shape and the idealisation of ‘thinness’ and ‘beauty’ (Hepworth, 1999; Malson, 1998). Other risk factors for the young include the mass media, advertising and fashion industry campaigners who place undue influence on promoting unrealistic body images to their market audiences as a means to attain success and happiness (Fouts, 2000; Grogan, 1999; Hamilton & Waller, 1993; Thompson & Heinberg, 1999; Tiggemann, 2002). For some young girls and boys this may lead to a ‘vicious cycle’ of unhealthy dieting and exercising to achieve the slender ‘Barbie doll’ or the ‘bulked’ up ‘GI-Joe’ look. Adolescence and the ensuing body changes associated with puberty are also seen as major risk factors (Garner, 1993). Anorexia may become a coping strategy in the face of the demands of adolescence.

3.7.3 FAMILIAL

Seminal work and more recent studies show family environment to be a risk factor, particularly those families with poor communication and conflict resolution skills. These families are generally controlling, value achievement and success, show an over-protectiveness of family members and display little emotional support (Dare, le Grange, Eisler & Rutherford, 1994; Foulkes, 1996; Grothaus, 1998; Horesh et al., 1996; McDermott, Batik, Roberts & Gibbon, 2002; Minuchin, Rosman & Baker, 1978; Selvini Palazzoli, 1974; Shugar & Krueger, 1995). Anorexia may be a mode for the adolescent to express his or her displeasure with the current family dynamic or it may become a bid for autonomy and separation from the family.

It should be kept in mind though that many young people may be exposed to the above potential risk factors, however this does not necessarily predispose them all to go on and develop an eating disorder (Ramjan, 2002). Family dysfunction (Marks, 2002; Wallin, Røijen & Hansson, 1996) and physiological disturbances may be a consequence rather than a cause in the onset of the disorder.

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3.8 TREATMENT

It is this uncertainty in regards to the condition’s aetiology that has lead to a plethora of treatment approaches. The major treatment settings include inpatient hospitalisation, day-patient or outpatient care. The main treatment approaches include family therapy, individual therapy, counselling, cognitive-behaviour therapy, psychotherapy, pharmacological treatments, motivational therapy and behaviour-modification approaches (Gordon, 2000; Perry, 2002). No single treatment has been found to be superior to another in the treatment of anorexia nervosa (Beumont et al., 2003; Finelli, 2001). There continues to be a paucity of research and controlled trials in the area of treatment effectiveness and management of the condition, especially for the adolescent population (Ben-Tovim, 2003; le Grange & Lock, 2005a, 2005b; Rosenblum & Forman, 2002; RANZCP CPG Team for Anorexia Nervosa, 2004; Treasure & Schmidt, 2002).

What is evident is that there has been a disturbing rise in the incidence of young people being diagnosed with anorexia nervosa (Lask & Bryant-Waugh, 2000) and there are high rates of recidivism among this younger population (Russell, Baur, Beumont, Byrnes & Zipfel, 1998). These young people are frequently being admitted in a medically unstable state to paediatric hospitals (Gowers & Bryant-Waugh, 2004) where nurses become their main care-givers on the ward. Research in the area of adolescent anorexia has overlooked the consequences of inpatient hospitalisation (Gowers & Rowlands, 2005; Gowers et al., 2000) and the effect behaviour-modification treatment programs have on therapeutic relationships. This thesis intends to narrow the theory-practice gap, by investigating how hospitalisation and the day-to-day nursing practice, within an inpatient behaviour-modification program impacts on the development of nurse-patient relationships.

3.8.1 TREATING CHILDREN AND ADOLESCENTS

Anorexia nervosa still remains one of the most difficult and confusing conditions to treat and there appears to be a growing trend for the hospitalisation and re-feeding of medically compromised children and adolescents with anorexia nervosa in paediatric acute care settings (Gowers & Bryant-Waugh, 2004). However hospitalisation should always be the
final option when other avenues have failed. Inpatient treatment may be required when there is a need for “crisis intervention”, a “change of environment” or “intensive treatment” (Vandereycken, 2003, p. 412). According to Kronenberg, Nachshoni, Neumann and Gaoni (1994), a paediatric setting rather than a psychiatric setting, has its advantages, as it allows the young person to receive treatment that is therapeutically age-appropriate, using a multidisciplinary approach to care. Additionally, the authors believed this milieu reduces the stigma associated with the disorder, enhancing the cooperation of both patient and family members in treatment (Kronenberg et al., 1994). Fisher and Kaufman (1996, p. 307) are of the same opinion and agreed that adolescents with eating disorders are “best managed on multidisciplinary adolescent units”. Additionally, Kronenberg et al. (1994, p. 169) insisted, that treatment for children and adolescents within these environments will only be successful if they embrace the elements of “consistency, understanding and firm limits”.

Medical professionals themselves believe the re-gaining of weight and nutritional rehabilitation is of utmost importance for this age group, to prevent the deleterious effects of malnutrition on their growth and physical development later in life (American Academy of Pediatrics, 2003; Fisher et al., 1995; Gilchrist et al., 1998). Weight restoration, to achieve a pre-determined ‘goal weight’, is seen as an important part of the recovery process (Rome et al., 2003). Many existing inpatient ward programs, based on behaviour-modification principles, are capable and successful in producing this weight gain (Jarman, Smith & Walsh, 1997; Moorey, 1991) as they provide supportive weight restoration and allow for the monitoring of medical complications within a safe environment (Marks, 2000; Simonds et al., 2000). Beresin, Gordon and Herzog’s (1989) recovery study, found that even though participants (adult women) had pessimistic feelings towards inpatient behaviour-modification type programs, they nevertheless considered hospitalisation as beneficial and some even described it as “life saving” (p. 118). Obviously though, recovery from anorexia nervosa is not as straightforward as weight gain alone (Duker & Slade, 2003). Hospitalisation and weight gain, along with adjunct therapies and interventions, (including the maintenance and subsequent disengagement of a therapeutic relationship), are all important factors for treatment to benefit the adolescent with anorexia.
This thesis focuses on one such inpatient program based on behaviour-modification principles. As discussed in Chapter One, the hospital under study does provide additional therapies on an individual basis to inpatients and discharged patients. These are designed to further improve psychological well-being and resolve underlying psychosocial issues. One such therapy being provided is the Maudsley model of family therapy, which is offered as an outpatient service to all patients once they are discharged from the program. However, these concomitant therapies do not form part of this study. Furthermore, as described in Chapter One, the rationale for the exclusion of these concomitant therapies were firstly, that nurses in this present study were not intimately involved in these therapies and secondly, the participants (both nurses and patients) felt ill-equipped to discuss them. The ward’s re-feeding program (‘The Level System’) is the principal form of treatment for all adolescents with anorexia admitted to this hospital and so the impact of nursing practice and hospitalisation on the formation of relationships within this behaviour-modification program, were the only treatment factors under study. For this reason the literature review is restricted and has been selected in order to provide a broad overview of behaviour-modification programs, essentially to enhance the reader’s understanding of the context of this study. A comprehensive critique of the principles of behavioural modification theory and behavioural theory generally, including the assumptions underlying learning and change is outside the scope of this thesis and is unnecessary to understanding this dimension of the context for this study. Thus, as stated in the introduction, a critique of ‘The Level System’ was not an aim of this thesis.

### 3.8.2 THE ADVENT OF BEHAVIOUR-MODIFICATION PROGRAMS

Much of the literature from the 1960s and early 1970s describes the employment of behaviour-modification techniques, predominantly ‘operant conditioning’ techniques, in managing cases of anorexia nervosa (Knibbs, 1993). As described earlier, the term behaviour-modification stems from behaviour therapy and behavioural psychology and originates back to the early work of psychologist B. F Skinner and his animal studies. Skinner demonstrated that a hungry pigeon in a box eventually learnt to peck at a key to obtain food and satisfy its hunger, that is, the pigeon learnt “that the receipt of food is

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1 As researcher and nurse, I had prior knowledge of the nurses’ and patients’ limited awareness of the concomitant therapies being provided. This was reinforced during interviews as both nurses and patients spoke of a lack of psychological interventions and therapies for adolescents with anorexia.

Chapter Three: Literature Review
contingent on pecking the key” (Feldman, 2002, p. 174). Behaviour-modification techniques, used in the treatment of anorexia nervosa, evolved from this seminal work.

The characteristics and basic principles of behaviour-modification therapy, applied to the treatment of anorexia nervosa, vary within individual programs, but primarily include the use of rewards or privileges for weight gain (positive reinforcement) and alternatively the loss of these for weight loss or failure to gain weight (Clare & Cuthbertson, 1998; Knibbs, 1993). Nasogastric feeding (tube-feeding) may be seen as a form of negative reinforcement, as the threat of a nasogastric tube, can negatively reinforce subsequent eating behaviours (Bruch, 1974; Kellerman, 1977; Knibbs, 1993). However, nasogastric re-feeding is generally initiated when a patient is medically compromised (Simonds et al., 2000). In contrast, a reduction in the amount of supervision or avoidance of bed rest, being made contingent on weight gain, represents as positive reinforcers (Jenkins, 1987).

Some of the earliest behaviour-modification programs removed all possessions, leaving the patient alone in their room devoid of radio, television, bathroom privileges, reading materials, phone calls or visitors, with the gradual re-instatement of these comforts, as weight was gained (Bachrach, Erwin & Mohr, 1965; Biley, 1989; Bruch, 1974; Clare & Cuthbertson, 1998; Moorey, 1991). According to Duker and Slade (2003, p. 69), proponents of behaviourism believe “...that anything that can be learned can also, given the appropriate techniques, be unlearned...”. Yet whilst there were advocates for behaviour-modification programs, there were also those in opposition to such programs, particularly when techniques were inappropriately used.

3.8.2.1 Critics and Advocates of Behaviour-Modification Programs

From the introduction of behaviour-modification programs and onward, commentators have warned against the use of ‘strict’ behaviour-modification programs by themselves in the treatment of anorexia nervosa (Biley, 1989; Bossert, Schnabel, Krieg & Berger, 1988; Bruch, 1974; Clare & Cuthbertson, 1998). This literature reported that initial behaviour-modification programs were highly punitive and restrictive, with their focus on weight restoration being detrimental to the formation of any supportive therapeutic relationship or
the resolution of underlying psychological issues\(^2\) (Bhanji & Thompson, 1974; Biley, 1989; Bruch, 1974).

According to Biley (1989, p. 22) such early programs verged on being ‘force-feeding’ regimes and were considered “degrading and de-humanising” for patients. In a paper published more than a decade earlier, Bruch (1974, p. 1421) whilst concurring that such programs did encourage weight gain, concluded that this outcome became a means of ‘escape’ for patients (they learned to avoid the punishment); many patients “eat[ing] their way out of hospital” thereby leading to relapse rather than recovery in the long term. Biley (1989, p. 22) further condemned these programs and claimed they “may also cause a feeling of distrust that makes the establishment of a positive therapeutic relationship difficult”. Furthermore, Duker and Slade (2003) went so far as to criticise some present day behaviour-modification regimes, that may be employed within hospitals for low-weight sufferers, as addressing weight exclusive of the person’s unique psychological problems. Duker and Slade (2003, p. 71) commented acrimoniously that: “Much of the original research in behaviour modification was done on the pecking responses of pigeons; but the procedure as it is used in cases of low-weight anorexia nervosa is rather more akin to taking the pigeon by the neck and shoving its beak on to the green button”.

In a study performed in the early eighties, Touyz, Beumont, Glaun, Phillips and Cowie (1984) compared a ‘strict’ and ‘lenient’ behaviour modification re-feeding program and discovered the ‘lenient’ program to be just as effective in weight gain and advantageous for both nurses and patients. The 31 patients who were treated with the ‘strict’ program were placed on strict bed rest with reinforce
tors provided for each 0.5kg of weight gained. Another 34 patients were treated using a ‘lenient and flexible’ program, which entailed the preparation of a contract with each patient, to achieve a minimum of 1.5kg per week following an initial one week of bed rest. Compliance with the contract meant these patients were not restricted to bed and free to mobilise around the ward. Patients on the ‘lenient’ program were aware and agreed that failure to achieve the set target weight each week meant they spent the following week on bed rest. This was the only restriction imposed on this group and they were given full access to their personal property (Touyz et al., 1984).

\(^2\) These earlier programs characteristically involved the removal of all possessions, activities and contact with others until weight was gained.
Not only were there no major differences in weight gain between the two groups, the ‘lenient’ program was shown to be more accommodating for patients, maintaining their autonomy. It was also less restrictive on the nurses’ time thereby allowing more time for the development of therapeutic relationships between the nurses and the patients (Touyz et al., 1984). Patients on the ‘lenient’ program were also more receptive to other therapies, which were offered to both cohorts, and staff reported decreased manipulation. The study showed that a greater percentage (24%) of patients were considered to be “extremely cooperative” while on the ‘lenient’ program whereas only 10% were considered to be “extremely cooperative” on the ‘strict’ program (Touyz et al., 1984, p. 519). The authors claimed that their “lenient treatment programme, despite its behavioural basis, provides sufficient opportunity for psychotherapeutic contact and for patients to maintain their autonomy during treatment to avoid…criticisms” (Touyz et al., 1984, p. 519) such as those raised by Bruch (1974) and discussed earlier.

Bossert et al. (1988) and Monkley (1987), similarly described contractual behaviour-modification programs, like Touyz et al.’s (1984) ‘lenient’ program, which enabled weight to be restored in an environment where mutually agreed upon goals were clearly set. These more ‘lenient’ programs still relied on a privilege system of rewards bestowed for weight gain and compliance and the loss of certain privileges for non-compliance. However, not all reinforcers were removed from patients, which made these programs more acceptable and less controlling than the stricter behaviour-modification programs initially implemented. Bossert et al.’s (1988) study demonstrated a more ‘humane’ approach in response to earlier criticisms of some programs. For instance, a patient who had not gained the required weight for that week was confined to their room for the day, but was still permitted to have meals with the other patients and attend therapeutic activities, including arts, occupational therapy and group sessions (Bossert et al., 1988).

Kellerman (1977, p. 390) believed behaviour-modification therapy to be the “treatment of choice for anorexia nervosa” and this still appears true today. Although the stricter, inflexible behaviour-modification practices described above are non-existent and outdated (Knibbs, 1993); most re-feeding programs within paediatric hospitals in Australia are still based on behaviour-modification principles (Anderson, 1996; Simonds et al., 2000; Touyz & Beumont, 1991). They are advocated because of their success in promoting weight gain for the medically compromised patient (Jarman et al., 1997; Moorey, 1991; Touyz et al., 2000).
1984) and used appropriately, in conjunction with other psychological and motivational therapies; they have shown some effectiveness in alleviating the physical and cognitive symptoms of anorexia nervosa (Beumont & Vandereycken, 1998). But as Biley duly pointed out: “Used in isolation, a behavioural approach to treatment has a poor success rate” (1989, p. 22).

3.8.2.2 Present-Day Behaviour-Modification Programs

Today there are no ‘strict’ behaviour-modification programs in existence. Re-feeding programs for adolescents with anorexia are based on the original principles of behaviour-modification but are ‘lenient’ in nature. According to Beumont and Vandereycken (1998, p.15), they are considerably “more humane but equally effective”. Weight gain, in today’s behaviour-modification program, is supported by a multidisciplinary team of professionals, mainly nurses, in a therapeutic and caring environment. Initially bed rest and continuous nasogastric re-feeding may be prescribed for the extremely emaciated adolescent due to medical compromise but as progress is made, confinement to bed is abandoned. These programs rely on rewarding adolescents with privileges (such as ‘gate-passes’) for their weight gain, improvement in eating habits and medical and psychological well-being, or alternatively the loss of privileges for continual unhealthy and destructive weight loss practices (Anderson, 1996; Simonds et al., 2000). As stated earlier, behaviour-modification therapy relies on the theory that all behaviours are learned and if behaviours are rewarded, they are more likely to be repeated (Moorey, 1991; Sloan & Mizes, 1999). As positive behaviours replace negative behaviours, these undesirable behaviours are eventually extinguished (Feldman, 1996, 2000).

There is general acceptance and agreement among experts in the eating disorder field that current programs are not as restrictive or punitive as earlier forms of behaviour-modification therapy. The patient is presented with greater choices, access to possessions and ideally is expected to work alongside staff in a mutual partnership to achieve set goals. Set goals of inpatient care include restoring a healthy weight within a safe environment, improving abnormal eating patterns and working towards changing unhealthy attitudes and behaviours (Anderson, 1996; Fairburn & Harrison, 2003; Marks, 2002). Team members, especially nurses, who spend the greatest time with the adolescents with anorexia, attempt to provide the adolescent with constant support to
manage their fears and encouragement to make the necessary changes to achieve a healthier and more positive outlook on life (Anderson, 1996; Halek, 1997).

3.8.3 DIFFICULTIES WITH TREATMENT

However the condition itself is definitely not an easy one for staff to treat effectively (Beumont, 2000). An Australian study by McDermott et al. (2001) confirmed that paediatric inpatient care for adolescents with anorexia, with a multidisciplinary team approach, can be a considerable financial burden because of the long length of admissions and frequency of relapse (‘revolving-door’). Relapse rates for this condition continue to be disturbingly high particularly within the first year after remission (Carter, Blackmore, Sutandar-Pinnock & Woodside, 2004; Fennig, Fennig & Roe, 2002).

The condition is particularly difficult to treat because many adolescents with anorexia are not motivated to change their behaviours (Bemis-Vitousek, 2000; Fairburn & Harrison, 2003). Many of these adolescents deny they are ill and disregard the seriousness of their behaviours, making it extremely difficult for health professionals to help someone who does not believe they need help (Deering, 1987; Duker & Slade, 2003; Marks, 2002; Muscari, 2002). Others who may come to realise the destructive nature of their behaviours may feel they need to correct this themselves because asking for help is a sign of weakness (Duker & Slade, 2003) and they feel they are unworthy of this help (Manley & Leichner, 2003). Consequently the patient with anorexia does not assume the traditional ‘sick role’ (Parsons, 1991, Turney & Singleton, 1997) and seldom seeks treatment on their own. They are usually reluctantly brought to hospital by concerned others (Bemis-Vitousek, 2000).

Many adolescents with anorexia are highly resistant to change because to relinquish their behaviours would mean ‘losing their identity’ (Bulik & Kendler, 2000; Muscari, 2002) or ‘being out of control’ (Halek, 1997). These issues can lead to power and control struggles between nurses and patients when patients are hospitalised in an acute care setting (Wolfe & Gimby, 2003). The adolescent with anorexia will use defensive strategies to maintain their eating disorder which they highly regard as a valuable asset because it defines who they are. Within treatment settings ‘sabotage’ becomes a predominant defensive strategy for the adolescent with anorexia. Manipulation of staff (Anderson,
1996) and of their weight by concealing objects in their clothing or by ‘water loading’ is common as well as secreting food in napkins, throwing food away from their trays (Bemis-Vitousek, 2000) or manipulating nasogastric feeds (Simonds et al., 2000).

In spite of these difficulties, many patients with anorexia nervosa do recover and many studies have acknowledged that recovery often took place through the formation of a solid, supportive relationship with a person they felt they could trust and that empathetically listened to them (Beresin et al., 1989; Garrett, 1998; Tozzi et al., 2003; Woods, 2004). Amanda Jordan, from the Eating Disorders Foundation of New South Wales, confirmed in a media article the importance of a therapeutic relationship for recovery from eating disorders. She stated, “[f]or long-term recovery, you really need to form a therapeutic alliance, where you not only tolerate the bad feelings a person has about themselves but you also invest them with belief” (Young, 2003, p. 2). Sallas (1985) agreed, that “[w]inning the war without having to do battle” is a complex task for nurses caring for someone with an eating disorder because of the likelihood of confrontation and the relationship transcending into an authoritarian relationship (p. 445). Sallas (1985) also described the formation of a therapeutic relationship as an essential element for effectively reducing conflict in nurse-patient interactions while allowing nurses to remain firm with treatment. Generally, this relationship is believed to promote healing for patients (Geanellos, 2005; Stickley & Freshwater, 2002; Taylor, 1995).

It would seem that skilled nurses have a unique contribution to make, as the primary caregivers for adolescents with anorexia on wards with behaviour-modification programs, considering their expertise, holistic approach to care and the substantial amount of time and energy they invest each day with patients in comparison to other multidisciplinary team members (Anderson, 1996; Grothaus, 1998; Halek, 1997; Marks, 2000; Muscari, 1998, 2002). They would be ideally suited to establishing a therapeutic relationship and this would assist patients with treatment compliance, ultimately leading to an improvement in their physical and psychological health. Thus, this would arguably decrease the ‘revolving door syndrome’ for adolescents with anorexia.
3.9 THE NURSE’S ROLE

Nurses, within this unique position, have a myriad of complex roles to play on a ward with a behaviour-modification program. They are expected to first and foremost provide holistic care; that is care for the adolescent’s physical, emotional, psychological and social health. They also play a role providing family members with the support and education they need to understand and cope with having an adolescent with anorexia nervosa (Anderson, 1996; Halek, 1997; Muscari, 1998).

As Beumont and Vandereycken (1998, p. 17-18) have aptly pointed out “[n]urses are at the forefront of the treatment of the anorectic inpatient. They have to implement the treatment regimes decided by the therapists, and are likely to bear the brunt of the patients’ and their relatives’ frustration with the restrictions that need to be imposed”. Not only must nurses implement the program guidelines, they must ensure that patients and family members consistently adhere to these guidelines as well. Supporting and educating the family about the illness is important to prevent family members from undermining the treatment process (Anderson, 1996; Marks, 2002).

Although the role of the nurse varies within individual programs, primarily most nurses within behaviour-modification programs, will monitor food intake and eating behaviour in a supportive manner; will ensure that patients eat meals within specified time frames; will replace missed calories with supplemental nasogastric feeds; will ensure adolescents adhere to bed rest requirements and visiting restrictions and finally they will make sure that adolescents do not engage in inappropriate behaviours such as purging, over-exercising, vomiting or manipulation. In addition, nurses make certain the adolescents attend school, group and physiotherapy as required and are weighed on weigh days. It is also the nurse’s responsibility to document the adolescent’s progress in the medical notes and through verbal communication so that appropriate treatment decisions are made at weekly meetings (Anderson, 1996; Marks, 2000, 2002; Simonds et al., 2000; Wolfe & Gimby, 2003).

Usually the adolescent with anorexia will arrive to the ward severely emaciated and in a medically compromised state. The nurse has another important role in regularly monitoring the adolescent’s medical condition, including temperature, heart and...
respiratory rate and blood pressure for any abnormalities (Wolfe & Gimby, 2003) and has a duty to report any irregularities as soon as they are detected. Similarly, it is important to monitor each patient’s mental state and cognitive functioning, thereby assessing for any co-morbidities (Halek, 1997) as well as assessing the adolescent’s capacity for concentration and comprehension of information (Marks, 2000, 2002). This is one reason why it is imperative that the nurse be aware of the physical and psychological effects associated with the condition (described on pages 32-33). The nurse must also monitor for re-feeding syndrome (Marks, 2002). Re-feeding syndrome is a severe fluid and electrolyte disturbance within the body that can take place when a severely malnourished person is suddenly re-fed either orally or with feeds via a nasogastric tube. When re-feeding is in progress an intracellular shift of potassium, magnesium and phosphate takes place that can lead to potentially lethal complications (Brooks & Melnik, 1995). Complications can include delirium, cardiac abnormalities and death (Marks, 2002).

As a consequence of the substantial amount of time nurses spend with these patients, they can also act as role-models for behaviour and as teachers educating adolescents about their illness, food, health and appropriate eating behaviours (Anderson, 1996; Halek, 1997; Marks, 2000, 2002). Nurses are equally in a position to monitor and assess for any emerging difficulties that an individual may be experiencing with peers on the ward (Creedy & Crowe, 1996; Marks, 2000, 2002). Sometimes adolescents with anorexia on ward programs compete with each other or compete for the nurse’s attention and instead of being a supportive influence, they end up undermining their own and others progress in the program (Marks, 2000, 2002). Nurses, who are responsive to this behaviour, can encourage and assist the adolescents to discontinue these self-destructive behaviours before they become unmanageable on a ward (DeLaune, 1991).

The above nursing roles are some of the many fundamental caring roles, nurses engage in, within an inpatient behaviour-modification program for adolescents with anorexia. The healing process, though, can be further enhanced through the establishment of a therapeutic relationship (Geanellos, 2005; Stickley & Freshwater, 2002; Taylor, 1995). Paediatric nurses within a ward based treatment program such as ‘The Level System’ would be ideally suited to this role since nurses devote the greatest amount of time and energy caring for these patients in comparison to any other health professional within an

3.9.1 THE THERAPEUTIC RELATIONSHIP

A plethora of literature within the nursing field, particularly mental health nursing, asserts that the formation of a therapeutic relationship is fundamental for the successful treatment, care and recovery of a person with anorexia (Deering, 1987; Garner, Vitousek & Pike, 1997; George, 1997; Halek, 1997; Lilly & Sanders, 1987; McNamara, 1982; Muscari, 1998; Sloan, 1999; Wolfe & Gimby, 2003). However establishing this relationship with an adolescent with anorexia is an extremely challenging task for nurses (Deering, 1987; Garrett, 1991; George, 1997; King & Turner, 2000; Ramjan, 2002, 2004) particularly within the context of a behaviour-modification program. Despite the recognition of its importance and potential, very little research has examined in depth the difficulties with forming this relationship and the reasons behind their development (Ramjan, 2004; Williams & Irurita, 1998). This thesis attempts to address this caveat.

3.9.1.1 Historical Origins of the Therapeutic Relationship

Although the therapeutic relationship has its origins in counselling, psychoanalysis and psychotherapy (Freud, 1913), it has gained increasing popularity within nursing practice, particularly, mental health nursing practice per se (Priebe & McCabe, 2006; Stickley & Freshwater, 2002; Welch, 2005). The concept was brought to the fore by nurse theorists such as Hildegard Peplau (Peplau, 1952, 1991) in the mid 20th century. Historically the earliest identifiable record of a therapeutic relationship, according to A. J. O’Brien (2001), was seen during the ‘asylum era’. A. J. O’Brien’s (2001) review highlighted the importance of this relationship and its influence on the caring practices of attendants within asylum care. According to A. J. O’Brien (2001), even though substantial evidence exists to suggest that psychiatric care during the 19th century was particularly inhumane with authoritarian attendants demonstrating their control and power over asylum inmates, there were also significant instances where therapeutic actions or interventions were evident. Some examples of the therapeutic interventions that took place included the provision of a secluded inmate with reading and writing materials and a pet cat and allowing another...
artistically gifted inmate to enter a design competition (A. J. O'Brien, 2001). This demonstrated that attendants did develop a type of bond or relationship with their charges and as a consequence of this connection some basic human needs were met. Hence, another example of the positive outcomes of this close bond or therapeutic relationship included the avoidance of restraint in many instances as a result of the attendants’ ability to engage positively with inmates in a caring and therapeutic manner (A. J. O'Brien, 2001).

3.9.1.2 Defining the Therapeutic Relationship

The therapeutic relationship itself is not an easily definable concept (Priebe & McCabe, 2006; Sumner, 2001) and is considered a complex relationship that is often unique to both context and the patient and nurse involved in the caring process (Sumner, 2001). McKlindon and Barnsteiner (1999) defined the therapeutic relationship as a reciprocal relationship that develops over time between the nurse, the young person and their family members. This relationship is “caring, clear, boundaried, positive and professional” and focuses on empowering not only the young person and their family but the nurse as well (McKlindon & Barnsteiner, 1999, p. 238). Seminal work by Rogers (1951, 1965), within psychotherapy, proposed that the relationship required three core conditions and these included empathy, an unconditional positive regard and congruence. Additionally, influential work by Garner, Garfinkel and Bemis (1982) described how the relationship between the therapist and patient with anorexia will only be successful, if the therapist shows ‘warmth and genuineness’, displays ‘understanding and acceptance’ of the patient’s experiences and is ‘open and honest’ in their encounters.

From a nursing perspective, Atschul (1972) discovered that the quality of the relationship between the nurse and patient is an important component of treatment. The patients in this study appreciated nurses who were friendly, kind and helpful. They especially cherished the nurse’s availability in the relationship, to spend time engaging in activities, talking openly with them and listening to their concerns (Atschul, 1972). Cameron, Kapur and Campbell (2005) explained that the therapeutic relationship between the nurse and patient is in essence an interpersonal, co-operative process that proposes to attain positive change and growth. Therapeutic relationships are goal-directed and these goals are mutually agreed upon by nurse and patient. Moreover, the relationship acts as a
mediator of change, thereby enhancing self-esteem, self-care and independence (McMillan et al., 2006).

According to Peplau (1952, 1991) the nurse-patient relationship encompasses four inseparable phases: ‘orientation’, ‘identification’, ‘exploitation’ and ‘resolution’. In brief, the phases proceed as follows: in the ‘orientation phase’, the main goal is to establish trust between patient and nurse; this then progresses towards a ‘working phase’ where problems are identified together and progress is made toward goal achievement; and finally the relationship ends or terminates in the ‘resolution phase’, this is where the patient has achieved a sense of independence and no longer requires the nurse’s assistance. Some relationships may move very slowly towards or may never enter the ‘working phase’ of the relationship because the patient or nurse are unwilling or unable to trust each other or the nurse has inadequate skills to develop the relationship further (Forchuk et al., 2000). Nevertheless, Taylor (1995) believes nurses and patients are engaging in social relationships on a daily basis and there are always opportunities for interpersonal closeness and interchange. She describes the nurse within the relationship as possessing qualities similar to those outlined by Rogers (1951, 1965). These are ‘presencing’ (being there for), ‘concern’ and ‘authenticity’ (Taylor, 1995, p.101).

An amalgamation of elements from all the above definitions can be found in the Nurses Association of New Brunswick’s (2000), definition of the therapeutic nurse-patient relationship. Their guidelines describe the relationship as follows:

*The nurse-client relationship is a helping relationship that is therapeutic in nature, is established to meet the needs of clients and is based upon trust and respect. A therapeutic nurse-client relationship is established and maintained by the nurse through the use of professional nursing knowledge, skills and caring attitudes and behaviours in order to provide nursing services that contribute to the client’s health and well-being. The relationship is based on trust, respect and intimacy and requires the appropriate use of the power inherent in the care provider’s role*  
(Nurses Association of New Brunswick, 2000, p. 24).

Welch (2005) reported that the therapeutic relationship is a concept that is frequently referred to within mental health nursing literature and is recognised as valuable but it still remains elusive. Welch (2005) attempted to operationalise the therapeutic relationship by
examining the experiences of psychiatric nurses. Nurses described the therapeutic relationship as possessing the following elements which overlapped with one another at times: ‘trust’, ‘power’, ‘mutuality’, ‘self-revelation’, ‘congruence’ and ‘authenticity’ (Welch, 2005, p. 163). Trust was described in terms of patients entrusting nurses with their personal stories and bringing this unique ‘gift’ to the relationship. Trust also involved the nurse and patient equally contributing to the relationship and this overlapped with the theme of ‘mutuality’. The relationship flourished when the nurse was able to share power and control with the patient while not giving all the control back to the patient. Nurses believed that patients appreciated those nurses who knew when to take control of a situation. There were instances when nurses felt their understanding of patient’s experiences, were enhanced during the relationship and they felt that they could reflect on these experiences when caring for future clients. This gave them a sense of the relationship not only benefiting the patient but benefitting themselves as well. This was considered to be an element of ‘mutuality’ within the relationship (Welch, 2005).

According to Welch (2005), there was no boundary crossing within the therapeutic relationship but opportunities for the nurse to share parts of themselves with the patient and this was considered ‘self-revelation’. ‘Congruence’ within the relationship related to nurses valuing their beliefs and being consistent with upholding these beliefs even if it meant disagreeing with a patient. In this way, nurses demonstrated their integrity to patients, thereby enhancing the unique relationship they had together. Finally, ‘authenticity’ within the relationship was also seen as essential. ‘Authenticity’, according to Welch (2005, p. 164) indicated, “a sense of completeness and seamlessness in the manner in which they were able to meld their selves into a professional persona with little or no conflict of interest, dissonance, distance or reserve”. In other words, nurses were able to be themselves, not transparent and artificial. This happened effortlessly with certain patients than with others but the more authentic the relationship, the closer it seemed. The nurses in Welch’s (2005, p. 164) study were adamant that, “if they [nurses] meant what they said, said what they meant, acted as they spoke and spoke as they acted, they would, in a famously rhetorical phrase, be living out the true nature of their creed”.

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Common elements described within the above definitions are also alluded to within related nursing literature as essential for the relationship to be both positive and therapeutic. Deering and Frederick (2003) proposed that the relationship needs to possess the elements of trust, professionalism, mutual respect, caring and partnership. George (1997) similarly suggested that the main elements of the therapeutic relationship include: trust and commitment, empathy, genuineness, a non-judgemental attitude and an unconditional positive regard. Ideally the relationship should be caring and nurturing, where the nurse demonstrates honesty, confidentiality, support, consistency, limit setting and maintains personal and professional boundaries (Halek, 1997). The most important of these elements (trust, empathy, limit and boundary setting) will be expanded below in relation to the difficulties nurses may face when attempting to form therapeutic relationships with adolescents with anorexia.

3.9.1.3 The Elements of a Therapeutic Relationship

3.9.1.3.1 TRUST

The most pivotal aspect of the relationship is the establishment of trust. Indeed trust is seen as the cornerstone of the alliance (Deering & Frederick, 2003; Moyle, 2003). According to Johns (1996), trust is a multifaceted term which has not been conceptualised or defined succinctly within the literature. There are varying levels of trust and trust can have different meanings for different individuals in certain contexts. Trust can include, but is not limited by, interpersonal trust; that is, belief in a person's words both verbal and written and trust in the competence of another to perform set duties; that is, confidence in a person's actions (de Raeve, 2002; Hagerty & Patusky, 2003; Johns, 1996). According to de Raeve (2002, p. 152), trust within the nurse-patient relationship also depends on the trustworthiness of the nurse and for the nurse to be considered trustworthy “she must care about her patients, not just for them”.

Trust within a therapeutic relationship is particularly important for the relationship to flourish. Within this trusting nurse-patient relationship an adolescent with anorexia may feel able to unburden themselves of their emotional distress (Clarke & Stokoe, 2001; Halek, 1997) and begin to accept they are ill and require help (Garfinkel & Garner, 1982). Yet it is often difficult for an adolescent with anorexia to have trust in a health care
professional during treatment as more often than not, they have experienced betrayal by
or deceit on the part of others in their life (George, 1997; Martin, 1987) or have had little
experience of care and nurturance and so mistrust those trying to provide it (Deering,
1987).

The adolescent with anorexia may be highly ambivalent about changing their behaviours
and may see the nurse as someone who is “proposing to fix one of the few parts of their
lives that they do not consider broken” (Bemis-Vitousek, 2000, p. 98) and that has actually
been both a means of survival and coping mechanism for them in society (Manley &
Leichner, 2003). The nurse, in many instances, may be regarded as untrustworthy
because the hospitalised adolescent views the nurse as someone who is taking away
their control and who has an obligation to see that they gain weight (Deering, 1987; King
& Turner, 2000; Ramjan, 2002, 2004; Wolfe & Gimby, 2003). These feelings of lost control
and powerlessness on the part of the hospitalised adolescent can heighten anxiety and
trust issues between the nurse and patient and can effectively be an obstacle to
therapeutic communication (Wolfe & Gimby, 2003).

Often nurses caring for adolescents with anorexia become disillusioned, frustrated and
discouraged by their work and consequently mistrustful of their charges (King & Turner,
2000; Ramjan, 2002, 2004). This is chiefly because improvements in health are not
instantaneous and relapse (‘the revolving-door syndrome’) or manipulation from these
particular patients is a common occurrence (Cameron et al., 1997; King & Turner, 2000;
Ramjan, 2002, 2004). This frustration on the part of nurses can also impede the formation
of a therapeutic nurse-patient relationship and can lead to eventual burnout and stress for
nursing staff.

Nonetheless, Muscari (2002) believes the development of trust between a nurse and an
adolescent with anorexia is not unattainable. According to de Raeve (2002) most patients
do covertly trust, that when the situation is critical, health care professionals have their
best interests at heart. This trust becomes more personal and unique as the nurse and
patient find out more about each other (de Raeve, 2002). Morse (1991) commented that
developing trust with a patient just takes time, perseverance and commitment on the part
of the nurse. A skilled nurse who is not affronted by the manipulation and understands
that manipulation is a ‘disorder-related’ issue (Gallop & O’Brien, 2003) can and will

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achieve trust with the adolescent with anorexia. Halek (1997) describes this nurse as someone who persistently demonstrates a warm, positive and encouraging attitude, is reliable and honest and who shows consistency in rule enforcement and competence in maintaining personal and professional boundaries.

3.9.1.3.2 EMPATHY

Trust within this alliance is further strengthened by a nurse who shows genuine empathy and is able to respectfully validate the adolescent’s feelings, including their fear and desperation as bona fide concerns (Marks, 2002). According to Alligood (1992), empathy can be a natural, inherent trait or a trained and learnt clinical skill. It entails accurately understanding the meaning and feelings of another and reflecting this understanding (Baillie, 1995; Reynolds & Scott, 2000). A skilled nurse with a holistic understanding of the aetiology of the disorder and the psychological and physical effects is best equipped to exude legitimate empathy and ultimately would be an asset in enhancing motivation for change in the adolescent with anorexia (Bemis-Vitousek, 2000). Bemis-Vitousek (2000, p. 98) explains that nurses caring for adolescents with anorexia need to understand that most adolescents with anorexia “want to be doing what they are doing”. Validation of this through therapeutic listening and an empathetic curiosity in understanding the patient’s position will inspire the adolescent to engage with the nurse in the re-discovery of their unique personalities separate from the eating disorder (de Groot & Rodin, 1998). Muscari (1998) believes this will then assist them with managing their anxieties, increasing their self-esteem and sense of self-worth.

Nurses, through a supportive and caring approach, can learn to listen without judgement (Deering & Frederick, 2003) and understand the adolescent’s personal difficulties in changing behaviours (Bemis-Vitousek, 2000) and can then work in a partnership to manage the adolescent’s anxieties and fears related to weight gain (Muscari, 2002). An important part of empathy is being able to separate the person from the eating disorder identity and encouraging sufferers to see themselves and their behaviours in this same way (Manley & Leichner, 2003). Ever so slowly, as a result of the nurse’s commitment to the relationship and genuineness, adolescents with anorexia will start to appreciate that nurses are here “to work with the patient against the disorder” (Marks, 2000, p. 120). Unfortunately, without a clear understanding of the complexities of this condition, nurses
often become perplexed and frustrated with the disorder and the patient (Ramjan, 2002, 2004). Regrettably, unresolved frustration can diminish the quality of care in the relationship and can lead to the provision of substandard care for adolescents with anorexia. Hence this will undoubtedly hinder their recovery.

3.9.1.3.3 LIMIT SETTING

Firmness and limit setting as reported earlier are also seen as important elements for a therapeutic nurse-patient relationship with adolescents with anorexia. Effective limit setting is achieved through firmness and consistency on the part of all members of the health care team in following through with the prescribed program guidelines (DeLaune, 1991; Marks, 2000, 2002; Nield-Anderson et al., 1999). DeLaune (1991) explains that nurses need to be clear and consistent with setting and following the rules of the program so that everyone receives fair, unbiased treatment. This will increase the patient’s trust and security in the nurse. The program guidelines themselves should be clear and direct with no opportunities for misinterpretation of its expectations. Marks (2002) adds, the provision of rationales for the use of limit setting will also ease an adolescent’s anxiety.

Often an untrusting and highly anxious adolescent will test these limits through manipulation. Manipulation is a means of assessing the nurse’s trustworthiness and consistency (DeLaune, 1991). Nield-Anderson et al. (1999, p. 27), defined manipulation as “a coping strategy that a patient employs to get his [or her] needs met without regard for others”. Manipulation of nursing staff can take many forms and commonly includes using intimacy, flattery and splitting (DeLaune, 1991; Nield-Anderson et al., 1999). Flattery and intimacy involves the patient creating a close, yet often insincere, relationship with a particular nurse in the hope of receiving special favours. If the nurse becomes entrapped in this type of manipulation the nurse-patient relationship is no longer therapeutic. The quality of care given will be compromised and the nurse’s objectivity and insight will be impaired. Splitting is also another frequently used tactic by adolescents with anorexia. Splitting or ‘playing staff against each other’ is when a patient categorises nurses as ‘good’ or ‘bad’ (Gallop & O’Brien, 2003; Nield-Anderson et al., 1999). The patient may also intentionally discuss their feelings about certain nurses in front of colleagues, creating friction, dissension and animosity among staff (Nield-Anderson et al., 1999). Setting limits
eliminates the further escalation of manipulation (Deering & Frederick, 2003; DeLaune, 1991; Nield-Anderson et al., 1999).

Manipulation of the treatment program can also occur with adolescents with anorexia. This can include things like sabotaging weight gain, concealing or discarding food, over-exercising and manipulation of nasogastric feeds (Duker & Slade, 2003). The consequences of maladaptive behaviours and the actions that will be taken in these instances need to be clearly outlined and consistently adhered to by staff in order to prevent further manipulation of staff or the program (Creedy & Crowe, 1996; DeLaune, 1991; Marks, 2002; Nield-Anderson et al., 1999). At times, nursing staff may need to use confrontation or other interventions, if the behaviour being displayed is particularly dangerous to the adolescent’s health (Muscari, 1998). For example, when a recalcitrant adolescent engages in self-harming behaviours such as burning, cutting or mutilating their bodies or unrelenting exercise, nursing staff may need to supervise or ‘special’ them twenty-four hours a day or place them on strict ‘bed rest’ (Duker & Slade, 2003). ‘Specialling’ and strict ‘bed rest’ have been described earlier in Chapter Two. These limits are not intended to punish and should not be used excessively but are there for safety reasons when an adolescent cannot control their own behaviours (DeLaune, 1991).

DeLaune (1991) explains that when nurses remain fair with setting limits, the adolescent comes to realise that certain ‘disorder-related’ behaviours will not be accepted or tolerated. Fallon (2004, p. 3) believes “[t]here is no failure in limit setting, only feedback from the patient that they choose not to comply and therefore live with the consequences of that decision”. The main obstacle to limit-setting occurs when nurses are inconsistent with following the rules of the program and therefore the adolescent’s insecurity and anxiety intensify and their overall care suffers (Muscari, 1998). This can happen when nurses get caught up in the manipulation tactics of the adolescent or feel personally affronted by their negative comments or behaviours (King & Turner, 2000; Marks, 2000).

3 Limits such as ‘bed rest’ or ‘specialling’ may be seen by some as a punishment. However within a behaviour-modification program, the patient in most instances, is aware and agrees that these limits may be implemented for maladaptive or unsafe behaviours on the ward. Sedation may be required when a patient does not agree and continues with unsafe practices.
Finally, boundaries are emphasised within the literature as another essential element for a therapeutic relationship. Early on in the relationship, the nurse and patient should both have a clear understanding of their roles and the expectations both have of each other within this relationship (Marks, 2000; McKlindon & Barnsteiner, 1999; McMillan et al., 2006). However, due to the intensity of this relationship, the patient and nurse can often become bewildered about the intention and nature of the relationship. The skilled nurse within a therapeutic relationship remains supportive and friendly but it is important that both parties are acutely aware that the relationship is a professional one and not a friendship (Manley & Becker, 2005; Marks, 2000, 2002; McKlindon & Barnsteiner, 1999).

Issues of transference and countertransference can occur when there is boundary confusion in the relationship. Transference occurs when the patient views the caregiver in the same terms as a current or previous relationship or transfers feelings felt for the primary relationship to the nurse (Gallop & O’Brien, 2003; Manley & Becker, 2005). For example the hospitalised patient may become overly dependant on the nurse for emotional support (Marks, 2000) or may even view the care-giver as an abuser (Manley & Becker, 2005). Conversely, countertransference or “any [strong] feelings or thoughts that the caregiver has about the patient” may also inhibit the relationship detrimentally if unresolved (Manley & Becker, 2005, p. 42). It is very easy for nurses to either become overly-involved or to withdraw from the relationship when countertransference issues have not been addressed (Gallop & O’Brien, 2003; Manley & Becker, 2005; Nield-Anderson et al., 1999; O’Kelly, 1998).

Countertransference reactions can lead to nurses labelling patients negatively as ‘difficult’, ‘manipulative’ or ‘non-compliant’ and thereby distancing themselves from the relationship (Gallop & O’Brien, 2003; Nield-Anderson et al., 1999; O’Kelly, 1998) or on the other hand, to label them as their ‘favourites’ because of their illness or personality and spend a disproportionate amount of time with them thereby neglecting others in their care (Holyoake, 1999; McMillan et al., 2006; Nield-Anderson et al., 1999). Manley and Becker (2005) believe unresolved countertransference issues lead care-givers to feel they are inadequate and unable to provide the patient with the appropriate care required to facilitate change. The nurse’s own self-esteem suffers and their emotional energy within...
the relationship dwindles and burnout eventuates. Physical care may be provided to the
detriment of the necessary psychological and emotional care (Nield-Anderson et al.,
1999).

Nurses working with patients with anorexia need to acknowledge their own personal
feelings about patients and the behaviours they display. Deering and Fredrick (2003, p.
59) labelled this “self-awareness”. The literature (Creedy & Crowe, 1996; Gallop &
recommends that these feelings be explored with supportive colleagues or supervisors on
a regular basis, otherwise care will be compromised and will not be beneficial for the
patient. Recognising these feelings through peer debriefing sessions and self-awareness
will prevent a nurse from acting on these feelings, such as by becoming over-controlling in
the relationship and this will ensure the therapeutic relationship remains unscathed
(Marks, 2000, 2002). O’Kelly (1998) advocated the recognition of countertransference in
nursing relationships, as it improves the quality of patient care, improves nursing
knowledge and insight and allows for the professional growth of the nurse.

From the above discussion, the main elements for a therapeutic relationship are
seemingly difficult but not impossible to achieve when caring for an adolescent with
anorexia. Thus the nursing literature does strongly recommend adequate training and
knowledge development alongside supervision, discussion and reflection on practice, for
those nurses caring for people with anorexia nervosa (Garrett, 1991; King & Turner, 2000;
Priebe & McCabe, 2006; Ramjan, 2002, 2004). The formation of a solid, therapeutic
relationship is pivotal for adolescents with anorexia to accept the help they need and
better manage the stress in their lives. This supportive, trusting relationship can assist the
adolescent to uncover other healthier avenues for control and can bolster their self-
esteeem. As self-esteem increases it will negate the adolescent’s need for manipulation
(DeLaune, 1991) and control thereby leading to their eventual healing, growth and
recovery from anorexia nervosa.
3.9.1.4 The Importance of a Therapeutic Relationship

Taylor (1995, p. 100) asserted that “[n]ursing practice has therapeutic potential as healing work” in which the nurse-patient relationship is the most critical aspect. The relationship is therapeutic not only for the patient but for the nurse as well as it entails ‘reciprocal caring’ (Taylor, 1995, p. 104). The quality of the relationship determines the extent of the healing process. Taylor (1995, p. 105) believes that healing is not akin to curing, but “[h]ealing is about caring with an open heart, in service to other people”. Healing occurs when the ‘cared for’ feels optimistic and either sees an improvement in their health or sense of self or on the other hand, now feels at ease about death (Taylor, 1995).

Gallop, Kennedy and Stern (1994) identified that a critical factor in a patient’s commitment to therapy and level of co-operation during therapy was their perception of the therapeutic relationship. Their study of therapeutic relationships between unit staff and patients with an eating disorder showed that over time the relationship strengthened and patients who stayed in the program rated this relationship as being of significant value. The authors claimed a limitation to their study was its small sample size (31 patients participated of which 21 completed the program and 18 staff members participated) (Gallop, Kennedy & Stern, 1994).

Similarly, a qualitative study using open-ended in-depth interviews, by Johansson and Eklund (2003, p. 342) of both inpatients’ (n=9) and outpatients’ (n=7) views on what they considered represents good quality psychiatric care, found that patients described the quality of the “helping relationship” between patient and staff as an indispensable factor. Johansson and Eklund (2003, p. 342) reported that satisfied patients in the outpatient sample described the relationship in terms of having ‘warmth’, ‘empathy’, ‘understanding’, ‘enough time’, and ‘being provided for’. Likewise the patients in the inpatient sample described the helping relationship and its quality as crucial yet additionally described a feeling of ambivalence about the depth of this relationship. Johansson and Eklund (2003) found that the inpatients yearned for a deeper relationship than what was being provided but then expressed trepidation about investing too much of themselves in this relationship. Nevertheless patients wanted their feelings to be respected and understood as meaningful and as having importance to them. The environment also played a part in the formation of relationships in the inpatient setting. These patients described how stability,
structure and consistency within the environment and among staff within the program allowed them to figuratively grow stronger away from the stresses of everyday life. In both settings the quality of the therapeutic relationship determined patients’ commitment to therapy (Johansson & Eklund, 2003). The authors described two limitations of their study, which included its small sample size and that the interviews were transcribed by hand rather than tape-recorded. Hand transcriptions are potentially problematic due to bias. Additionally pertinent data can be missed (Johansson & Eklund, 2003).

Beresin et al.’s (1989) recovery study of thirteen adult women with anorexia, found that women with anorexia nervosa proposed that the formation of a therapeutic relationship acted as a significant agent of change in their lives. As a consequence of someone truly listening and understanding their situation, they were able to re-define themselves. Similarly Garrett’s (1993, p. 112) recovery study illuminated that recovery for her participants was an ongoing process of which healthy “[r]elationships often became a positive substitute for the importance of food”. Garrett (1993) discovered that nurturance through friendships with others assisted the participants in the transformative process of discovering their own unique identities.

Finally, a grounded theory qualitative study by Kai and Crosland (2001) which explored the healthcare experiences of thirty-two people with a mental illness showed that participants rated the therapeutic relationship as being a vital element during contact with mental health services. The quality of the therapeutic relationship was determined by the health professionals’ ability to listen effectively, their ability to display empathy and understanding which then produced the necessary trust for open communication and negotiation. Kai and Crosland’s (2001) participants stressed the importance of building this solid relationship with one care-giver rather than having multiple care-givers involved as this assisted with the provision of continuity of care.

The above cited studies demonstrate consistent support for therapeutic contact, including talking and listening to patients, as a critical indicator of quality patient care (Whittington & McLaughlin, 2000). According to Whittington and McLaughlin (2000, p. 259) “the great majority of in-patient psychiatric care remains premised upon notionally therapeutic interaction between patients and health-care professionals”. These health care professionals are predominantly nurses within an inpatient setting such as a behaviour-
modification program for adolescents with anorexia. Not surprisingly, eating disorder experts have argued that, “the success of any anorexia nervosa unit ultimately rests on the expertise and dedication of the nursing staff” (Touyz & Beumont, 1991, p. 90).

As outlined above, nurses play a number of key roles within a behaviour-modification program, none as pivotal as the formation of a therapeutic nurse-patient relationship. It is somewhat surprising though, given the recognition of the importance and potential of the therapeutic relationship, that very little research has undertaken an in-depth examination of the difficulties experienced by paediatric nurses in forming such a relationship with adolescents with anorexia and the reasons behind the development of these difficulties (Ramjan, 2004; Williams & Irurita, 1998).

### 3.10 RESEARCH STUDIES EXAMINING THE THERAPEUTIC RELATIONSHIP

Much of the wider literature and many of the studies that specifically explore the therapeutic relationship have examined it from the psychiatric nurse and mental health care worker’s perspective or the psychiatric client’s perspective. These healthcare professionals are generally working in psychiatric settings or community settings with patients with a multitude of psychiatric conditions. Much of the literature has acknowledged the difficulty for nurses in managing anorexia; however, there remains a dearth of research studies specifically examining the establishment and maintenance of therapeutic relationships with people with anorexia, especially adolescents with anorexia, within an inpatient setting. Priebe and McCabe (2006, p. 72) stated, “[d]edicated research on the therapeutic relationship, the centrepiece of psychiatric practice, is just at the beginning”. Detrimentally, the potential power and healing nature of the therapeutic relationship within nursing practice, is also frequently overlooked (Cameron et al., 2005). Research in the area of adolescent anorexia has similarly ignored the consequences of inpatient hospitalisation (Gowers & Rowlands, 2005; Gowers et al., 2000) and the effect treatment modalities, such as behaviour-modification programs, have on therapeutic relationships. Thus this thesis intends to narrow the theory-practice gap, by investigating how hospitalisation and the day-to-day nursing practice within an inpatient behaviour-modification program impacts on the development of nurse-patient relationships.
Campbell, Surgenor and Snell (2001) insisted on the need for further research into understanding the therapeutic relationship from the patient’s perspective. Thus, this thesis will also address this limitation.

An exploration of some of the broader research has revealed numerous factors which foster and hinder therapeutic relationships. Some of the research that has explored the nurses’ and patients’ perspective, on the factors that foster and inhibit therapeutic relationships, are discussed below.

### 3.10.1 STUDIES EXAMINING FACTORS WHICH FOSTER AND HINDER THE THERAPEUTIC RELATIONSHIP

#### 3.10.1.1 The Nurses’ and Patients’ Perspective

As has been asserted earlier, nurses are crucial players in the care and treatment of young people with anorexia nervosa of which the formation and maintenance of a therapeutic relationship between the nurse and patient is of central importance. However, as also discussed, the formation of therapeutic relationships can be fostered and hindered by varying factors. A clinical nurse specialist, working within an inpatient behavioural program, in Jarman, Smith and Walsh’s (1997) interpretative phenomenological study, felt he needed to maintain control over the child’s eating behaviour, thereby disempowering the child. The clinical nurse specialist described taking a “fixed and directive therapeutic style” within this setting (Jarman et al., 1997, p. 148). He felt that in this setting he needed to take the stance, “yes, you’re going to eat and we’re going to make you eat” (Jarman et al., 1997, p. 148). Obviously the subsequent ‘battle for control’ between the young person with anorexia and the nurse would be a major obstacle to the formation of a therapeutic relationship. Indeed a Canadian study, using an interpersonal focus and Leininger’s (1985) method of qualitative analysis, by Forchuk et al. (2000), within a psychiatric hospital, explored ten nurses’ experiences of the positive and negative factors influencing relationships. This study suggested that control within the relationship needed to be balanced. One nurse explained that “it [control] should not be too strict and not too lenient, I keep a firm hold” (Forchuk et al., 2000, p. 7).
Similarly numerous studies (Cleary et al., 1999; Forchuk et al., 2000; Morse, 1991; Whittington & McLaughlin, 2000; Williams & Irurita, 1998) have shown that not having enough time to engage with patients appears to be another major obstacle affecting the ability of nurses to form and maintain therapeutic relationships. Whittington and McLaughlin’s (2000) observational study of 20 psychiatric nurses from three units in Northern Ireland found that a very small amount of nurses’ time (6.75%) was dedicated to one-on-one psychotherapeutic contact with patients. Less than half their time (42.7%) was spent engaging in direct patient care and even then little of this time was appropriately used to talk about or listen to patient concerns. Conversations that took place were often of a short duration and social in nature rather than therapeutic. Whittington and McLaughlin (2000) discovered nurses in this study spent approximately a third of their time attending to administrative work in offices or talking with each other. In fact, 75% (15 out of 20) of the nurses studied appeared to have ‘a fear of not knowing what to say’ as they did not rate themselves highly as having the self-confidence or training to engage in psychotherapeutic care (Whittington & McLaughlin, 2000). Whittington and McLaughlin (2000) stated that some limitations of this study included its small sample size of one setting, the potential for observational processes affecting nurses’ behaviours and each nurse being observed for one shift, which may not have been a typical shift.

Similarly, studies have described how work patterns such as patient assignment, days off, weekends, rostered shift work (Morse, 1991; Forchuk et al., 1998, 2000) and attending to other nursing and non-nursing duties (Cleary et al., 1999; Forchuk et al., 2000) all interfered with the amount of time nurses spent with patients. Nurses, in Cleary et al.’s (1999, p. 111) study, described how ward life within an acute psychiatric inpatient setting was unpredictable and ‘something always comes up’ that interferes with nurses’ contact time with patients. Obstacles included answering the phone, new admissions, discharges, critical incidents, helping other staff or wards, escorting patients to appointments and last but not least the abundance of paper work (Cleary et al., 1999).

Increased nursing workloads and higher patient acuity also impact on the amount of time nurses spend with each patient (Cleary et al., 1999; McQueen, 2000; Micevski & McCann, 2005; Moyle, 2003; Wolfe & Gimby, 2003). Sicker patients or those considered sicker may often be given priority over other patients in a nurse’s care (Cleary et al., 1999; Micevski & McCann, 2005; Morse, 1991; Ramjan, 2002, 2004; Wolfe & Gimby, 2003) as they may be
considered more deserving of care (Bailey, 1998; Ramjan, 2002, 2004). Interestingly, patients both in Forchuk et al.’s (1998) and Moyle’s (2003) studies similarly believed that the unavailability or invisibility of the nurse, the nurse’s attitude towards their work and patients and their distancing behaviours lead to a mutual withdrawal of both parties from the relationship; in particular the patients did not feel they were being comforted or nurtured within the relationship.

Not only are time constraints and the unavailability of the nurse a deterrent to therapeutic relationships but multiple care-givers are also a major problem. Many studies (Cleary et al., 1999; Forchuk et al., 1998, 2000; Garrett, 1991; Kai & Crosland, 2001; Morse, 1991; Williams & Irurita, 1998) describe how primary nursing is essential when attempting to form a therapeutic relationship with a patient and that multiple care-givers or changes in staff leads to inconsistency of care. In Forchuk et al.’s (2000) study, nurses felt that if a strong rapport was established with the primary and an alternative nurse then the patient felt more at ease within the relationship. These nurses believed that it was also important for the set routine to be consistently adhered to by that nurse as this demonstrated the nurse’s reliability within the relationship.

Williams and Irurita (1998) argued that individual patient and nurse characteristics including personality clashes can also affect the formation and maintenance of therapeutic relationships. As described earlier obstacles to the therapeutic relationship include over-involvement of the nurse and the consequent impairment of their judgement. Likewise, Morse (1991) asserted that a lack of commitment on the part of the nurse is also an impediment to the relationship. Morse (1991) explained that burn out can ensue where the nurse becomes “unwilling to invest emotional energy in the relationship” (p. 462). Morse’s (1991) study described how nurses who were reluctant for the relationship to progress hindered the relationship by depersonalising the patient, by appearing pre-occupied, not providing the patient with pertinent information and by being overly vigilant and not trusting the patient. These nurses attended to physical care tasks with little other therapeutic involvement with the patient. Nurses further impeded the relationship by reporting confidential information in their notes or to others thereby breaching trust within the relationship. However, Morse (1991) explained that some nurses justified this violation as a necessity for safe and efficient patient care. Acknowledging with the patient that this
‘breach of privacy’ may be necessary is part of forming the rules or boundaries of the therapeutic relationship.

Morse (1991) also found that patients hindered the progression of a relationship by not trusting the nurse and by behaving in a demanding or manipulative manner. Morse (1991) explained that these patients do not allow the nurse the opportunity to get to know them personally as they refuse to share information or ‘open themselves up’ to the nurse. This led to the patient and nurse distancing and avoiding each other and this was evident by the nurse-patient encounters becoming shorter, less official and less personal in nature (Forchuk et al., 1998, 2000; Morse, 1991; Moyle, 2003). The utilisation of distancing and avoidance strategies are further obstacles to a therapeutic relationship and are usually due to a lack of confidence or guidance in relationship building (Cleary et al., 1999).

Negative attitudes and even labelling or blaming patients for the futility of relationships is a further impediment to relationship building (Forchuk et al., 2000; Olsen, 1997). Forchuk et al. reported that nurses in their (2000) study held the patients responsible when relationships were ineffective. Nurses described these patients as hindering the progress of the relationship and used disparaging terms to label them as “difficult”, “frustrating”, “superficial” and “not co-operative” (Forchuk et al., 2000, p. 5). Some nurses had preconceived ideas about patients, they ostracized, disliked or feared patients (Forchuk et al., 2000) or considered them objectionable (Morse, 1991) and this then affected the care they gave them. The nurses’ frustration with the patient affected the time they spent with them which again led to burn-out and consequently avoidance and distancing in the relationship (Forchuk et al., 2000; King & Turner, 2000; Moyle, 2003; Ramjan, 2002, 2004). Three out of the ten dyads in Forchuk et al.’s (2000) study did not progress smoothly through Peplau’s (1952, 1991) phases (discussed earlier) but rather progressed from an ‘orientation phase’ to a ‘grappling and struggling’ phase to a final ‘mutual withdrawal’ phase when these factors hindered the therapeutic relationship. In many instances, such as that described above, care may be given to patients but this care will unfortunately be the bare minimum and will focus on providing technical skills rather than holistic, psychosocial care (Bailey, 1998; Moyle, 2003; Williams & Irurita, 1998).

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4 A dyad was a working partnership between one nurse and one patient (usually from admission to discharge). The nurse assignment could be altered if difficulties were encountered in the relationship.
Two Australian studies, examining the knowledge, perception and attitudes of health care professionals to patients with an eating disorder, discovered that these workers had fairly negative attitudes (Cameron et al., 1997; Fleming & Szmukler, 1992). Fleming and Szmukler (1992) surveyed medical and nursing staff (including students), by distributing in person or through representatives, questionnaires to a convenience sample of 497 people. Of the 352 respondents, the nurses were more likely to see patients with eating disorders as responsible for their illness and having the ability to “take self control” (Fleming & Szmukler, 1992, p. 442), the implication being that they ‘could’ and ‘should’ do so. Fleming and Szmukler (1992) discovered that knowledge affected attitudes and that there was a correlation between greater knowledge and a decline in negative attitudes. The link between knowledge level and attitude is reinforced by the study’s finding that nurses were considered the least knowledgeable of all the health care workers in defining eating disorders and recognising DSM criteria for anorexia and bulimia nervosa (Fleming & Szmukler, 1992).

The other Australian study (Cameron et al., 1997) reported similar findings. The authors studied school health nurses, adolescent health workers, dieticians and students of nursing and dietetics, using focus groups and individual interviews. Consistent with Fleming and Szmukler (1992) they reported that participants showed a “lack of sympathy” because they considered people with eating disorders to be “creating their own illness” (Cameron et al., 1997, p. 27). Student nurses in the study classified an eating disorder as either being a mental illness, addictive behaviour or self-harm. Those nurses, who had classified eating disorders as a mental illness, were more sympathetic in their responses; while those that classified eating disorders as addictive behaviour or self-harm were more insensitive and judgmental in their responses (Cameron et al., 1997). Cameron et al. (1997) concluded, a lack of knowledge, education and training were some of the main reasons for the negative attitudes and prescribed labels (Bailey, 1998; Cameron et al., 1997).

Not surprisingly the factors that foster therapeutic relationships are in conflict with the factors that inhibit such relationships. Patients in Forchuk et al.’s (1998) study described factors including nurses being accessible, dependable and consistent in their words and actions. The clients described how the relationship advanced when nurses respected them as people, showed a closeness, genuine liking and had trust in them as patients.
Patients with a severe mental illness from L. O’ Brien’s (2001, p. 179-180) hermeneutic phenomenological study explained that they particularly valued three aspects of the nurse-patient therapeutic relationship and these included: “having someone looking out for me”, “working in collaboration” and “being understood and gaining understanding”. They described how having this relationship with one person who was genuinely interested in them reduced their hospitalisations and allowed them to spend more time in the community. The nurses, in O’Brien’s (2000, p. 187) study, similarly described how “being there”, “being concerned”, “establishing trust” and “facilitating transition” were all important aspects for nurses attempting to form therapeutic relationships with clients. Moyle’s (2003) patients, who were diagnosed with major depression, described how being nurtured and comforted by the nurse was important as this helped them to feel safe within their new environment, while consequently nurses focusing on physical care tasks and objectifying the patient in terms of their illness and symptoms were viewed as extremely unhelpful.

There are obvious recurring elements, within all the studies, which are considered influential and imperative for the formation and maintenance of healthy therapeutic relationships. Dearing’s (2004, p. 158) grounded theory study, of nurses caring for people with schizophrenia, described these main elements succinctly in four themes: ‘knowing’, ‘socializing’, ‘normalizing’ and ‘celebrating’. Nurses needed to ‘know’ their patients in order for trust to form and a bond to develop and they could not ‘know’ their patients without ‘socializing’ with them, which meant spending time talking and interacting with them. ‘Normalizing’ entailed both patient and nurse strategising about concerns and impediments to recovery and how these could be resolved to ensure treatment compliance. This included finding ways to make medication compliance a routine part of daily life, nurses assisting patients to organise their time and participate in social activities that would reduce social isolation and loneliness in the community and lastly teaching and planning healthy lifestyles for them in terms of diet, exercise, sleeping patterns, smoking cessation and how to manage other medical conditions such as diabetes or hypertension. Nurses celebrated achievements and accomplishments made by their clients by expressing their happiness with patient’s progress, praising and reinforcing positive change, achievement of goals and successes (Dearing, 2004).
Dearing (2004) asserted that rapport was established in an environment where availability of time was apparent and where comfort, understanding and care were provided by nurses. Nurses listened to concerns and worked together with the patients to alleviate their concerns. Support and non-confrontational approaches were used to facilitate the relationship. Nurses displayed an empathetic attitude, felt positive about recovery and guided their patients to make the right decisions. Nurses felt that their working relationship with patients assisted patients in their recovery and with their compliance with treatment. Dearing’s (2004) nurses proposed that within the therapeutic relationship they were “truly caring for them as people, not seeing them as an illness, recognizing the uniqueness of them, and giving them a sense of empowering [sic] and a sense of control over their own lives. It’s letting them know they are in charge of their recovery” (p. 161).

In evaluation of the minimal literature examining the therapeutic relationship or nurses caring for people with anorexia nervosa, not unexpectedly the same themes emerged. A recent Australian grounded theory study of ten paediatric nurses by Micevski and McCann (2005) described elements that fostered therapeutic relationships between paediatric nurses and adolescents with anorexia. Once again nurses described how ‘building a rapport’, ‘being supportive’ and ‘developing trust’ were all important aspects of the relationship (Micevski & McCann, 2005, p. 105). Contextual factors which inhibited relationships included ‘unit protocols’, unclear ‘treatment plans’, ‘nurses’ workloads’, ‘insufficient education’ and ‘nurses’ perceptions of patients’ (Micevski & McCann, 2005, p. 105). Micevski and McCann (2005) argued that nurses’ being supportive of each other in this challenging area was crucial for the building of strong therapeutic relationships.

Ryan, Malson, Clarke, Anderson and Kohn (2006) provided an account of the experiences of fifteen nurses, caring for children and adolescents with anorexia nervosa, from three wards of two large metropolitan hospitals in Australia. An interview based discourse analytic methodology, revealed three main constructions. Nurses characterised their approach to nursing patients with an eating disorder as either ‘loving or empathetic support’, as ‘discipline and surveillance’ or as ‘constant and ever-present care’ (Ryan et al., 2006, p. 129-130). The authors argued that nursing may be seen as a type of ‘non-

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5 Note: the available literature on establishing therapeutic relationships with adolescents with anorexia does not explicitly outline whether nurses are working within behaviour-modification programs but to the reader it strongly suggests this type of program is in place. I am assuming there may be reluctance or uneasiness about using the term behaviour-modification and thus authors favour more ‘generic’ terms. This is unfortunately not helpful for someone attempting to review the literature.
specific supportive therapy’ as nurses descriptions of nursing as being ‘loving or empathetic support’, aligns with the elements necessary for a therapeutic relationship. However, the authors have not accounted for the other two elements, ‘discipline and surveillance’ and ‘constant and ever-present care’ in their claim and where these then fit in. The authors described two main limitations of their study, which included the cautionary generalisation of findings and that interviews may be open to varying interpretations (Ryan et al., 2006).

King and Turner (2000) provided a phenomenological account of the experiences of five paediatric registered nurses, caring for adolescent females with anorexia nervosa, in Victoria, Australia. The authors described how these nurses embarked on a journey when they cared for adolescents with anorexia. Six themes emerged from this study: (1) ‘personal core values of nurses’, (2) ‘core values challenged’, (3) ‘emotional turmoil’, (4) ‘frustration’, (5) ‘turning points’ and (6) ‘resolution’ (King & Turner, 2000, p. 142).

The nurses in King and Turner’s (2000) study initially expressed core values that they believed in, such as ensuring privacy, being trusting, maintaining confidentiality, being an advocate, providing fair treatment and being non-judgemental. These elements all form part of a therapeutic relationship. However these values were challenged as they cared for adolescents with anorexia. The nurses became distrustful of patients and of their behaviours and at times, they themselves became demoralised and felt like they were failures. They expressed “emotions of sadness, anger and being disheartened” (King & Turner, 2000, p. 142). The major emotion for these nurses was overwhelming frustration in having to battle against the adolescents for compliance with unit protocols. Many distanced themselves as a protective mechanism while others attempted to seek other solutions. Finally though, the nurses reached a point of satisfaction with the care they provided. They realised “that the quality of their care was not the reason why their patients did not attain wellness” (King & Turner, 2000, p. 143). On reflection the nurses were able to re-examine their values and saw these adolescents as being unwell. They discovered that caring for adolescents with anorexia was an enormous “learning experience” (King & Turner, 2000, p. 143).
My undergraduate Honours project (Ramjan, 2002) extended the work of King and Turner (2000). My original intention was to provide rich data on the development of therapeutic relationships between adolescents diagnosed with anorexia and paediatric nurses. However, I concluded that paediatric nurses were struggling to develop these relationships so the study was modified to explore the difficulties and obstacles hindering the formation of therapeutic relationships (Ramjan, 2002, 2004). It was not my intention to replicate King and Turner’s (2000) study but my findings concur with theirs. My naturalistic study (Ramjan, 2002) of ten registered nurses working within two acute wards of a children’s hospital in Sydney, Australia revealed four themes. The themes that emerged were: (1) ‘struggling for understanding’, (2) ‘struggling for control’, (3) ‘struggling to develop therapeutic relationships’ and (4) ‘suggesting solutions’.

The nurses in my study (Ramjan, 2002), like those in King and Turner’s (2000), had no formal mental health training. These nurses struggled to understand anorexia and its recovery processes. Many nurses believed that these adolescents ‘had caused their own harm and needed to fix it themselves’ (Ramjan, 2004, p. 498). This frustration created pessimism and disillusionment both of the adolescent’s ever achieving recovery and of this type of work. Some of the nurses considered it to be ‘a waste of time’ (Ramjan, 2004, p. 498). There appeared to be a continual power struggle for control taking place between nurses and patients with anorexia. There was also evidence of mutual distrust. For nurses this distrust primarily resulted from the adolescents’ manipulation. Nurses also presumed that adolescents did not trust them as well. Thereby the manipulation, mistrust and the struggle for control were identified as the main obstacles to the formation of therapeutic relationships in this study. An additional set of obstacles to therapeutic relationships for some nurses were ‘blaming the victim’, ‘labelling’ and ‘having favourites’ among patients (Ramjan, 2002, 2004).

Lastly, Garrett’s (1991) seminal study of nurses caring for severely anorexic patients in five eating disorder units of Sydney hospitals also revealed how nurses respected the importance of a trusting relationship. Garrett’s (1991) nurses described the challenges and the rewards that they faced in this type of work. They discovered that listening to their patients increased their awareness and knowledge of the disorder. As with the above studies on the therapeutic relationship and anorexia nervosa, recommendations were

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made for greater education, training and support for nurses and changes to treatment plans and protocols.

According to Welch (2005) the formation of a therapeutic relationship is an extremely challenging task which due to its importance requires the appropriate validation within mental health settings. Welch (2005) has further advocated that nurses require adequate training and practice in this skill. And of particular importance for this study, Dearing (2004) proposed that the nurse-patient relationship is a concept that is not being rightfully embraced in nursing practice. Indeed, Whittemore (2000) asserted recovery may be doubtful for patients, without this relationship with a nurse. In opposition to Welch’s (2005) arguments, ‘The Level System’ program, in this study acknowledges the therapeutic relationship only once within the entire policy document and this relationship requires much extensive validation as it currently has been given very little prominence within the policy document. As pointed out in the Context Chapter, the acknowledgement of such an important issue is made, during an explanation of the rationale behind the visiting restrictions of the program. Disappointingly, the therapeutic relationship within ‘The Level System’ program is not given the validation and support it rightly deserves.

The formation of a therapeutic relationship with an adolescent with anorexia may be even more challenging and complicated for the paediatric nurse on a ward with a behaviour-modification program and this thesis reveals these difficulties in greater depth. No research to date has compared and contrasted insights, from both adolescents with anorexia and their paediatric nurses, into how hospitalisation and day to day nursing practice, within an inpatient behaviour-modification program, impacts on the development of nurse-patient relationships and the significance of this for patient healing and recovery. This thesis ‘bridges this gap’ and addresses this deficit. This study also further enhances lay understandings of the nursing care for adolescents with anorexia within a behaviour-modification treatment program. This chapter concludes with adolescent and adult patients’ experiences of hospitalisation before the next chapter discusses the methodology of this study.

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6 As asserted to earlier, there appears to be a reluctance to clarify whether programs are behaviour-modification in nature. There is also a dearth of research examining the adolescent’s views on treatment. Thereby this examination of the literature focuses on hospitalisation in general (both adolescent and adult perspectives), not specifically within the context of behaviour-modification programs (although some treatment programs appear to be behaviour-modification programs).
3.11 PATIENTS’ PERSPECTIVES ON HOSPITALISATION

Not only is there a paucity of research in the area of adolescent anorexia and the therapeutic relationship, there is similarly a dearth of research examining the adolescent’s views on the treatment they receive in hospital (Colton & Pistrang, 2004; Creedy & Crowe, 1996; Gowers & Bryant-Waugh, 2004) and their perceptions of the nurse-patient relationship (L. O’Brien, 2001). Some surveys have examined the patient’s perspective regarding nursing care and the ward milieu (Anderson, Lampropoulos, Clarke & Kohn, 1999; Nusbaum & Drever, 1990). Anderson et al. (1999), in their survey of Australian adolescents’ satisfaction with inpatient care on an adolescent ward found that the adolescents appreciated treatment being effective as well as age-appropriate. They highly valued having peers on the ward with the same condition as this diminished their sense of isolation and difference. They were also pleased that they were consulted about treatment decisions and listened to, which in turn gave them a sense of control over the decision-making processes that were taking place. Anderson et al. (1999, p. 58) reported that they respected that their opinion was listened to and in the surveys the adolescents’ remarked “we know best how we feel”. The ward environment needed to be fun and friendly, with the opportunity for people to engage in diversional activities. Anderson et al. (1999) found that patient satisfaction with the ward’s ambience and routine as well as the care provided was instrumental in attaining greater compliance with treatment.

Similarly, adolescents with an eating disorder (n=19), in Colton and Pistrang’s (2004) interpretative phenomenological study of inpatient eating disorder units in the United Kingdom, also described pleasure with the support and understanding they received from others on the ward with the same condition. This allowed them to share experiences with someone who truly understood them. However, Colton and Pistrang’s (2004) participants also acknowledged that being in close proximity with others with the same condition was also negative and harmful with competition among patients being rife, some patients learning negative behaviours from others, and some patients expressing fear and upset in seeing others in a distraught state (Colton & Pistrang, 2004). Colton and Pistrang's (2004) participants also acknowledged the positive and negative aspects of treatment in that they appreciated the collaborative nature of the treatment program and felt as though they were being heard, but at times they felt they were being punished by the restrictions of the program. Yet Colton and Pistrang (2004) argued that essentially the structure and
consistency provided the patients with much needed stability. According to the authors some of the limitations of this study, were its small sample size and that it was conducted on two inpatient units in the United Kingdom thus limiting the generalisation of findings more widely and some concerns were expressed regarding the validity of accounts. However, the authors believed that accounts were ‘open’ and ‘honest’ (Colton & Pistrang, 2004). Colton and Pistrang (2004, p. 314) also stated that “the qualitative approach did not allow an examination of associations between such variables as family background, illness duration, stage of change and experiences of treatment”.

As with the literature on the therapeutic relationship, most of the literature available on patient’s perceptions of relationships focuses on the psychiatric patient in a community or psychiatric setting. Müller and Poggenpoel’s (1996) phenomenological study explored thirteen psychiatric patients’ perceptions of their interactions with psychiatric nurses in South Africa. The patients in this study described fairly negative experiences of being cared for within a psychiatric setting. Müller and Poggenpoel (1996) described how patients felt that nurses lacked the qualities of open-mindedness and acceptance and treated everyone in a stereotypical fashion. The patients also felt that nurses took on a custodial role and as caretaker they enforced rules and made decisions without promoting patient participation. Although the patients described the nurses as caring and friendly they felt the relationship lacked empathy and closeness with the latter being seen as vital elements required for the formation of a therapeutic relationship. Some of the interactions between psychiatric nurses and patients in this study were deemed to be not therapeutic, with some patients reporting instances of physical abuse. Müller and Poggenpoel (1996) declared that “if nurses were more knowledgeable (intellectually and emotionally) about the internal world experiences of their patients, they would render more adequate therapeutic intervention” (p. 143).

On the other hand, L. O’Brien’s (2001) Australian study described earlier discovered more positive relationships forming between adult clients with severe mental illness and their community psychiatric nurse. These relationships were deemed to be therapeutic by clients as clients described how they appreciated ‘having someone there’ to provide them with safety, security and the reassurance they needed to cope with their illness. The relationship was strengthened because clients were working in partnership with the community psychiatric nurse. The client’s described the nurse as an ally and advocate for

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them who also respected and supported them. They felt that they were given choices and allowed to execute these choices. Lastly they felt that these nurses truly understood them, trusted them, spent genuine time with them and did not judge them. These are all crucial elements for a therapeutic nurse-patient relationship. The five clients in this study believed their relationship with these nurses was “life-sustaining” (L. O’Brien, 2001, p. 183) without which they would probably not be able to survive in the community. L. O’Brien (2001) discovered that for these clients their self-esteem was elevated through having someone who genuinely believed in them as a person and provided them with optimism and support to cope in the community with a mental illness. Thus it can be seen from the above studies, that psychiatric patients have viewed their relationships with psychiatric nurses, in both positive and negative ways.

As reported earlier, thirteen women with anorexia in Beresin et al.’s (1989) study, similarly believed that recovery was assisted by the formation of a therapeutic relationship characterised by someone who genuinely listened and expressed concern. Not all patients with an eating disorder have reported negative experiences of inpatient hospitalisation. Some patients perceive the environment to be supportive and helpful when their psychological needs are being addressed. They feel a sense of safety and security in an environment that removes them from external stressors. Discharge for these people can be a daunting experience as the support may not be continued and they are expected to resume their normal everyday activities. Relapse can be a positive experience as the patient returns to a place they consider a ‘safety net’ from the outside world (Gowers et al., 2000).

With control being a central feature of anorexia nervosa; this means that many young people are ambivalent about accepting inpatient treatment (Gowers & Bryant-Waugh, 2004). Many adolescents ‘eat to get out’ (Moorey, 1991). For these adolescents with anorexia the hospital environment can be linked with an increased sense of vulnerability and an increased sense of a loss of control (Eivors, Button, Warner & Turner, 2003). Patients with an eating disorder, in both Eivors et al. (2003) and Malson, Finn, Treasure, Clarke and Anderson’s (2004) studies described the intense focus on symptoms and pathology within treatment to the detriment of understanding the patient as a person. In fact, Malson et al. (2004) described how some patients felt that health care professionals ignored their opinions and felt they were unfit to partake in discussions about treatment

Chapter Three: Literature Review
because “it’s the illness talking” (p. 485). Those patients in Colton and Pistrang’s (2004, p. 312) study also described how staff did not see them as unique individuals but as “just another anorexic”. Colton and Pistrang’s (2004) patients felt treatment primarily focused on gaining weight and they wanted further psychological interventions.

Buston (2002) undertook a grounded theory study which utilised semi-structured interviews and a questionnaire to examine the experiences of adolescent users of mental health services. The author reported that some of the adolescents with anorexia perceived and described their treatment in negative terms with some relating feelings of mortification as a result of the infringement of their privacy and the strict treatment routines. The women with anorexia in Beresin et al.’s (1989) recovery study, similarly expressed strong negativity towards inpatient hospitalisation yet also described it as helpful. The negative factors included the behavioural program’s emphasis on weight gain. They described the behavioural techniques that were being used as demeaning. The patients described how “[t]hey felt devalued, humiliated, and condemned being constantly watched” (Beresin et al., 1989, p. 118). Their time in hospital was made even more frustrating when staff did not possess an ‘empathetic understanding’ of their condition. In addition, participants believed that little attention was given to the transition from hospital to home or school which made their reintegration back into society significantly more difficult. Nevertheless, most of these women did feel a sense of security and safety within the hospital environment and felt relieved that someone was taking over control and making decisions for them. The monitoring that was so despised by some was also consequently seen as an aspect of staff showing care by others (Beresin et al., 1989).

As demonstrated throughout this chapter, the nursing literature strongly advocates that a therapeutic nurse-patient relationship is vital in assisting healing or recovery. As nurses provide continuous care for adolescents with anorexia while hospitalised, it would appear that they would be ideally suited to forming such relationships with patients on the ward. Despite the limitations noted for individual studies cited, overall the literature demonstrates a strong consistency in findings across a diverse range of clinical settings and conditions. Further, as this review demonstrates there has been no research to date which has obtained insights from both the adolescent with anorexia and the paediatric nurse, into how hospitalisation and the day to day nursing practice, within an inpatient behaviour-modification program impacts on the development of such relationships.
Furthermore, as Buston (2002) and Colton and Pistrang (2004) have asserted, and the foregoing review confirms, there is a dearth of qualitative research examining the adolescent’s viewpoint of treatment. Cameron et al. (1997) argued that with much of the research on the therapeutic relationship centred on psychiatric nurses and psychiatric adult patients, there is a great need for more qualitative research in the area of adolescent anorexia nervosa. This thesis contributes to the research evidence by addressing both of the above identified deficits in the literature.

Many challenges hinder the formation and maintenance of therapeutic relationships and these challenges may be even more pronounced for nurses working with adolescents with anorexia within a behaviour-modification treatment program. Through an understanding of the obstacles, strategies can be devised to improve these relationships, which it can be reasonably argued, will ultimately increase nurses’ job satisfaction and improve the quality of patients’ lives. Deering (1992) emphasised the importance of therapeutic relationships and that an examination of the various behavioural interventions used within programs would enhance nursing practice. Deering (1992) also argued that with the high rates of recidivism following inpatient hospitalisation, research needed to evaluate how much flexibility is possible within an inpatient program while still retaining its success? Both nurses and adolescents with anorexia can provide valuable insights on improving hospital treatment and nursing practice within a behaviour-modification program (Deering, 1992). The next chapter (Chapter Four) discusses the methodological approach used for this study.
Chapter Four

METHODOLOGY

“As constructivists aiming to understand the different ways in which people make sense of their worlds, we must try to gather data that reflect as fully as possible the construct systems of our participants”

Nagy & Viney, 1994, p. 16.
4. METHODOLOGY

The employment of the ‘naturalistic’ paradigm (Guba, 1981; Guba & Lincoln, 1981; Lincoln & Guba, 1985) also known as the ‘constructivist’ paradigm (Guba & Lincoln, 1989) allowed me to ‘enter and explore the worlds’ of patients with anorexia nervosa and the nurses who care for them. This particular methodological approach was considered the most viable in effectively gaining an appreciation of the daily experiences of ward life, for adolescents with anorexia and their nurses. One of the reasons why this mode of inquiry was particularly apt for this study was because this study relied extensively on ‘human constructions’ of reality as a basis for understanding the ‘world view’ of patients with anorexia and the nursing staff who cared for them. This is consistent with Erlandson, Harris, Skipper and Allen’s (1993, p. 9) viewpoint as they argue that “Lincoln and Guba’s naturalistic inquiry and constructivism…offers a workable rationale for performing significant research in human settings”. This approach enabled an in-depth analysis of both nurses’ and patients’ perceptions of the ward environment, the treatment program and the nursing practice within that program, to elicit a deeper understanding of the impediments to therapeutic relationships. This chapter both briefly outlines the philosophy behind naturalistic inquiry and then explores in-depth how the elements of naturalistic inquiry have been applied within this study.

4.1 NATURALISTIC INQUIRY

The naturalistic or constructivist paradigm evolved from the work of Egon Guba and Yvonna Lincoln (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985). This inquiry is useful in reconstructing and understanding “real-world situations” as they are ‘brought to life’ by the participants within the natural context (Patton, 2002, p. 40). The data obtained from a naturalistic study is ‘context-dependent’ thereby generalisations to other settings are impossible (Erlandson et al., 1993). Nevertheless an in-depth understanding and explanation of social phenomena and interactions as they occur within a particular context (such as on an adolescent ward) is possible and this is another reason why naturalistic inquiry was chosen for this study. Participants’ constructions of everyday life and participants’ meanings cannot be detached from their context in this study (Nagy & Viney, 1994).
Additionally naturalistic inquiry is based on negotiation (Koch, 2000). Writing of its use in an evaluation study, Koch (2000, p. 118) argued that, “[t]he appeal of a ‘negotiation’ process is that the evaluation strives to give its stakeholders a voice or the opportunity ‘to have a say’ about things that affect them”. This was particularly crucial for this study as both nurses and patients were the most knowledgeable about the nurse-patient relationships being formed within this treatment setting and, as described in Chapter One, I also particularly wanted the adolescents’ voices to be heard rather than restrained. Thus, through a naturalistic approach, I was able to discover the unique, situation and context-dependent meanings of interactions and relationships for both nurses and patients; the two main stakeholders involved in the Eating Disorder Program.

Before elaborating on how naturalistic inquiry has been applied within this study, a brief discussion of the basic assumptions and the five axioms (basic beliefs) of naturalistic inquiry are discussed below to give the reader a clearer understanding of this methodological approach.

### 4.1.1 BASIC ASSUMPTIONS OF THE NATURALISTIC PARADIGM

According to Denzin and Lincoln (2005, p. 24), “[t]he constructivist paradigm assumes a relativist ontology (there are multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a naturalistic (in the natural world) set of methodological procedures”. In other words, the participants are able to describe their distinctive, mental constructions of reality which may differ from others (Guba & Lincoln, 2005; Koch, 2000). Epistemologically, the researcher and study participants must work together throughout the research process in order to mutually construct knowledge or understandings of phenomena. These constructions are continually tested and modified as differing viewpoints arise and result in previous constructions being reassessed and replaced with newer more sophisticated and mature constructions (Charmaz, 2003; Guba & Lincoln, 1981, 1989, 1994, 2005; Lincoln & Guba, 1985). The methodological procedure used is the ‘hermeneutic-dialectic’ process (Guba & Lincoln, 1989). It is ‘hermeneutic’ in the sense that it is ‘interpretive’. The researcher and participants ‘interpret’ the co-created constructions of reality. It is also ‘dialectic’ because it involves the ongoing ‘negotiation’ among those involved regarding the meaning of varied constructions so as to obtain a ‘consensus’ (Appleton & King, 1997, 2002; Guba & Lincoln, 1981, 1989; Lincoln & Guba,
Thus, as Gadamer (1989) has asserted hermeneutics is the study of ‘texts’ or more broadly language. Consistently, according to Cohen (2000, p. 5) “the object of [such] research is both language [as well as] the individual user of the language”.

Through the negotiation process and the process of comparing and contrasting divergent experiences within the natural environment, the researcher attempts to achieve a consensus or shared meaning among participants that enhances the insights gained from individual constructions (Appleton & King, 1997, 2002; Guba & Lincoln, 1994; Ford-Gilboe et al., 1995; Hinshaw, 1999; Lincoln & Guba, 1985; Weaver & Olson, 2006). As constructions always remain time and context-bound, there is no fundamental ‘truth’ in existence (Charmaz, 2003; Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985; Miller & Crabtree, 1999). According to Ford-Gilboe et al. (1995) “truth is both complex and alterable based on ongoing experiences and their meaning to the person” (p. 17).

Although both qualitative and quantitative methods can be applied in naturalistic inquiry, qualitative approaches are favoured by naturalists as a means of obtaining ‘thick descriptions’ (Erlandson et al., 1993). Clifford Geertz (1973) originally defined the concept ‘thick description’ and according to Muecke (1994), thick description allows for a “coherent interpretation that engenders understanding of differences” (p. 196). Participants' stories are the best way to elicit rich, detailed data which then assist with understanding individual experiences within a particular context (Ford-Gilboe et al., 1995).

Both relevance and rigour are important to naturalistic research, however relevance is paramount (Erlandson et al., 1993). These issues will be addressed later in the chapter. Grounded theory (Glaser & Strauss, 1967) is also preferred as it allows for the constant comparison of results (Lincoln & Guba, 1985) as data collection and analysis occur simultaneously throughout the research process (Charmaz, 2005). According to Polit and Hungler (1995, p. 643) grounded theory is “an approach to collecting and analysing qualitative data with the aim of developing theories and theoretical propositions ‘grounded’ in real-world observations”. This is accomplished by way of collecting rich, ‘thick descriptions’ of data and the line by line analysis of verbatim interview transcripts (Ryan & Bernard, 2003).
The research design in naturalistic inquiry stems from the research itself and as per its name, the natural setting is preferred over a controlled or laboratory setting as context is imperative to meaning (Erlandson et al., 1993). Finally, the primary research instrument in naturalistic inquiry is the human researcher (Erlandson et al., 1993; Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985) because of the human researcher’s adaptability and flexibility to act in response to unexpected situations (Appleton & King, 2002). The human researcher is also, according to Patton (2002), capable of discovering and interpreting constructions and then verifying these with participants (‘member checking’).

Within this chapter (and also Chapter One), the ‘first person’ rather than the ‘third person’ is used to remain true to the elements of naturalistic inquiry. According to Lincoln and Guba (1985, p. 365) case reporting within naturalistic inquiry “should be informal”. There should be adequate detail so as to enable the reader to feel a sense of “déjà vu” if they were to enter the research site (Lincoln & Guba, 1985, p. 365). In this way, Chapter Two: Context, attempts to provide the reader with enough detail to vicariously experience the research site and ‘The Level System’ program under study. The ‘first person’ has also been used within Chapter Four to emphasise the importance of my contribution, as researcher, to the study. As asserted earlier, the researcher co-creates understandings with participants and is thus an invaluable member of the study (Lincoln & Guba, 1985). Without the researcher the study would not be possible as the researcher is in charge of the process of analysis and this role needs to be made as transparent as possible.

In naturalistic inquiry it is also imperative to understand the step by step processes taken by the researcher. Emden and Sandelowski (1998) reported that “goodness [in qualitative research] is as much about where and how researchers derive their beliefs, assumptions, motivations and ways of working, as about judgement on research procedures and findings reached via the application of specific criteria” (p. 207). Both the researcher’s tacit knowledge (intuitions, apprehensions or feelings) and propositional knowledge (theoretical knowledge) are enhanced during a naturalistic study and through the choices he/she makes (Erlandson et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985). In fact, the researcher’s personal intuitive experiences influence the inquiry process and choice of subject matter in naturalistic inquiry (Appleton & King, 2002). Figure 1: Naturalistic Inquiry, on the following page summarises the characteristic flow of a naturalistic study.
FIGURE 1: Naturalistic inquiry (adapted from Lincoln & Guba, 1985, p. 188)
4.2 THE FIVE AXIOMS OF NATURALISTIC INQUIRY

The five axioms (basic beliefs) of naturalistic inquiry are briefly explored below to enhance the reader’s understanding of this methodological approach.

4.2.1 AXIOM 1: THE NATURE OF REALITY (ontology)

Naturalistic inquiry assumes there are “multiple constructed realities” that need to be examined holistically for understanding (Lincoln & Guba, 1985, p. 37). The dissimilarities among “multiple realities” in essence consolidate and strengthen the researcher’s understanding of the social phenomena under study (Appleton & King, 2002; Erlandson et al., 1993). The individual reconstructions amalgamate to attain a ‘common’ meaning or understanding of the social phenomena that is more sophisticated and more insightful than individual constructions (Ford-Gilboe et al., 1995; Guba & Lincoln, 1994; Schwandt, 1994).

Nurses and patients within my study at times painted dissimilar pictures of ‘life on the adolescent ward’, yet it is these unique variances within and across participants that provide rich meaning about the different types of relationships that formed and the interactions that took place between the nurses and patients with anorexia nervosa. The ‘shared’ constructions along with those ‘not shared’ allowed for greater insight into ‘life on the ward’ that was situation, time and context-dependent.

4.2.2 AXIOM 2: THE RELATIONSHIP OF KNOWER TO KNOWN (epistemology)

The researcher and participants are “inseparable” and mutually influence each other (Lincoln & Guba, 1985, p. 37). As Erlandson et al. (1993, p. 15) explained research methods should never distance the researcher from the “human interaction that is the heart of the research”. Schwandt (1994, p. 118) also asserted that through “complex processes of social interaction” people make sense of their experiences and attribute meaning to them. To fully and accurately comprehend the activities and interactions that
take place one must also be a participant or observer of those activities (Erlandson et al., 1993).

As a nurse myself who has worked on the ward for six years and continues to work on this adolescent ward, I was acutely aware of the jargon employed and the activities that nurses and patients were involved in as part of the ward’s Eating Disorder Program. As a junior nurse, I frequently had the opportunity to care for adolescents with anorexia. Currently, as a senior nurse on the ward, these instances have become much less frequent. Nevertheless, being a part of one of the communities under study and an ‘insider’ both had its advantages and disadvantages as will be explained later in this chapter.

To maintain credibility, it was important for me to control any unintentional bias or participant ‘reactivity’. Lincoln and Guba (1985, p. 94) explain that participants may react or respond differently when they are aware of the study’s aims or of “being tested” in some way and as a result they may inadvertently distort their constructions to satisfy the study’s aims. This is called ‘reactivity’ (Lincoln & Guba, 1985). The co-constructed data needs to remain true to the study participants and it needs to be affirmed and verified by the study participants as accurate constructions that have not been unduly influenced by the researcher’s prejudices (Erlandson et al., 1993; Leininger, 1994; Lincoln & Guba, 1985). I have used reflexive diary entries to assist me in ‘bracketing’ my own personal thoughts, feelings and preconceived ideas throughout the research process so that these do not adversely affect the co-constructed realities. The purpose and relevance of reflexive diary entries will be explored in greater detail in section 4.10.1.5. As Patton (2002, p. 570) explains, naturalistic inquiry acknowledges that the researcher’s values and beliefs can influence the study and these need to be minimised through “conscious and committed reflexivity”. The researcher needs to reflect on and analyse how their perception of reality interacts with the participants’ perceptions of reality (Patton, 2002).

4.2.3 Axiom 3: The Possibility of Generalisation

Generalisations cannot be made to other settings; data from a naturalistic inquiry has the greatest meaning for the individual ‘context’ under study (Erlandson et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985; Patton, 2002). However, ‘working hypotheses’ can
be designed for another setting if there is a substantial amount of ‘thick description’ of events or circumstances of a particular context that allows for transfer of understanding to the ‘new’ context to be studied (Erlandson et al., 1993; Guba, 1981; Guba & Lincoln, 1989; Lincoln & Guba, 1985). According to Erlandson et al. (1993, p. 16) naturalists “settle for a deep understanding and explication of social phenomena as they are observed in their own contexts”.

In Chapter Two a detailed description of the context (natural setting) has been provided for the reader. Within this chapter a comprehensive examination of the study processes undertaken by the researcher including information on the study participants and selection criteria, the data collection and analysis methods used, along with the techniques used to maintain trustworthiness in the study, are described. In Chapter Five: Results, verbatim interview excerpts are utilised to bring the participants’ voices to life. This rich, detailed data (‘thick description’) allows a reader to determine the transferability and applicability of observations and findings or ‘working hypotheses’ from this study to another similar context or the same context at a different point in time.

4.2.4 AXIOM 4: THE POSSIBILTY OF CAUSAL LINKAGES

There are no cause and effect relationships in naturalistic inquiry. The researcher and participants and the elements of the context are in a state of “mutual simultaneous shaping” (Lincoln & Guba, 1985, p. 38). According to Lincoln and Guba (1985) “[e]verything influences everything else, in the here and now” (p. 151). The researcher, his or her actions and the situation or events at that time influence the participant, his or her actions and the situation or events and vice versa. Together the above interactions create and shape meaning for the context under study for that particular time (Guba & Lincoln, 1989; Lincoln & Guba, 1985). Lincoln and Guba (1985, p. 155) described it as a “photographic slice of life” in the “here-and-now”.

As Charmaz (2003, p. 270) explained “[t]he social world is always in process, and the lives of the research subjects shift and change as their circumstances and they themselves change”. The constructions created by participants in this study may have different meanings for another set of participants or the same set of participants at a different point in time. This may be a result of altered circumstances including personal

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growth and maturation of participants or changes to the patient mix, staff mix, ward or program dynamics. My study findings were inevitably context and time dependent and so naturalistic inquiry was the most feasible approach to obtain a grasp of the ‘unique shapings’ that took place between this particular set of nurses and patients, on this particular ward, at this particular point in time.

4.2.5 AXIOM 5: THE ROLE OF VALUES IN INQUIRY (axiology)

All naturalistic inquiry is value-laden. The inquiry is influenced by the researcher’s beliefs and values, the choice of paradigm, the choice of substantive theory and the values embedded within the context (Guba & Lincoln, 1989; Lincoln & Guba, 1985). The inquiry can be as Lincoln and Guba (1985, p. 38) described: “value-resonant” or “value-dissonant”. Dissonance implies that the four variables set out above conflict with each other while resonance suggests they support each other. The significance of the data collected depends on whether there is resonance or dissonance among the researcher’s values, choice of paradigm, theory and context. Resonance in the inquiry is imperative for the acquisition of reliable data (Lincoln & Guba, 1985).

Throughout this chapter I report on the influence my ‘values’ and beliefs had on the choice of research problem to be studied, how my ‘values’ affected the choice of paradigm and the methodology selected for guiding the inquiry and for collecting and analysing data, how context has shaped the study and lastly how the beliefs of all participants within the study were equally influential in creating the constructions of reality.

4.3 THE NATURALISTIC NATURE OF THIS STUDY

4.3.1 GETTING STARTED

This journey of ‘discovery’ and ‘interpretation’ of life on an adolescent ward catering for patients with anorexia nervosa, from the perspective of both the nurses and patients, was personally for me one of both highs and lows. What follows is a succinct review of my research journey including the major decisions I have made from the time I embarked on this journey until I reached my final destination.
My initial dilemma was the issue of ‘getting started’ and identifying a research question to study. I spent a considerable amount of time reviewing literature and procrastinating over the question: ‘What exactly did I want to explore’? Identifying a general area of study was the easy part. Since my undergraduate nursing studies I have shown a partiality and passion for mental health nursing and when I started working as a clinician six years ago on an adolescent ward this interest narrowed to the area of adolescent anorexia nervosa.

After a great deal of thought and deliberation I decided to extend my previous undergraduate research project (Ramjan, 2002, 2004), which looked at the establishment of therapeutic relationships with adolescents with anorexia from the perspective of the nurse and found nurses to be “struggling to develop” these relationships. There continues to be a paucity of research specifically looking at adolescents with anorexia and the establishment and maintenance of therapeutic relationships and the barriers to such relationships. I realised that this was an area that still needed further investigation. Additionally, the increased number of paediatric hospitalisations and the ‘revolving door syndrome’ among adolescents with anorexia (Marcus, 2006; McDermott et al., 2001; Rhodes & Madden, 2005) also concerned me greatly.

Despite positive comments from patients advocating the therapeutic potential and healing nature of nurse-patient relationships, these relationships remain astoundingly under-researched for people with anorexia nervosa. Patients in Geanellos’ (2005) study felt that their recovery from a hospital admission after illness or injury was significantly enhanced by the nurse-patient relationship. For instance, these participants optimistically remarked that the nurse-patient relationship “was a marvellous thing to your well-being, a total aid to your recovery” and “[i]t was the best therapy of the lot, it made a world of difference” (Geanellos, 2005, p. 246). So with the therapeutic potential of nurse-patient relationships in mind, I decided I would examine in greater depth the impediments to such relationships with adolescents with anorexia by examining what effect, an eating disorder program, the hospital environment and the way nurses practiced, had on the formation of these relationships on inpatient wards. Since I currently worked part-time on an adolescent ward, I myself have directly witnessed the frustration that nurses, patients and family members have experienced with an inpatient treatment program for adolescents with anorexia. Thus this study was in part stimulated by a desire to reduce this dissatisfaction.
Through my research I wanted to make a constructive difference to the nurses’ and adolescents’ quality of life. In particular, I wanted the adolescents with anorexia to have their ‘voice’ heard rather than their ‘voice’ being suppressed by more powerful stakeholders. To enhance this current study, I decided it would be best to interview the stakeholders who were the most knowledgeable about the issue of therapeutic nurse-patient relationships: the nurses and the adolescents themselves. I also felt that by comparing and contrasting, at least two different adolescent wards in Australia providing care for adolescents with anorexia nervosa, this would further extend the knowledge in this area.

My first step was to find out which hospitals had programs for adolescents with anorexia and the types of programs that were in place. By searching the Internet I began my quest for the names of government, non-psychiatric hospitals with inpatient programs for adolescents with anorexia. The list was too exhaustive so I decided to narrow it down to children’s hospitals with adolescent wards and inpatient programs, since I worked on an adolescent ward in a children’s hospital. The list was then narrowed down to eight large metropolitan children’s hospitals within Australia.

With my list of paediatric hospitals in hand I then emailed each of them, explained my proposed project ideas (to investigate whether the formation and maintenance of therapeutic nurse-patient relationships, between adolescents with anorexia and nurses, were possible within an inpatient treatment program) and asked for further information about their current inpatient treatment program. I had an excellent response rate with all eight hospitals responding in some way to my initial enquiries. Most hospitals explained that inpatient care was specifically designed to achieve medical stability with further treatment being provided to patients as an outpatient service. All the hospitals that responded directed me to the people specifically in-charge of the programs or people who would be able to further assist me with my enquiries. Further email correspondence was sent out either to a Consultant, Nursing Unit Manager, a dietician or a nursing staff member at each of these particular hospitals with a request for a copy of their inpatient program or further clarification on their inpatient treatment. I was provided with further information on six of the eight hospital programs for adolescents with anorexia. Two of the children’s hospitals did not respond again to any of my recurrent queries.
Three out of the remaining six children’s hospitals were based in New South Wales and their programs were found to be, on inspection, very similar. I then decided to choose one program from each state to study. I purposely chose to study the children’s hospital at which I currently work. Being familiar with the program at this site allowed me to have greater insight and a different perspective into the ward dynamics than would someone without this experience and also being known to the site can make accessibility easier as well, which is important in a naturalistic study (Erlandson et al., 1993; Lincoln & Guba, 1985). I then focused on obtaining research approval from one hospital from each state that had responded to my email enquiries (four hospitals in total). These hospitals also needed to show support of the study being conducted on their wards and support of their staff and patients being interviewed face-to-face. The Nursing Unit Managers (NUM) at each of the four children’s hospitals were interested in the study as described to them in my email correspondence and were very keen for their wards and their staff to be involved. I was now extremely enthusiastic about ‘getting started’ on this research. Email remained the easiest method of communication, although phone contact was made on occasions.

I then began the demanding task of compiling ethics proposals for each of the hospitals. This process took several months. Once finalised, these proposals needed to be reviewed and accepted by the Head Consultant of each Eating Disorder Team who then needed to sign with their approval before the application was submitted to each individual hospital’s Ethics Committee. Each NUM advised that they would forward the proposal on to their respective team members for review when the proposal was ready.

As I will now explain, the next steps of the process did not go so smoothly. My euphoria soon turned to despair. It felt like someone had a tight hold of my heart and was slowly, painfully squeezing the life out of me. I was now ready to send out the ethics proposals and was ‘thrown a curve-ball’ as the Nursing Unit Manager at one of the hospitals had unexpectedly changed. I was confronted by someone ‘new’, someone that I had not been in correspondence with over the last few months and who unfortunately did not seem as interested in my project. The correspondence I received from this NUM gave me the impression that as an ‘outsider’, I was a threat. Although this is my opinion, I felt that this NUM was afraid that as an ‘outsider’ I would be coming in and opening a ‘pandora’s box’ of sorts that this NUM preferred to leave unopened. The NUM did advise that the
information about my project would be passed onto the Head Consultant of their Eating Disorder Team but suggested that I email them directly.

I emailed this Consultant numerous times asking whether the Team would be interested in this project and whether they would like to review a copy of the ethics proposal however I received no reply at all. The secretary emailed me back once saying that at that time the Consultant was overseas on conference but would reply to me on return in a week’s time. I waited but still no reply or acknowledgement of any of my numerous emails. As time is precious during a doctoral candidacy, I decided at this stage it would be best to relinquish this children’s hospital from my selection due to an apparent lack of interest and subsequently the support which would be necessary to facilitate the research.

An ethics proposal was then sent out to the Nursing Unit Managers at the other three children’s hospitals for review by Team members. The wait for feedback became a lengthy process taking several months for each hospital. The wait was tense and the outcome completely devastating for me. Three months later the NUM at one of the remaining three hospitals emailed me back saying that their Team members had reviewed my proposal but were not able to “commit” to this project due to “other demands” and “limited resources”. They were sorry for the delay in responding and the proposal did not go to their Ethics Committee. From my research diary excerpt you can see that I was desperate for good news:

30th March 2004

Today’s another demoralising day. I have just received an email from the NUM of the adolescent ward in [X]*. She politely writes: ‘Several members of our team have now looked at your proposal and consider that our team and program are not able to commit to this’. I feel like I have been thrown into an abyss and I can’t get out. I am in the depths of despair. I have been lead to believe through emails that these wards and their nursing staff are very interested in pursuing and being part of my project only to be faced once again with rejection. Perhaps though, I should not lay all the blame on the nurses. They may genuinely have been interested in taking part but maybe the other members of the team were not as eager to have a ‘post-graduate student’ and an ‘outsider’ enter ‘their’ domain and undertake qualitative research on ‘their’ eating disorder program and ‘their’ patients. I can only surmise that this may have been the ‘true’ reason why I have been so devastatingly rejected after being so highly supported up to this point in time. I can only keep praying that the team at [Y]** and my hospital accept the proposal.

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My last chance to do a comparison lay with the remaining two children’s hospitals, of which one was my place of employment. The Nursing Unit Manager at the children’s hospital in which I was not employed was very supportive of my project throughout and very helpful in relaying information to me via email or on the phone. Good news came when the Team at this hospital asked for some modifications to be made but on the whole thought it was a very worthwhile study. The Team decided that it would be better for me to undertake on-line interviews with their patients after discharge as this they felt would be less threatening to patients. They still thought it would be possible within my time-frame even though it would take longer to achieve a sample as I would have to wait weeks to months until patients were discharged from the hospital program.

At first I was disappointed that I would not be able to have face-to-face contact with inpatients at this hospital. I felt that it would detract from the quality of data being collected. I once again had this feeling that perhaps being an ‘outsider’ made me somewhat of a threat and that perhaps the ‘gate-keepers’, i.e. the Eating Disorder Team, were denying me access to their patients because they were protective of their patients, territorial or both (again this was my perception at the time). I nevertheless agreed to the modifications, sent out the new proposals for acceptance and then these were forwarded to their Ethics Committee for the next meeting. After another long wait, the Ethics Committee at this particular hospital was not happy with the idea of on-line interviews with patients and, not surprisingly, suggested face-to-face interviews or telephone interviews for richer data and a more accurate comparison between hospitals. I sent the Ethics Committee a letter explaining that, originally, I had wanted to undertake face-to-face interviews but the Team had suggested on-line interviews. I was caught in a bind. The Eating Disorder Team at this hospital wanted on-line interviews with discharged patients and their Ethics Committee preferred face-to-face interviews with inpatients.
Time was ticking away and my patience growing thin. As a sole researcher and student I would not be influential enough to change the Team’s mind and even if I did, I would have to re-submit another Ethics proposal and then wait months again for the next Ethics Committee meeting and then months more for a response. The task of reconciling the ‘political conflict’ between the Team and their hospital’s Ethics Committee would have been too time-consuming (physically and financially) for a doctoral candidate living in another state. All I could think about was that I needed to start collecting data now. I was absolutely terrified that I would not gain ethics clearance from any of the hospitals chosen and thereby I would need to re-evaluate my situation and whether I would be capable of completing a doctoral thesis on my chosen area of study or completing one at all within the allocated time-frame.

My only salvation came when I received a letter from the children’s hospital at which I work. My ethics submission had been approved with some minor adjustments. They agreed without hesitation to face-to-face interviews with their staff and their inpatients with an eating disorder. I decided that since I did not have the time to persuade the other hospital’s Team to accept my original proposal, my study would have to be an in-depth study of the program and nursing practice at one hospital only. It appeared again that the Team at this last site were unwilling to provide me access to their patients, thus suggesting I undertake online interviews instead of face-to-face interviews with inpatients. In retrospect I decided, that I should not compromise my original research aim, which was to undertake face-to-face interviews with inpatients or discharged patients who had been cared for on wards with treatment programs for adolescents with anorexia. As I could not undertake the face-to-face interviews with patients at this last site then I would need to unfortunately abandon this site as well.

Regardless of the abandonment of alternate sites for comparison, this did not diminish the strength of my study findings. It is important to note, that a comparison of programs was originally intended to enhance the knowledge base in this area, nonetheless an in-depth exploration of one program can also augment current understandings in this area. Retrospectively, the site utilised in this study was “the best site within the inquirer’s resources” (Erlandson et al., 1993, p. 64). It ensured the successful completion of this study within an appropriate time-frame.

Chapter Four: Methodology
So once I had made minor adjustments to the accepted proposal, which reflected my new position regarding an in-depth study of one hospital program, I was able to start the data collection and analysis process. I would have enjoyed doing a comparison of at least two different models of care on different adolescent wards but in hindsight see that the obstacles to ethics clearance may have been a blessing as it would have been too great a task in the limited time-frame of a doctoral candidacy. I now realise that the interview data I have gathered from one hospital is enough to probably write two individual theses and was more than sufficient to achieve the project's aim.

4.4 THE SITE AND ITS CONTEXT

As explained earlier, no full generalisability to another context is ever possible within naturalistic inquiry and consequently no study can specifically detail every aspect of a context. However, a good study can paint detailed enough pictures that promote understanding and “that bring the researcher or reader vicariously into the setting” (Erlandson et al., 1993, p. 18). Chapter Two: Context has attempted to provide the reader with this detail about the site, the ward environment and details of the eating disorder program under study.

As asserted earlier, the selection of a site and accessibility to this site is an important part of naturalistic inquiry. The researcher needs to be able to capitalise on the opportunities provided by that site to explore and observe day-to-day contextual interactions so that the problem can be explored in depth, as the data collected has the most relevance for the site, context and time in which it was collected (Erlandson et al., 1993; Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985). This would not have been possible within the other proposed sites without their full support and this was not forthcoming. Lincoln and Guba (1985, p. 301) suggested that it is important for the researcher to spend time in the site under study and called this activity “prolonged engagement”. The researcher needs to spend enough time in the site, to feel enmeshed in the culture, to become aware of any distortions being introduced into the study either by participants or oneself and to be able to establish a trusting relationship with those the researcher intends to interview (Lincoln & Guba, 1985). Prolonged engagement is discussed further when discussing the trustworthiness of this study.
This particular site had many advantages. I have worked for six years on this adolescent ward and continue to work here and have established interpersonal relationships with the ward staff and many of the patients. As a consequence of my familiarity with the staff, I had relatively easy access to and support from ‘gate-keepers’ including the Nursing Unit Manager of the ward, the Head Consultant of the Eating Disorder Team and other allied health staff including dieticians, which made gaining entry to this site much less complicated than it was for me gaining entry to the other sites, as discussed earlier. My enmeshment in the culture of this ward and the program enhanced my ability to establish a rapport and develop a trusting relationship with those I chose to interview. Erlandson et al. (1993, p. 56) describe the interactivity of naturalistic inquiry and explain that “[r]apport, trust, congeniality, and other aspects of interpersonal relationships between researcher and respondents is an ongoing process that begins with the initial contact with the gatekeeper(s)”. My understanding of and participation within this culture also gave me a unique insight into the workings of the staff, patients and program dynamics that perhaps an ‘outsider’ observer would not be able to identify as visibly. This insight and understanding of the culture allowed me to focus questions and prompt participants for further information in order to fully comprehend the complexities of both communities under study as they related them through their story-telling.

Nevertheless, a disadvantage of being a member of one of the communities under study was the “danger of the researcher over-identifying with the respondents and thereby destroying the value that can be brought to shared constructions by an outside observer” (Erlandson et al., 1993, p. 59). I cannot dismiss my own closeness to the study participants and my own biases. In fact, Patton (2002, p. 65) explains “[w]riting in the first-person, active voice communicates the inquirer’s self-aware role in the inquiry”. In response to my awareness of the possibility of over-identification with respondents (i.e the nurses), I have used strategies to account for this, such as ‘reflexive diary writing’, ‘peer debriefing’ and ‘member checking’ (Lincoln & Guba, 1985) to validate the co-constructions developed.

I have used reflexive diary writing to monitor my own personal thoughts, preconceived ideas, values and feelings about the research experience and the data collection and analysis processes. These entries are a record of my learning and growth as the study progressed. My own unique ‘constructions’ were not always identical to my interviewed
participants so I continually needed to ‘bracket’ my own feelings, judgements and values so that they did not impinge and influence the members under study. The use of weekly diary entries assisted with controlling the bias and allowing relevant data collection to transpire. In addition, I had supervisors that have not worked with adolescents with eating disorders and therefore, during our discussions together, they have provided me with their unbiased thoughts and feedback on the research processes taken by me and the ‘shared constructions’ that have developed. This provided a sense of authentication from professionals who were not directly involved in care (Lincoln & Guba, 1985). I also used ‘member checking’ to ensure that the ‘images’ and ‘co-constructions’ were verifiable and identifiable by the participants themselves (Lincoln & Guba, 1985). These and other strategies are discussed again later in further detail when discussing the trustworthiness of the study. As per a naturalistic study, I attempted at all times to be as open and non-controlling as possible to whatever emerged throughout the research process, keeping a close check on my own personal feelings and values (Patton, 2002).

Lastly, the hospital environment was also the ideal site for the conduct of interviews. Interviews were all conducted in a private interview room on the adolescent ward. It allowed current inpatients and nurses and those patients that had been discharged from the program, the opportunity to re-live experiences, sights, sounds and smells and recall events and stories. It allowed me to observe the daily workings of the ward from two perspectives: the perspective of being an ‘outsider’ when I entered the ward in a researcher capacity and as an ‘insider’ when I worked on the ward as a nurse and was immersed in the day-to-day ‘culture’ of the community.

4.5 CREATING WORKING HYPOTHESES

Working hypotheses are present before the research is started in naturalistic inquiry. These hypotheses are continually modified and refined throughout the research process (Erlandson et al., 1993). My initial working hypothesis was conceived as a consequence of my undergraduate research project and I tentatively stated it as: “Therapeutic relationships are a difficult ‘balancing act’ for nurses and patients within an Eating Disorder Program”. This working hypothesis was refined as themes and patterns emerged as a result of the data collection and analysis processes (Erlandson et al., 1993).

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As I have explained, I wanted to delve deeper into the ‘world’ of the patient and nurse on an adolescent ward and examine their experiences within a behaviour-modification eating disorder program. I proposed to find out whether relationships between nurses and patients with anorexia were affected by the inpatient treatment program (‘The Level System’). My previous research revealed that paediatric nurses working on a medical ward and an adolescent ward were ‘struggling to develop therapeutic relationships’ with adolescents with anorexia (Ramjan, 2002, 2004). Thus, through an in-depth analysis of both the nurses’ and the patients’ perceptions of the ward environment, ‘The Level System’ program and the daily nursing practice within that program, I wanted to attain a deeper understanding of the impediments to the formation of therapeutic relationships. Ultimately, as a consequence of this study, I desired an enhancement of the knowledge-base of nurses and of lay understandings in the area of therapeutic relationships and the nursing care for adolescents with anorexia nervosa.

4.6 HERMENEUTIC-DIALECTIC PROCESS

The next step of the process entails the researcher entering the field and engaging in the ‘hermeneutic-dialectic process’ (Guba & Lincoln, 1989). Guba and Lincoln (1989, p. 149) described that this process does not intend “to justify one’s own construction or to attack the weakness of the constructions offered by others, but to form a connection between them that allows their mutual exploration by all parties”. By using the trusting relationship that has formed between researcher and participants to its full potential and the ‘hermeneutic-dialectic’ approach, the participants are free to express their stories in their own words with the researcher listening to these stories and clarifying consensual and divergent views, as opposed to challenging these perceptions of reality, to ultimately achieve more sophisticated and insightful co-constructions of reality (Charmaz, 2003). The ‘hermeneutic-dialectic’ process involves: purposive sampling, inductive data analysis, the development of grounded theory and the stabilisation and refinement of the emergent design. As shown in Figure 1, these steps are repeated as required until redundancy is achieved and the theory and design are stabilised (Appleton & King, 1997, 2002; Lincoln & Guba, 1985).
4.7 SELECTING PARTICIPANTS

Erlandson et al. (1993, p. 82) explained that purposive sampling is fundamental in naturalistic inquiry and is used “to maximize discovery of the heterogeneous patterns and problems that occur in the particular context under study”. Patton (2002, p. 230) concurred that purposive sampling allows for the selection of “information rich cases” for an in depth investigation of a phenomenon. According to Patton (2002) “[i]nformation-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research” (p. 230). Thus in naturalistic inquiry, purposive sampling is essential for revealing and extracting the ‘multiple realities’ and insights about phenomena rather than attempting to achieve generalisations (Appleton & King, 1997; Erlandson et al., 1993; Lincoln & Guba, 1985; Patton, 1990, 2002).

For this study, I needed to identify participants who were best-suited to share their constructions and experiences (Appleton & King, 2002) and who were able to shed light on the interactions and relationships between nurses and adolescents with anorexia within this ward program. Using purposive sampling, registered and enrolled nurses working on the adolescent ward of this children’s hospital in Sydney, Australia were invited to participate in this study, if they had more than one year’s experience working with adolescents with anorexia\(^1\). Excluded from the study were pool, casual and agency nurses, as they may not have had sufficient experience or adequate contact time with patients to contribute to the aims of this research. Furthermore, adolescents with anorexia currently being treated on the adolescent ward and those who had been discharged from the program were also invited to take part in the study. Excluded from the study were medically and cognitively unstable patients (ie. patients who were in severe denial of their illness and those who were unable to concentrate for long periods of time) or patients with additional severe psychiatric co-morbidities (eg. self-harming/ suicidal ideations), as determined by their treating physician. At the time of recruitment, no adolescent inpatients or discharged patients met any of these latter exclusion criteria.

\(^1\) The one year’s experience working with adolescents with anorexia needed to be on the unit/ward under study. However, it did not matter if they had also worked on other units/wards caring for adolescents with anorexia in the past.
Information sheets and consent forms were distributed to all permanent staff nurses working on the adolescent ward (registered nurses and enrolled nurses). Of 20 consent forms sent out 16 were returned to my internal mailbox signed. Two enrolled nurses and fourteen registered nurses had agreed to participate. I chose to interview the enrolled nurses first as I knew that the enrolled nurses spent the greatest amount of time caring for patients with anorexia nervosa on the ward. Interviews were conducted between June-December 2004.

The first enrolled nurse was interviewed once only and following this initial interview I discovered that many issues were being uncovered and these had been rather superficially addressed in this first interview. I examined the emerging themes from this initial interview and discovered the themes fell into two major categories: nursing practice issues on the ward and relationship issues. Consequently, I decided it would be best to conduct two separate interviews with the remaining nurses in order to expand the depth and breadth of this context-dependent data. All the remaining participants agreed to two interviews being conducted. The second enrolled nurse was then interviewed regarding nursing practice issues and then re-interviewed the following week about relationship issues. Separating the two major topics and conducting two rather than one interview did make for a more focused and coherent interview in each case.

The registered nurses had similar experience levels and had spent comparable amounts of time caring for the eating disorder patients on the ward and I felt that any one of them would provide me with valuable insights. Nevertheless, I chose to interview those nurses who had the most experience first, as ‘experience’ was an important element to fully understanding the difficulties being encountered by the nurses on the ward. I stopped interviewing after completing interviews with ten nurses (2 enrolled nurses and 8 registered nurses) even though more nurses were available for interview. In naturalistic inquiry it is not always possible to determine at the outset the specific numbers of participants required but the naturalist intends to achieve a maximum variation of in-depth rich data (both typical and divergent insights) (Guba & Lincoln, 1989; Lincoln & Guba, 1985; Patton, 1990, 2002). Since the maximisation of data is important in naturalistic inquiry, sampling ends, according to Lincoln and Guba (1985, p. 202), “when no new information is forthcoming from newly sampled units; thus redundancy is the primary criterion”. After completing 19 interviews with nurses (i.e 2 each, except for one participant
who was interviewed only once), I felt that I had achieved redundancy of data and a maximum range of experiences and variations among nurses had been captured that were uniquely context-specific. Recruitment of nurses terminated at this point as no new themes emerged during the analysis.

Out of the ten nurses recruited for this study, four were male and six were female. Participants’ ages ranged, at the time of interview, from 23 years to 42 years of age. They had from 2 to 8½ years experience working with adolescents with anorexia and from 3 years to 20 years experience as nurses. A profile of the nurses interviewed for this study is provided in Table 2 below. This information was obtained at the time of interview. Note that pseudonym names, used later in Chapter Five: Results, have not been identified alongside individual profiles to maintain the nurses’ anonymity.

Table 2: Nurse Participant Profiles

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>No. of Children</th>
<th>Yrs. EN or RN*</th>
<th>Yrs. AN**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>23</td>
<td>Single</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Male</td>
<td>32</td>
<td>Married</td>
<td>1</td>
<td>9</td>
<td>5½</td>
</tr>
<tr>
<td>Male</td>
<td>36</td>
<td>Married</td>
<td>2</td>
<td>16</td>
<td>5</td>
</tr>
<tr>
<td>Male</td>
<td>37</td>
<td>Married</td>
<td>0</td>
<td>16</td>
<td>7½</td>
</tr>
<tr>
<td>Female</td>
<td>42</td>
<td>Married</td>
<td>4</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Female</td>
<td>28</td>
<td>Married</td>
<td>1</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>30</td>
<td>Married</td>
<td>2</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Female</td>
<td>29</td>
<td>Single</td>
<td>0</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Female</td>
<td>30</td>
<td>Married</td>
<td>2</td>
<td>9</td>
<td>8½</td>
</tr>
<tr>
<td>Female</td>
<td>29</td>
<td>Single</td>
<td>0</td>
<td>4½</td>
<td>4½</td>
</tr>
</tbody>
</table>

*Indicates the number of years working as an enrolled or registered nurse  
**Indicates the number of years working with adolescents with anorexia
Six inpatients that were being treated during the time period (June-December 2004) when interviews were being conducted were also selected for interview and invited to participate and all six agreed. Patient and parent consent forms were signed. Four discharged patients were purposively selected from the hospital’s database by the researcher. These four patients were specifically chosen as they had had multiple re-admissions to this hospital for treatment and had spent the longest time period as inpatients in comparison to others from this database. These four patients were phoned at home by the researcher, after consultation with the Clinical Nurse Consultant (CNC) from the Adolescent Medicine Unit, and invited to participate in this study as well. Contact was made with the CNC first to determine whether these patients fitted the criteria as she was still in contact with them and saw them when they attended outpatient appointments. All four adolescents were happy to take part in the study. The four discharged patients reported their experiences in retrospect, while the six current inpatients reported their views in the here and now. The adolescent patients were only interviewed once. Redundancy of data was achieved after 10 interviews and no further adolescents were recruited for this study.

Out of the ten adolescent patients recruited for this study, one was male and nine were female. Adolescents’ ages ranged at the time of interview from 11 years to 18 years of age. The number of inpatient admissions to this ward for anorexia nervosa per patient ranged from 1 admission (i.e this was their first admission) to 14 admissions. Duration of stay on the ward ranged from 5 days to 109 days and the average duration of stay per patient ranged from 33 days to 58 days. A profile of the adolescent patients interviewed for this study is provided in Table: 3 on the next page. The first four profiles (top to bottom) represent the four discharged patients. The next six profiles represent the inpatients. Again this information was collected at the time of interview and pseudonym names have not been identified alongside profiles to maintain the adolescents’ anonymity.
### Table 3: Adolescent Patient Profiles

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Yr. at School</th>
<th>Lives with..*</th>
<th>Siblings **</th>
<th>No. of admissions</th>
<th>Days per admission (Range)</th>
<th>Days per admission (Average)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>17</td>
<td>11</td>
<td>M° &amp; Step- F°</td>
<td>1 B°</td>
<td>14</td>
<td>7-109 days</td>
<td>37.7 days</td>
</tr>
<tr>
<td>Male</td>
<td>14</td>
<td>8</td>
<td>M° &amp; B°</td>
<td>1 B°</td>
<td>4</td>
<td>33-70 days</td>
<td>44.5 days</td>
</tr>
<tr>
<td>Female</td>
<td>18</td>
<td>TAFE</td>
<td>M°, F° &amp; S°</td>
<td>1 S°</td>
<td>5</td>
<td>15-71 days</td>
<td>42.4 days</td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
<td>10</td>
<td>M°, F°, B° &amp; 2 S°</td>
<td>1 B°, 2 S°</td>
<td>13</td>
<td>5-73 days</td>
<td>38.6 days</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>10</td>
<td>M°, F° &amp; B°</td>
<td>1 B°</td>
<td>6</td>
<td>14-57 days</td>
<td>36.5 days</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>8</td>
<td>M° &amp; B°</td>
<td>2 S°</td>
<td>1</td>
<td>48 days</td>
<td>48 days</td>
</tr>
<tr>
<td>Female</td>
<td>11</td>
<td>6</td>
<td>M°, F°, B° &amp; S°</td>
<td>1 B°, 1 S°</td>
<td>1</td>
<td>58 days</td>
<td>58 days</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>8</td>
<td>M° &amp; B°</td>
<td>1 B°</td>
<td>1</td>
<td>49 days</td>
<td>49 days</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>9</td>
<td>M° &amp; 2 B°</td>
<td>2 B°</td>
<td>1</td>
<td>33 days</td>
<td>33 days</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>8</td>
<td>M°, F° &amp; S°</td>
<td>1 S°</td>
<td>1</td>
<td>39 days</td>
<td>39 days</td>
</tr>
</tbody>
</table>

* Indicates who the adolescent lives with. (M°-mother, F°-father, B°-brother, S°-sister)

** Indicates the adolescent’s siblings. (B°-brother, S°-sister)
4.8 GATHERING DATA

The main aim of gathering data in a naturalistic inquiry is to be able to re-construct reality as accurately and holistically as possible so as to be verifiable and on par with the setting’s residents’ constructions and the context (Erlandson et al., 1993). According to Erlandson et al. (1993, p. 81) this means that the researcher must “experience what the ‘natives’ experience and…see that experience in the way that they see it”. As stated earlier within naturalistic inquiry the primary data gathering instrument is the researcher. The researcher uses all five senses and intuitions to gather, analyse and construct reality from the data obtained from the participants and the context (Guba & Lincoln, 1981; Lincoln & Guba, 1985). Data can be gathered from a variety of different sources and in numerous ways. The four general sources of data in a naturalistic study are: interviews, general observations, documents and artifacts (Erlandson et al., 1993). With the exception of artifacts, each has been sourced in some way for this study. It is also important to note that data collection and analysis occur simultaneously in naturalistic inquiry (Appleton & King, 1997, 2002; Erlandson et al., 1993; Guba & Lincoln, 1981; Lincoln & Guba, 1985). Data analysis will be explained separately.

4.8.1 INTERVIEWS

Lincoln & Guba (1985, p. 273) explained that the dialogue and interactions that take place between researcher and participants is a dialectic experience which allow the researcher and participant “to move back and forth in time-to reconstruct the past, interpret the present, and predict the future”. Interviews aid the researcher in holistically understanding the interpersonal, social and cultural aspects of the environment (Erlandson et al., 1993). The interview process allows a researcher to enter into the world of another, to listen to their stories, their voices and meanings and then confirm that these constructions of reality have been truthfully understood (Patton, 2002).

For this study interviews were in the form of semi-structured interviews (see Appendix: Interview Schedule). Semi-structured interviews allow for predetermined questions to guide the inquiry and keep it on track but the inquiry remains open to discuss unplanned issues or issues illuminated by the participants (Hutchinson & Wilson, 1994; Sarantakos,
The initial issues and questions that I wanted to explore with participants became more focused, refined and specific as a result of my learning and understanding from each interview. In addition, interviewing patients and nurses from a ward where I work, ensured that I understood the vocabulary, jargon and medical terms used by the participants during their interviews. This assisted in the accurate interpretation and understanding of insights. As Erlandson et al. (1993, p. 87) pointed out “[w]ords and expressions have different significance in different cultures, and individuals exchange these verbal values to communicate”. Thus an outside researcher, without a health background or a background in eating disorders, may not understand the true meaning behind words such as “skinnies”, “slinkies”, “bolus”, “bolus exchange”, “NG”, “kangaroo pump”, “bed rest”, “pan” or “bottle”.

As reported earlier all interviews were conducted in a private interview room on the ward. I also conducted these interviews whilst off duty. Hence I was dressed informally and not in my regular nursing uniform. This I hoped left participants feeling less threatened and more open and at ease during the interview process. Each encounter commenced with an informal chat as a form of ‘ice-breaker’. Our conversations did not relate to my study and so were not tape-recorded. For example, when interviewing the discharged patients, I found out a little about how they were coping at home, school and what part-time jobs they were currently engaged in. I also offered them a drink to bring into the interview room. Following this I reiterated the purpose of this study and that anonymity and confidentiality would be maintained through the use of pseudonyms. The participants were again informed that the data would form part of my doctoral thesis and would later be disseminated at conferences or published in a refereed journal.

Each interview began with an open question such as “Can you please tell me about the nursing care for adolescents with anorexia on this ward?” General questions guided me throughout the interview process yet I remained open to explore any issues that the participant brought up unexpectedly within our conversations. I listened empathetically to their stories maintaining a non-judgemental stance but also listened critically so as to make evaluations (DeVito, 1994). DeVito (1994) explained that one can only fully understand another’s meaning until they empathetically listen to them, that is “to feel with them, to see the world as they see it, to feel what they feel” (p. 84).
Recorded audiotapes of the interview ensured that everything said was captured on tape. Interviews took place over 7 months. The interviews lasted from 1.5 hours to 2.5 hours. The advantage of tape recording interviews meant that I could listen to previous interviews and refine subsequent ones. A disadvantage in tape-recording interviews may have included participants responding in a certain way as a result of the presence of the recording equipment. They may have been consciously aware that what they said was being tape-recorded. I tried to reduce this disadvantage by making the participants feel as comfortable as possible prior to the interview and tried to make the presence of the tape recorder on the table as inconspicuous as possible. I had great respect for the people under study and for their generosity of time and was acutely aware of the need to avoid including any detail in the data that might identify participants. The use of pseudonyms in particular is a standard practice to give as great an assurance of privacy as possible. A further disadvantage of recording interviews can include malfunctioning equipment and thankfully this did not happen to me.

The only hurdle that I was presented with during the interview process was that I needed to terminate one of the interviews with a current inpatient on the ward. The adolescent became very emotionally upset when she recalled events about being cared for by a particular nurse on the ward. I offered this patient the opportunity to speak with a social worker, nurse, counsellor or anyone else of her choosing but she refused and said “I’m okay”. She reported that she did not understand why she was so upset. I suggested, since she did not want to speak with anyone, that she spend some time writing in her journal as a form of catharsis. When I checked on her later, after speaking with her nurse for that shift, she was writing in her diary. She had recomposed herself and reported again that she was okay now. I asked if the questions were in any way upsetting and she said “no” and again stated that she did not understand why she had become so upset. However, her nurse had reported to me that this particular patient’s birthday was nearing and nursing staff believed that she was feeling extremely homesick. This event nevertheless made me reassess and think about my position and role on the ward as a nurse, as can be seen in my diary entry below.
15th November 2004

Last week the blood drained from my face during my interview with [X]*. I felt pale and nauseated as she spoke. I did not realise that she was this afraid and this unhappy to have [Y]** as her nurse. I felt sorry, ashamed and a sense of guilt for being a nurse on the ward and not knowing her pain. I truly felt like a bad person, a co-contributor to her agony. I felt horrible, most of that week following the interview, but I have realised in hindsight that I and other nurses are not such bad people. There have been many interviews conducted with patients and on the whole they attest to the job well done by nurses in difficult circumstances. I do genuinely feel that we as nurses must be helping in some small way. [X] has only spoken negatively about this one nurse, others have not made her feel this way. I have to keep this in mind along with the fact that she is very young and very homesick at the moment but I am glad that [X] has disclosed these feelings to me.

-Writing within brackets not in original diary entry and removed to maintain anonymity.

*[X] represents the adolescent’s name

**[Y] represents the nurse’s name

During interviews, probes were used to encourage participants to provide me with examples and a clearer picture of their constructed realities (Sarantakos, 1993). According to Lincoln and Guba (1985, p. 271) probes include using silence, thereby letting the respondent know it is their turn to talk, using sounds such as “uh-huh” or “umm” and prompts such as “Could you tell me more about that?”. Throughout interviews I made sure that I had understood their version of events by rephrasing what they had said and awaited their approval or disapproval and clarification. According to Erlandson et al. (1993) it is important to remember that in naturalistic inquiry the interviewee is the expert and the researcher is attempting to gain an appreciation of their constructed realities without unduly influencing these constructions. Rather Erlandson et al. (1993, p. 93) pointed out, “[t]he interviewer should focus on obtaining the fullest picture that can be communicated of the interviewee’s relevant constructions of reality”.

Once redundancy of data was achieved, interviews were terminated. Lincoln and Guba (1985) argued that a final summarising of the interview allows for ‘member checking’ to occur and for any amendments or additional information to be given. I summarised the most significant data within our conversations and allowed participants time to clarify or amend their responses. I allowed time for reflection to occur and asked if there was anything else they would like to finally add. Then I thanked them for their participation and
provided them with a small thank you gift for their time. I also informed them that I may need to talk to them again in the near future for further clarification of information or for the opportunity to check the analysis of data and all participants agreed to this contact.

4.8.2 OBSERVATIONS

Observation is another source of data collection. It is a method that can be used to ascertain the workings and culture of the environment and the people within this environment in the here and now. According to Guba & Lincoln (1981, p. 193) “observation…allows the observer to build on tacit knowledge, both his own and that of members of the group”. My observations for this study were unstructured observations and these observations were a result of my own experiences and time spent working on the ward. I unobtrusively made mental notes for myself and observed the surroundings and certain interactions of staff with patients as a work day progressed. Observations were but a very small part of this study as interviews remained my main source of data. I thought that some observation would aid in “capturing the life” on the ward for the outside observer (Erlandson et al., 1993, p. 96). Some of the seminal observations made were reported earlier in Chapter Two: Context.

One observation not included in the earlier chapter is worth noting here. On some days, when particular nurses were caring for the adolescents, there was little or no conversation at mealtimes. On other days, when different nurses were looking after these same adolescents, there would be a significant amount of social interaction among all at the meal table, so much so that the adolescents would joke ‘Could you please stop talking to me so I can finish my meal on time?’: Conversations around the meal table included general talk about pets, family, weekend leave, likes, dislikes and sometimes talk gravitated to issues of food and weight. Every now and then at the meal table there would be subtle competitions among the adolescents themselves, for example who could eat the slowest, who could get away with not having as much butter. On occasions there would also be subtle teasing. One adolescent may remark ‘There’s lots of butter on your sandwich’ or an adolescent may remind someone at the table that they have not eaten something that is on their meal plan. For example an adolescent may remark ‘You’re supposed to have two bread equivalents, aren’t you?’.
I believe that being an insider; this gave me an advantage for providing reliable information about the workings of the ward. I was able to observe daily activities like mealtimes and “see the operational meaning of what they [participants] have said” (Erlandson et al., 1993, p. 81). I was also able to use some of the observations that I had made as probes for my questions in my interviews. I was able to see if what a nurse said correlated with what that nurse actually did. As Hodder (2003, p. 158) reported “‘[w]hat people say’ is often very different from ‘what people do’”. On many occasions, participants not only mentioned these incidents and observations within interviews but also interpreted and validated these observations.

According to Erlandson et al. (1993) interviews and observation enrich one another and thus they enhance understanding of the context, the meanings participants ascribe to their constructions of reality and they enhance data analysis. It is, however, impossible to describe every single observation and interaction that takes place within a setting and I have but touched the surface in attempting to provide you with such a background in Chapter 2: Context.

### 4.8.3 MEDICAL RECORDS AND DOCUMENTS

Other sources of data in naturalistic inquiry are documents and records. Medical records, obtained via the hospital’s database, assisted with the collection and checking of the demographic data which was first obtained from the adolescent participants prior to each interview. These medical records also verified the accuracy of accounts relating to the number of admissions and enabled me to accurately calculate duration of stay (number of days for each admission). According to Erlandson et al. (1993, p. 99), the word document “refers to the broad range of written and symbolic records” and includes diary entries, memos, works of art, photographs and brochures. Documents that I have used for this study include the eating disorder program, meal plans, a floor map, photographs, memos, fieldnotes (reflexive diary entries and memos) and the weekly group schedule outlining the group activities each week. Nursing notes were not analysed for this study. Interview transcripts and fieldnotes were the main sources of data for analysis. Documents, such as the eating disorder program and meal plans, were used to aid in the interpretation of what existing rules or guidelines were in place and whether they were being followed by nurses or whether they were being modified to suit individual patients.
4.9 DATA ANALYSIS

As stated earlier, in naturalistic inquiry data collection and analysis occur simultaneously (Appleton & King, 1997, 2002; Erlandson et al., 1993; Lincoln & Guba, 1985; Perry, 2005). Inductive analysis occurs and this according to Patton (2002, p. 453) “involves discovering patterns, themes, and categories in one’s data. Findings emerge out of the data, through the analyst’s interactions with the data”. Thus obviously the findings are ‘grounded’ in the data.

Marshall and Rossman (1989) explained that data analysis is a time when the data acquires its meaning. Participants’ voices come to life and the researcher shares in understanding these contextually oriented experiences. Data analysis requires time and thought and is not a linear process. It is a time for building grounded theory and discovering relationships among categories of data (Marshall & Rossman, 1989). According to Erlandson et al. (1993, p. 113) data analysis is a dynamic and “interactive process” which takes place both while data is being collected at the site and then away from the site. This technique allows the researcher to make decisions regarding revising strategies so as to obtain new rich insights and more sophisticated shared constructions of reality that are both time and context bound.

According to Lincoln and Guba (1985), data analysis entails reconstructing the constructions accumulated from the context into meaningful wholes. The process has three stages unitising, categorising and negative case analysis (Appleton & King, 2002; Erlandson et al., 1993; Lincoln & Guba, 1985). Erlandson et al. (1993) reported that unitising data, means taking data and separating them into the smallest units that have meaning for the context under study. It may be a few words, a sentence or an entire paragraph. These units are then coded by the researcher. The next step, categorisation (Glaser & Strauss, 1967; Lincoln & Guba, 1985), involves taking these units of data and placing them into categories of ideas. Lastly, negative case analysis (Becker, Geer, Hughes & Strauss, 1961; Lincoln & Guba, 1985; Miles & Huberman, 1994; Patton, 2002; Strauss & Corbin, 1990, 1998) involves including the deviant pieces of data, those that perhaps do not support the majority of the ‘constructions of reality’. This enhances the thick description of the phenomena under study and provides an opportunity for the multiple realities to be understood (Erlandson et al., 1993).
Thus data analysis is a continuing interactive process that includes continually refining the study design, testing and modifying working hypotheses and constantly comparing the results of analysed data as new insights emerge until redundancy is apparent. The hermeneutic-dialectic approach ensures that constructions (both convergent and divergent) are true to and verifiable by the participants within the time and context of the study (Appleton & King, 1997, 2002; Erlandson et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985; Schwandt, 1994).

For this study interview transcripts and fieldnotes were the main sources of data for analysis. The interview audiotapes were transcribed, using a word-processing program, by myself and with the assistance of a transcription typist. Each transcribed interview was re-checked for accuracy by re-listening to the audiotapes. These interviews were then transferred to a computer disk copy as well as printed out as hard-copies.

After reading and re-reading the transcriptions, line-by-line, numerous times, analysis began with a thematic analysis procedure (Erlandson et al., 1993; Kellehear, 1993; Taylor, 1998b). According to Roberts and Taylor (1998, p. 406), thematic analysis is “[a] method for identifying themes, essences, or patterns within the text”. Using a ‘colour coding’ method, I highlighted sections of text that were representative of similar nuances within the text. Once this was completed, I re-read through each highlighted section and placed a single word or a few words next to each colour, to label the essence of these ideas (Taylor, 1998b). Due to the sheer quantity of data gathered during this study, thematic analysis also occurred with the assistance of a computer package called NVivo 2.0 (Bazeley, 2004; QSR International, 2002). This software assisted with managing the substantial amount of data while monitoring analysis decisions and retrieving emerging themes (Tak, Nield & Becker, 1999; Taylor, 1998b). ‘Memos’, which are documents for storing ideas within NVivo 2.0, were created and these were linked to interview transcripts at points where notations or reflections were required to remind me of important decisions or incidents or for recording relationships among themes (Bazeley, 2004; QSR International, 2002; Robson, 2002). Manual thematic analysis and the NVivo 2.0 program assisted with coding and categorisation of data.
Refinement of the study occurred throughout the research process. As stated earlier I needed to revise my initial interview questions. Initial interviews produced new issues that needed to be explored with future participants. For instance my very first interview with a nurse made me realise that I would need to undertake two separate interviews with future participants (one on nursing practice issues and another on relationship issues). There were too many areas to cover in just one interview and the nurses had a wealth of information and insights. I had to re-focus questions and then test my original tentative hypotheses for relevance. Conversely with patients, I realised that after my initial interview, one interview would be sufficient. The adolescent patients did not disclose as much detail in their responses. This was perhaps a result of their level of maturity and young age. Some adolescents were also difficult to engage for long periods. All areas were still adequately covered with a focus on what the interviewee felt was most important to them.

At the end of each interview I sat down and scribbled on paper what I had learnt that day from the adolescent or nurse, what additional issues were introduced and were these important to the study? Did my observations validate what the participants had said in interviews and what did I need to ask in the follow up interview with each nurse? There was a sufficient break between the first and second interview (with nurses) as this allowed me time to process the responses from the first interview and refine questions for the subsequent interview.

I continually examined the data for recurring themes and interpretations that best represented the constructed realities of my participants. Working hypotheses were repeatedly tested for relevance. This was achieved through ‘member-checking’ constructions with nursing staff and patients on the ward (they may or may not have been directly involved in the study). My supervisors also served as ‘peer debriefers’: neither has direct patient contact and so were able to be a ‘devil’s advocate’ for me challenging my hypotheses and constructed realities. In order to further establish the legitimacy of this study, the criteria for establishing trustworthiness in a naturalistic study are examined below.
4.10 TRUSTWORTHINESS

To persuade others of the merit, the viability and the valuable contribution to knowledge development of a study, criteria are used to assess its rigour (Guba & Lincoln, 1981; Lincoln & Guba, 1985; Patton, 2002). Aroni et al. (1999), reported “[r]igour is the means by which we attempt to show integrity and competence” (p. 1). Rigour within a naturalistic study is termed “trustworthiness” (Patton, 2002, p. 546). The traditional positivist criteria of rigour namely ‘internal validity’, ‘external validity’, ‘reliability’ and ‘objectivity’ have analogous criteria within the naturalistic paradigm and these respectively are ‘credibility’, ‘dependability’, ‘transferability’ and ‘confirmability’ (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985). Lincoln (1995) also stated that these aforementioned naturalistic standards for assessing the quality of a study were also standards for maintaining ethical research. These naturalistic criteria and how they have been used within this study are now discussed.

4.10.1 CREDIBILITY

According to Roberts and Taylor (1998, p. 399), credibility is a “[m]eans of ensuring rigour in qualitative research, whereby participants and readers of the research recognise the lived experiences described in the research”. According to Schwandt (2001) there is congruence between the participants’ views and the researcher’s representation of these views. Credibility is established using techniques such as prolonged engagement, persistent observation, triangulation, peer debriefing, member checking, negative case analysis, referential adequacy and using a reflexive diary (Erlandson et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985), all of which have been utilised in this study.

4.10.1.1 Prolonged Engagement and Persistent Observation

Prolonged engagement entails spending time within the context in order to familiarise oneself and become immersed in the culture. This technique also assists with developing a rapport and trust with participants and enables cross-checking and verification of observations made, with interview data, thus reducing any intentional or unintentional distortions (Erlandson et al., 1993; Leininger, 1994; Lincoln & Guba, 1985).
engagement was a technique that I used to maintain credibility within this study. As previously mentioned, I have worked and continue to work on the ward that I have chosen to study and this enabled me to have insight into the idiosyncratic workings, context and culture of the ward and its members. I was able to gain the trust and support of both nurses and patients as I have over time developed a rapport with them due to my presence on the ward. This rapport and trust hopefully enabled participants to feel comfortable rather than threatened by my presence. According to Appleton and King (1997), this respectful and trusting relationship creates profundity and richness of data. An awareness of my academic respectability in terms of my previous research project and this being published in a refereed journal, may also have allayed anxieties and increased trust among participants, in my abilities to undertake research. A disadvantage for me may have been that some participants, nurses in particular, may not have provided as much depth in their responses because they may have felt that this information was obvious for a person who works on the ward.

Initially I thought that some patients would feel that my agenda would be to support the nurses and therefore would not be open and honest with me. Judging by their openness and candidness during interviews, it appeared that the adolescent patients were pleased to find out that I wanted to improve their quality of care, and that I wanted them to tell me as ‘experts’ how they truly felt about their relationships with staff and the nursing care they received. The fact that this information would remain anonymous was seen to be particularly important. I found that being a nurse on the ward did not detract from patients discussing nursing staff in a negative manner. Again judging by their responses, it appeared that the patients saw me not only as a nurse and as someone familiar but also as a researcher and were happy to provide their input and be an agent of change for improving care for future adolescent patients with anorexia nervosa.

As a member of the group of nurses, I had to avoid what anthropologists’ label “going native”, which involves losing the researcher perspective (Lincoln & Guba, 1981, p. 4; Lincoln & Guba, 1985, p. 303) and thus biasing the study by unintentionally endorsing the insights of the nurses. Strategies to avoid this included firstly an awareness of this possibility and keeping reflexive diary entries as well as memoing within NVivo 2.0. These strategies assisted me with bracketing my realities from those of my participants so that the ‘constructed realities’ created were mutual constructions representing the participants’
realities of life on the ward and not my own. Again my research supervisors helped me to maintain the researcher perspective by either not being too judgemental or too defensive of nursing practice and the program on the ward as they themselves did not work in this area or have a close affinity with this treatment program. Through my interactions and prolonged engagement in this setting, I had sufficient opportunity to build relationships with participants so as to obtain rich, in-depth data.

Persistent observation is another source for obtaining credibility in a naturalistic inquiry and goes hand in hand with prolonged engagement. According to Lincoln and Guba (1985, p. 304) persistent observation adds “salience to what might otherwise appear to be little more than a mindless immersion”. Persistent observation provides the depth to the study while prolonged engagement provides the scope (Lincoln & Guba, 1985). Through persistent observation the researcher can decide what is most relevant and what requires further exploration in order to fully comprehend the world view of the participants. It also enables negative cases to be identified and explored and understood in terms of the context and its members. For this study, persistent observation was not an official process, as I did not keep formal notes of all my daily interactions and communications with participants on the ward during the research period. However as a nurse working on the ward, I did have many an opportunity to see and hear things and as a researcher I mentally noted what I saw and heard and then made informal diary entries when I returned home, if I thought that the event had significance for the study.

The fact that I am a normal part of the context allowed me to make these unobtrusive and informal observations and this has allowed me to reflect on what participants have said in interviews and then judge these verbal accounts to see if they matched against my own diary entries of the same critical events. Working on the ward has been an advantage as I have had opportunities to watch other nurses care for adolescents with anorexia (for example, take them for meals and observe their interactions with them during these mealtimes). This enabled me, as an ‘insider’, to recognise inconsistency or mismatch between actions and words.
4.10.1.2 Triangulation

Triangulation is an additional technique that increases credibility in a study. Triangulation entails using numerous sources of data, methods, investigators or theories to validate insights or ‘constructed realities’ (Denzin, 1989; Erlandson et al., 1993; Lincoln & Guba, 1985). I used multiple sources of data and multiple methods in this study to increase my confidence in findings. In terms of the sources of data, both patients with anorexia and nurses were unobtrusively observed and formally interviewed for this study and their consensual and divergent perspectives of life on the ward were explored. In terms of the multiple methods, different data collection modes were used including interviews, observations, medical records and documents and fieldnotes (such as reflexive diary entries and memos). I reviewed documents such as the current eating disorder program guidelines and the meal plans to verify the recollections and accuracy of both patients and nurses descriptions of the treatment program’s rules and regulations. I used the computer database to verify the accuracy of patient recall of their admissions to hospital which they verbally disclosed at the start of each interview. Lastly, as asserted earlier, my informal observations were used to verify verbal interview data.

4.10.1.3 Peer Debriefing and Member Checking

Peer debriefing is another strategy that I have used to maintain credibility in this study. My supervisors, as unemotionally involved members, played “devil’s advocate” (Erlandson et al., 1993, p. 140; Lincoln & Guba, 1985, p. 308); they provided me with constructive criticism and feedback about my working hypotheses and the formulation of ‘constructed realities’ from interview data, so that the study continually refined itself and retained momentum. Additionally, Lincoln and Guba (1985, p. 308) proposed that “debriefing sessions provide the inquirer an opportunity for catharsis, thereby clearing the mind of emotions and feelings that may be clouding good judgment or preventing emergence of sensible next steps”. Family were a great motivational source as well as a sounding board for me to vent frustrations, especially in regards to the rejection I received concerning ethics approval from interstate hospitals, early on in the research process. My Nursing Unit Manager (NUM), colleagues on the ward and friends were also a major source of support and were available to lend a sympathetic ear when I needed it most.
Having the support of my family, colleagues, friends and supervisors encouraged me to complete this study in minimal time.

The next strategy, member checking, is an imperative assessment for credibility in naturalistic inquiry (Guba & Lincoln, 1989; Lincoln & Guba, 1985; Taylor, 1998a). Lincoln and Guba (1985) described member checking as a dynamic and interactive process that occurs formally and informally throughout the research process. Members of the context under study are given the opportunity to validate constructions, interpretations and conclusions as faithful, compatible and familiar to them. They are provided with the opportunity to correct any misinterpretations. As Sandelowski (1986, p. 30) pointed out “…truth is subject-oriented rather than researcher-defined”. Constructions need to remain lucid and meaningful re-constructions of life through the participants’ eyes and through participants’ voices. Constructions that do not remain true to the respondents’ views or that are foreign to the respondents are excluded from the study (Erlandson et al., 1993; Lincoln & Guba, 1985).

For this study member checking was informally carried out at the completion of each interview and during the interview. I would use the time at the end of an interview to summarise the main ideas that had been brought forth by the participants and awaited verification or correction. During the interviews themselves, I would paraphrase what the respondent had said if I felt confused and awaited acknowledgement that I had understood their meanings correctly.

Informal conversations that took place on the ward with both patients and nurses provided an opportunity for me to re-affirm the emerging themes and interpretations from the data. Sometimes these conversations took place at the meal table with patients, at other times in the medication room while drawing up antibiotics with other nurses or in the staff tearoom. Finally, every participant in this study, together with the Nursing Unit Manager of the ward, was provided with an electronic copy of the results chapter of this study. Most participants provided verbal feedback acknowledging the authenticity and accuracy of the experiences and insights presented. As Erlandson et al. (1993, p. 30) pointed out, credibility is attained when the multiple realities depicted “rings true” for the participants’ in the setting. The re-constructions, both consensual and divergent thinking, ‘rang true’ for the participants in this study. No study participant rejected the findings or refuted the
interpretations and insights presented. In fact, two of the discharged adolescents and one of the inpatients emailed me with written commentary and positive feedback, congratulating me on the study findings and the accuracy of the exemplary portrayal of life for nurses and life for patients with anorexia on the adolescent ward. According to Thomas and O’Kane (1998, p. 345) allowing young people to participate and contribute to the interpretation of data enhances its credibility.

4.10.1.4 Negative Case Analysis

Lincoln and Guba (1985, p. 309) explained negative case analysis is a process of “continuously [refining] a hypothesis until it accounts for all known cases without exception”. As I have reported earlier, in naturalistic inquiry it is important to examine all the ‘multiple realities’ holistically; that is, not only the consensual realities but also the divergent or conflicting realities within a context in order to appreciate a thorough understanding of the phenomena under study. As Lightfoot (1983, p. 13-14) explained “the truth lies in the integration of various perspectives rather than in the choice of one as dominant and ‘objective’;...I must always listen for the truth...not disregard it as outside the central pattern”. As such I have attempted throughout this study to present all possible viewpoints encountered, avoiding prematurely concluding the study without a thorough in-depth investigation of the phenomena under study.

4.10.1.5 Referential Adequacy Materials and the Reflexive Diary

Within a naturalistic study the data is context-dependent and consequently must be examined and interpreted alongside contextual data. Referential adequacy materials are materials that assist the reader in obtaining a holistic view of the context under study (Erlandson et al., 1993; Lincoln & Guba, 1985). Erlandson et al. (1993) reported that "[v]ideotapes, documents, photographs, and any other materials that provide a ‘slice of life’ from the context being studied will provide a supportive background that communicates to the reader a richer contextual understanding of the researcher’s analyses and interpretations" (p. 31). This study contains photographs of the ward environment (eg. Moroccan Area). It also has a floor map to assist the reader in better understanding the layout of the context under study. Chapter Two: Context has described
the eating disorder program elements. Examples of meal plans are also provided for the reader’s perusal in the appendixes. These materials assisted me in providing an ‘outsider’ with a more in-depth picture of the context under study and have assisted me to recall the ward structure when analysing data away from the site.

The reflexive diary is a “diary in which the investigator on a daily basis, or as needed, records a variety of information about self…and method” (Lincoln & Guba, 1985, p. 327). I have not myself been disciplined enough to write daily diary entries but I have been making weekly entries. These entries describe methodological decisions and timelines for the study as well as reflection on feelings, thoughts and critical incidents. The collection of papers that I have made rough weekly entries on constitutes my reflexive diary. The NVivo 2.0 program has also helped me to make mental notes to myself through the memoing facility while I was engaged in coding data. This information forms part of the audit trail for this study (described below). Excerpts from my diary were provided earlier in the chapter.

4.10.2 TRANSFERABILITY

As noted earlier, transferability or the generalisability of findings to another context is not truly possible in a naturalistic study (Erlandson et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985; Tobin & Begley, 2004). The data obtained in naturalistic inquiry is ‘context-dependent’ and has the most relevance for the social setting from which it has emerged. According to Lincoln and Guba (1985, p. 316) the naturalist “can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility”. Transferability decisions are possible through two avenues: thick description and purposive sampling (Erlandson et al., 1993; Lincoln & Guba, 1985).

4.10.2.1 Thick Description and Purposive Sampling

The Context Chapter has attempted to provide the reader with thick descriptions of the social setting under study as well as details of the treatment program, so that the reader has a sense of being in the setting or at least a better understanding of the setting. Thick
descriptions of events, issues and interactions were examined and described as often as possible. The decisions made throughout the research process, including selection of participants and data collection methods, have also been provided. Finally verbatim interview excerpts are provided in Chapter Five: Results so that the participants’ voices can be heard. Perry (2005, p. 42) reported, verbatim excerpts kept within the context “allows knowledge to be revealed without forcing interpretation”.

In addition naturalistic inquiry relies on purposive sampling as another method to achieve transferability. As reported earlier, I have used purposive sampling to select both typical and divergent cases for the phenomena under study so as to report and capture all the existing ‘multiple realities’. It would seem that redundancy had been achieved.

4.10.3 DEPENDABILITY AND CONFIRMABILITY

Dependability ensures that the research is “logical, traceable and clearly documented” (Tobin & Begley, 2004, p. 392). According to Lincoln and Guba (1985) dependability ensures that if the study was repeated with the same or similar participants in the same or a similar context then the findings would be unchanged. According to Tobin and Begley (2004, p. 392) confirmability, on the other hand, “is concerned with establishing that data and interpretations of the findings are not figments of the inquirer’s imagination, but are clearly derived from the data”. The audit trail is an important strategy employed by researcher’s to keep them on track and accountable.

4.10.3.1 The Audit Trail

According to Streubert and Carpenter (1995) an audit trail allows other researchers to follow the decisions and thinking processes of the original researcher in terms of the processes undertaken and the methods used. Aroni et al. (1999, p. 7) described audit trails as a “mode of transparency”. It entails maintaining appropriate records of the entire research process. An audit trail was made possible in this study. I have kept adequate records of all raw materials used and collected including interview schedules, notes, critical incidents, transcripts, tape-recordings, documents, reflexive diary entries, peer
debrieving notes, ethics proposals and NVivo 2.0 analysis decisions. These are kept within
a locked filing cabinet in the researcher’s home or saved in computer files and on disks.

4.11 AUTHENTICITY

Authenticity, a fifth and final criteria, was added to the four described above by Guba and
Lincoln (1989) to ensure that all the differing constructions are sought out and honoured
fairly during the evaluation process. They describe authenticity as having five criteria:
fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical
authenticity (Guba & Lincoln, 1989). According to Patton (2002, p. 546), authenticity is
“reflexive consciousness about one’s own perspective, appreciation for the perspectives
of others, and fairness in depicting constructions in the values that undergird them”.

Fairness was maintained by portraying a range of realities, both typical and divergent
cases, and each being given equal consideration and attention (Guba & Lincoln, 1989,
1994). Participants have enhanced their constructions, insights and understanding of
nursing care for adolescents with anorexia and the concept of the therapeutic relationship
through critical reflection processes (‘ontological authenticity’) (Guba & Lincoln, 1989,
1994). Participants have similarly become more understanding of others standpoints and
positions through ‘member checking’ and the dialectic interview process (‘educative
authenticity’) (Guba & Lincoln, 1989, 1994). Action and decision making occurred as a
result of the learning experiences and new insights gained by participants who took part in
the study (‘catalytic authenticity’) (Guba & Lincoln, 1989, 1994). Finally, participants
demonstrated empowerment as a result of their participation in the study and the
knowledge gained from listening to, reflecting on and understanding their own and others’
points of view (‘tactical authenticity’) (Guba & Lincoln, 1989, 1994).

4.12 ETHICAL CONSIDERATIONS

Fontana and Frey (2005, p. 715) stressed that “[b]ecause the objects of inquiry in
interviewing are humans, extreme care must be taken to avoid any harm to them.
Traditionally, ethical concerns have revolved around the topics of informed consent
(receiving consent by the respondents after having carefully and truthfully informed him or
her about the research), *right to privacy* (protecting the identity of the respondent), and *protection from harm* (physical, emotional, or any other kind). This study ensured that these three variables were intrinsically adhered to throughout the research process.

Ethical approval for this study was obtained from the children’s hospital in which this study was conducted and the University of Western Sydney. Before any interviews were arranged with potential participants, the study’s aims and purpose were verbally explained to both the nurses and patients. All participants were then provided with a Participant Information Sheet (see Appendix: J & K) and the adolescent patients were asked to provide their parent/s with a copy of a Parent Information Sheet (see Appendix: L), which further explained the research study. Informed consent (see Appendix: M) was obtained from nurses, adolescent patients and their parent/s. Any questions they may have had regarding the study were fully explained by the researcher. Following this a mutually convenient time was organised for the interviews. Before interviews commenced, I advised the adolescents that, if during their interview they disclosed anything that may potentially lead to the risk of harm to themselves or others, then it would be my responsibility to pass on the information to a health professional in a position to do something to protect them or the other person. No information of this kind was relayed during interviews.

Participation in the study was voluntary and participants were able to withdraw from the study at any time. If, for any reason, certain questions caused the participants distress of any kind; they were free to not answer these questions or to stop the interview recording. To my knowledge the questions asked did not cause distress to the interviewees. However, one of the adolescent patients did become very upset during the interview while recounting her story and the interview was stopped at this time by the researcher. The adolescent was offered the opportunity to speak with a social worker, nurse, counsellor or someone else of her choosing but she declined. The interview was not re-scheduled as the adolescent had completed most of the interview by this stage and there was no need for further clarification of her responses.

All information from this study has been kept anonymous and confidential. Pseudonyms and codes have been used throughout the research process. A password protected file contains a list of participants’ names and corresponding pseudonyms. All data collected

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for this study, including computer files, disks, audiotapes, fieldnotes and transcripts are kept in a locked filing cabinet in the researcher’s home. These will be stored for five years after which the information will be erased, deleted, destroyed and shredded respectively.

4.13 FINAL NOTE

This study is influential in that it adds to the knowledge we have about young people with anorexia nervosa and their nursing care. Traditionally, children or young people are seen as dependent on adults and in many ways their knowledge is dismissed or discounted. But children and young people have ‘voices’ and being heard is the difficulty they face. The young people with anorexia nervosa in this study were empowered through their participation. Their knowledge was respected as valid and their ‘voices’ were heard. This research has given power to young people by elevating them to a central position rather than being ‘interpreted’ through adults, as is generally the case in research. John (1996, p. 22) stated research with children and young people allows adults to “look at the world with their eyes and hear their own articulations of their experiences and, importantly, communicate with them”. This particular study methodology has allowed the many varied ‘voices’, both adult and young, to be heard and I have been very fortunate and very privileged to listen and be part of their stories.

To conclude, a quote from Kahlil Gibran (1970, p. 20), beautifully elucidates the importance of listening to the voices of the young:

    Your children are not your children.
    They are the sons and daughters of Life’s longing for itself.
    They come through you but not from you,
    And though they are with you yet they belong not to you.
    You may give them your love but not your thoughts,
    For they have their own thoughts.
Chapter Five

RESULTS

“everyone ... must follow the rules”

Kesey, 1988, p. 25.
5. FINDINGS AND ANALYSIS OF THE RESULTS

5.1 INTRODUCTION

The aim of this study was to extend in much greater depth my previous work on therapeutic relationships and the nursing care for adolescents with anorexia. This current study explored both the nurses’ and patients’ perceptions so as to obtain an ‘insider’s view’ of the lived experience of ‘working’ and ‘being cared for’ within a particular behaviour-modification inpatient treatment program (‘The Level System’). Through an analysis of the treatment program, the ward environment and the nursing practice on the ward it was discovered that the ‘prognosis was poor’ for the formation of therapeutic relationships. Therapeutic relationships were not easily constructed and maintained in this type of working environment.

The four themes chosen reflect the similarities of ‘life on the ward’ to that of ‘prison life’. The prison analogy was not deliberate\(^1\); there were clear parallels between ‘life on the ward’ to ‘prison life’ which assisted with the creation of themes for this study. In many ways life for an adolescent with anorexia on the ward mirrored life for a prison inmate. Nurses and doctors became analogous to prison officers within this program known as ‘The Level System’.

It should be noted that the metaphor presented in this thesis is based on ‘stereotypical’ conceptions of ‘living’ and ‘working’ in prisons which may not correspond to the reality of the prison system of today. It does however; correspond to the typical images presented in the popular media. The presentation of the images within this thesis arises from the experience and ‘stories’ of study participants who would be unlikely to have an ‘evidence based understanding’ of the prison system, but are more likely to reflect the stereotypical images present in the popular media to which they are more likely to be exposed.

\(^1\) The ‘prison analogy’ and associated prison terms arose spontaneously from interviewees themselves. After they arose, the researcher did not explicitly or deliberately use the analogy in the remaining interviews for additional interviewees to respond to.
Though dated the Tupper and Wortley (1990) article depicting prison life in early Australia, is used throughout the analysis to support the metaphor as the depictions confirm the essence of stereotypical representations presented in the popular media, even though these representations may no longer be indicative of the current situation in prisons today.

To alleviate confusion patients throughout this thesis will be assigned a number ¹ after their name. Nurses will be assigned a number ² after their name.

5.2 ENTERING THE SYSTEM

5.2.1 ‘WHAT’S THE OFFENCE OFFICER?’

There were two ways that an adolescent with anorexia entered the system. The adolescents described how they had either been brought in to the emergency department, in some cases under false pretences, by a concerned family member or had been attending a clinic appointment when a decision was made for admission straight to the ward. Megan¹ described how she thought she was “en route for a holiday” when she was suddenly admitted to hospital.

_We were actually en route for a holiday…I didn’t even know we were stopping at the hospital. We were stopping in for counselling or something. I didn’t know…Then I found out straight away that I was being admitted and my parents had to leave within…half an hour of dropping me off (Megan¹)._ 

For many of the adolescents this was their very first hospitalisation. Megan¹ described her admission as a “terrible, traumatic” experience. The other adolescents described many emotions including their fear, confusion, anger and depression as a consequence of discovering that they were to be admitted to the ward for treatment. Danielle¹ “never thought that someone could come into hospital for that kind of condition” and it made her think, “I shouldn’t be in here”. In retrospect, Cameron¹ and Melinda¹ believed, “it was needed to be done”. Danielle¹ agreed that “finding out about all the harmful sides (sic) that this illness can do to you, then you start to realise: Well, I should be in here”.

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The concept of deviance, which is “norm-breaking behaviour” (Roach-Anleu, 1997, p. 220), can be applied to adolescents with anorexia nervosa. Refusing food for ‘fear of becoming fat’ and engaging in unhealthy weight loss practices is seen as a form of ‘deviance’ by a society that perceives this behaviour as unacceptable. Roach-Anleu (1997) asserted, social norms are generally decided upon by powerful, authoritative people who take offence at the behaviour, such as those within medicine (psychiatry) and law. Responses to deviance involve imposing formal and informal sanctions to re-establish the ‘status quo’ and modify unruly behaviours (Roach-Anleu, 1997).

Psychiatry legitimises such sanctions on the basis of helping those who are harming themselves and their health. Similarly formal sanctions including imprisonment are administered as a form of punishment for ‘criminal deviance’ by the legal system (Roach-Anleu, 1997). According to Roach-Anleu (1997, p. 226) the person labelled as ‘deviant’ “may seek to resist or ignore that interpretation of them and their behaviour”. This can be a formidable task against such powerful forces as the police, criminal law courts and in this instance, medical professionals.

When the adolescent with anorexia enters the ward, they are placed on a program called ‘The Level System’. As explained in Chapter Two, it is ‘loosely’ based on behaviour-modification principles. Nurses were in consensus when they described the adolescent with anorexia as not adhering to socially acceptable standards and as not having “what we would class as a normal eating habit or a normal view of food”. Most nurses described the program as “changing or altering a particular behaviour…that’s self-harming…deliberate or obvious…into something that’s healthier”. They saw their role within ‘The Level System’ as helping the adolescent to return to a normal eating pattern of “3 square meals a day”. This is similar to how “prisons and their associated regimes are designed primarily to contain but also to correct or rehabilitate” the prison inmate and their ‘deviant’ behaviour (Cameron, 2001; Tupper & Wortley, 1990a, p. 2, current author’s emphasis; Walsh, 2006).
5.2.2 ‘LOCKED-UP’

Obviously these adolescents, like prison inmates, were unable to discharge themselves so there was an expectation from nurses of some sort of rehabilitation while within the system. Rehabilitation is viewed as an expectation and a core positive outcome for the individual within both settings: rehabilitation of health and healthier eating habits for the adolescent with anorexia and rehabilitation of ‘the self’ for the prison inmate. Coincidentally, an Australian Minister Tony Kelly recently commented on an Australian Radio News program that inmates are not only in prison as a form of punishment “but to try and correct the behaviour of people locked up inside so that when they do return to our community that [sic] they are no longer a threat” (“Minister defends Milat”, 2006, p. 1).

This response bears a remarkable resemblance to those of the nurses in this study and their desire to correct the eating habits and behaviours of adolescents with anorexia, so they can reintegrate with their peers. Thus, some nurses viewed behaviour-modification as the removal of an undesired behaviour (i.e a problem to be eradicated). For example, Gabrielle² explained the term behaviour-modification as follows:

> It means basically that there is something that is not within the ‘norm’...that is not even socially accepted...Basically there is some behaviour for them that is not beneficial to them. So therefore we have to help them change that...For an eating disorder their whole eating behaviour is inappropriate. Their thought processes are not ‘normal’ (I say that very lightly yeah) but those kinds of things. So we try to modify that...so they are not so separated from...the other teens and to...bring it into what we would see as being a healthy behaviour to have (Gabrielle²).

‘The Level System’ was described as a four tiered system. It originally had five levels but has been condensed to four levels at present. Level One is complete ‘bed rest’. The adolescent must remain on their bed at all times. The adolescents may or may not have the privilege of using the toilet dependent on the doctor’s orders. Therefore they will be required to ‘buzz’ the nurse to use the toilet or may be given a bed pan. Riley², a nurse, explained that on Level One they “start nasogastric feeds”. Veronica² added, that the feeds may “be continuous feeds or overnight feeds...and they need more frequent observations”. Donna², a nurse, remarked that being placed on Level One could be seen, by the adolescent with anorexia, as being comparable to “being locked up in jail...isolated from everyone else”. Cameron¹, an adolescent, verified this when he explained during his
interview that being on the program made him feel “quite cooped up”, like being “in jail in a way”.

Cameron¹ described these sentiments as follows:

> You feel quite cooped up kind of. It feels like you're in jail in a way...So...it can be quite depressing too...Not being able to see your friends and go outside and stuff like that... (Cameron¹).

Being on ‘The Level System’ meant that there were limitations placed on personal liberties for the adolescent with anorexia. The commonalities are clearly evident in the descriptions of Level One restrictions related by the nurses and patients in this study to the restrictions that may be placed on personal liberties while in prison. According to Poole (1997, p. 175) “a prison inmate may be searched, undressed, bathed, disinfected, fingerprinted, forced to wear a uniform, and given a number rather than their name”.

Danielle¹, an adolescent, explained Level One as follows:

> If you're medically unstable, you'd be on Level One...That's usually 'bed rest' and sometimes you can get provisions to go to the toilet or sometimes there's none...So basically Level One is staying on your bed...Sometimes you can go to school and group in a wheelchair and you can go to meals in a wheelchair...It just depends on the patient (Danielle¹).

On Level One and Level Two of the program the adolescent is restricted to the ward. On Level Three and Level Four the adolescent can leave the ward with a parent, staff member or responsible adult for twenty minutes and forty minutes per day respectively. Working through the levels increases your chances of making “your way out the door”: Paige² explained, as the adolescent progressed up the levels they received greater privileges “in terms of gate passes, number of visitors, used to be [restrictions on] phone calls [but] not so much anymore. That is too hard to monitor (laughs) um...but it [‘The Level System’] basically gives us guidelines as to what they can and can’t do”.

Oliver² believed they are on Level One “not as a punishment but because they are medically unstable”. In his eyes, Level One was a necessity for those adolescents who were gravely undernourished and nurses and doctors had an obligation to provide this medical care.

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Level One is when the child is at their sickest and they need to be on ‘bed rest’ for medical reasons…and involved in each level is how much visitation they can have, how often they can leave the ward and for how long um all that sort of thing (Oliver²).

Riley² explained the other levels of the program. He felt, as many of the other nurses in the study did, that ‘The Level System’ was a “reward system” for adolescents with anorexia. He described Level Five of the program but this level of greater independence and responsibility for the adolescent has disappeared from the program altogether. Patients were now discharged on earlier levels without reaching Level Five.

Level Two...they’re pretty much off ‘bed rest’. They may still be on feeds. They’ve got their meal plan all set out. But they’re still ward restricted. They...can go to school and group...Level Three, which is what most of them stay on up until discharge. They can have 20 minutes off the ward twice a day and Level Four is pretty much exactly the same. Level Five, which we never see anymore, is pre-discharge, where they’ve been able to sit there and eat their meals by their own bed...Usually it’s about two days before they get discharged...so they get into a habit of doing that...They can...pretty much leave the ward when they want to go for walks (Riley²).

Danielle¹, an adolescent, who had been admitted a number of times to the ward, also remarked that Level Five was no longer in use. However she appreciated this Level when it was operational as it made her and others on the program feel like a “normal patient”.

Then there’s Level Five, which is, you’re basically treated as a normal patient and you’re allowed to eat without supervision. But, that’s very rare that girls would go to that (Danielle¹).

In general nurses believed the program’s intentions were “honourable”. The aim was to “identify what’s causing the child to behave in this way” and to “get them physically better as well as mentally better”. Oliver² insisted that the adolescent’s condition also affected the family as a whole and saw the program as “very much about getting the family well, as well, so that the adolescent doesn’t lapse back into these behaviours”. Nurses saw the program as “holistic” as a result of its multidisciplinary team of health care workers. Yet most felt that the program did not address the psychological side of the illness as much as it addressed the physical side of getting them “medically safe to be at home”. Therefore, many nurses believed it relied too heavily on adolescents reaching their target “goal
“weights” for discharge to the detriment of the adolescents obtaining the necessary psychological help.

5.2.3 ‘LEARNING THE ROPES’

Each and every adolescent described their daily routine in exactly the same way. Their day was set out and planned from morning until night and the routine had little or no variation. The daily routine for adolescents with anorexia very much resembled the ‘institutionalised’ daily routine for a prison inmate. It remained fixed and constant while other adolescents on the ward had the freedom and flexibility to change, as they pleased, when and how they did things during the day.

Patients without an eating disorder were allowed to have friends or relatives visit, for as much or as little time as they liked, during visiting hours. They also woke late and had breakfast late on weekends but the adolescents with anorexia were required to remain faithful to their schedule. The day for an adolescent with anorexia was set out for them like ‘clock work’: their timetable assigned times for waking up, showering, eating, sleeping, going to school, going to group activities like art and craft sessions, going to physiotherapy and when they could have their visitors or free time (see Appendix N1).

Danielle¹ explained the routine:

*We get up in the morning. We have showers, and get ready, get changed and stuff, get our school gear packed. And then we have breakfast, and we go to school straight after breakfast, and then after school we have morning tea then go back to school, and then we have lunch, and then we have bed rest for half an hour after lunch and then we have half an hour just mingling around, just free time. Then we've usually got Group at 2 o'clock and that goes for an hour and a half. Then straight from Group we go to afternoon tea and then after afternoon tea we have free time, for a couple of hours which is usually visiting hours and then we have dinner and then we have bed rest again for half an hour and then we have free time after that until supper and then after supper we get ready for bed and go to bed. Three times a week we have physio and that's either at 11 o'clock or 3 o'clock (Danielle¹).*
The adolescents were allowed certain small concessions because these did not impinge on the program. They were “allowed to decorate” their own personal bed spaces and were “certainly allowed to be individuals” in terms of the way they dressed. They were “not forced to…wear hospital pyjamas”. Thomas² remarked the ward did become like a second home for them. The adolescents tried to “brighten up the place” and make it more comforting by bringing in their own eiderdowns and by decorating their bedsides with “arts and crafts…their pictures of their pets, pictures of family and friends, things that they have painted…[and] cards from school friends…” This can be seen as akin to the prison inmate who may be allowed to decorate or keep approved personal possessions in his cell (“Department of Corrective Services” [DCS], 2002; “Just Oz”, 2004).

*They do up their bedsides. So...just like it is their own bedroom they get the posters up and start playing their music and hanging out and they bring their own doonas in. So...they just get rid of sort of the hospital aspect of their bedside so it doesn't look like a hospital bed...with...all their favourite stuff around (Zac²).*

Tupper and Wortley (1990a, p. 3) proposed that a prison as a society of its own “has its own values, sanctions and status system”. A new inmate must quickly ‘learn the ropes’ to survive in the system and his survival will depend on “how well he adapts to the prison ethos” (Easteal, 2001; Tupper & Wortley, 1990a, p. 3). Similarly an adolescent with anorexia newly admitted to the ward must learn the routine and rules set out for them and accept them in order to progress up the levels. The adolescents quickly learn that they need to ‘stick together’ and support each other if they are to ‘survive’ just as “solidarity in the prison setting can be a key element in survival” (Tupper & Wortley, 1990a, p. 3).

Wilson (2003) also described the ‘group loyalty’ among young black men in prison, with one interviewee stating: “we’re all one, we’re all black. We stick together” (p. 419).

Though dated, an Australian prison slang glossary compiled by Tupper and Wortley (1990b, p. 3), described “a social grouping of prisoners” as a “click”, of which it is imperative to belong to, to ensure physical and psychological well-being while in prison. Zac², a nurse from the ward described similar sentiments in that like wolves, he noticed an evident “pack mentality” among the adolescents with anorexia. He commented: “they are quite a close knit bunch, so they usually go around in a group and...they’ll talk to each other about issues and get information off each other before they come to you. So it is
almost like a ‘pack mentality’ where they hit you all at once so um you have to be on your toes (laughs)” (see Appendix N2 & N3).

…they usually band together. They are interested when another one of their own are coming in and want to surround that new person and ah support them…whether it be in ah sneaky tasks or just to help them deal with hospital (Zac²).

Zoe¹ described her numerous admissions into ‘The Level System’ as being both positive and negative. A positive experience for her as with many of the adolescents was the support she received from the other inpatients with anorexia nervosa. However, it was interesting to note in the quote below that her mother described entering the program as being akin to entering “a prison” and the similarity of how inmates pick up bad habits from one another.

Zoe¹ acknowledged her mother’s interpretation of the ward setting as accurate. She described how one of her negative experiences from her time within the system was unfortunately a consequence of developing too close a bond with the other patients on the ward. She realised that patients with anorexia on entering the system learnt bad habits from each other which were detrimental to their well-being and delayed their progress.

The insights expressed correspond to Tupper and Wortley’s (1990a, p. 7) descriptions of prison life in early Australia: “It has been said many times that prison is a university of crime and that the young prisoner learns skills and techniques and makes associations that mean they may perform their anti-social craft more efficiently when leaving prison”. Consistently, Roberts and Hough (2005, p. 297) recently reported that worldwide public opinion remains largely unchanged today with many people describing “prisons as schools for crime”.

Zoe¹ explained her positive and negative experiences below:

Some of the experiences were positive because you can get support from the other eating disorder girls but then sometimes like when I told my mum about it, she sort of explained it, that it’s a bit like a prison, like you come in and you know one little trick and then you learn everybody else’s, so like it makes a negative aspect because you learn ways to sort of trick the system (Zoe¹).
It was evident that the adolescents with anorexia within the first few days of ‘entering the system’ began to learn the routine and rules of the ward program. After main meals Zoe explained that the adolescents had ‘bed rest’ for half an hour and this time was utilised by the ‘first-timer’ as an opportunity to learn more about ‘The Level System’ program. Zoe stated, “if there was a new girl in, she would always ask questions then”. As Tupper and Wortley (1990a, p. 7) reiterated, the ‘first-timer’ in prison has to quickly settle in by familiarising themselves with their surroundings and the prison culture in order to prolong their continued existence.

On arrival to the ward, the adolescents were generally provided with a copy of the program which included the ward timetable. The program included an explanation of the rules and expectations for mealtimes. As described in the accounts below, the adolescents discussed these main guidelines for meals further in their interviews with particular attention being given to things they were not allowed to do. It seemed that it did not take the newly admitted adolescent with anorexia long to familiarise themselves with the routine and for them to ‘learn the ropes’ from the other patients. The adolescents were extremely knowledgeable about the ward routine and the rules and expectations of ‘The Level System’ program. Their understanding was comparable to that of the nurses.

The adolescents reported that their meals needed to be eaten within a specific time frame. They were aware that main meals should be eaten within half an hour and mid-meals should be eaten within twenty minutes. They understood that food should not be brought in from home as this allowed the medical team and nursing staff to monitor their oral intake while in hospital; that is the calories being eaten each day.

All the adolescents described the customary guidelines for having meals in a similar fashion. They stated that their meals needed to be eaten in the dining room under the supervision of a nurse and that no-one was to leave their seat once meals had commenced or until everyone had finished. The nurse would get things for patients if necessary after everyone was seated. No swapping of items was to take place as patients were expected to eat what they had ordered and what had been sent by the kitchen each day. Everyone was to eat at a normal pace and with the proper utensils. There was to be no inappropriate shredding or cutting of food into tiny pieces. Every adolescent reported that each bread serve needed to have at least a quarter of a small individual packet of
butter or margarine on it. Additional toppings were also required. Vegemite, as a topping, was allowed only once per day at morning tea time. This rule was made as a consequence of vegemite having an excessive salt content which was being abused by some of the adolescents with anorexia.

Below some of the adolescents explained these rules as follows (see Appendix N4 & N5):

Well, we’re not allowed to, say if we have a banana, we’re not allowed to cut it into tiny little pennies or anything. I suppose we could if we are putting it on our cereal or something. We wouldn’t be allowed to cut bread into...6 or 8 pieces...We try and kind of eat things...politely...Not shred up the bread and rip it up...and leave crumbs...and wipe the butter on the napkin and things like that (Sara¹).

Well if we burn our toast, we’re not allowed to scrape it (Amber¹).

...you are only allowed vegemite once a day...you have to use a quarter of the butter per bread or equivalent (Isabel¹).

The adolescents were aware that they would either be placed on a meal plan or a ‘bolus-exchange’ plan as part of ‘The Level System’ program. The nurses explained that the size of the meal plans were dependent on each individual patient’s nutritional requirements. Some meal plans included an additional 1000mls of overnight high calorie feeds called “Ensure”. These feeds were placed in a feeding bag and given with the assistance of a pump, down a patient’s nasogastric tube while they slept.

If an adolescent was on a ‘bolus-exchange’ meal plan this meant that each portion of their meal was also allocated a set volume of a high calorie liquid “supplement drink” called “Ensure Plus”. If they did not eat the entire portion of a food group on their meal plan, they were required to have the full bolus equivalent. The bolus was given by a nurse who filled a large empty syringe with the necessary amount of feed and then pushed this slowly down the end of the nasogastric tube. The nasogastric tube was then flushed with water and capped off. The adolescent was allowed to drink the bolus from a cup if their nasogastric tube had recently been removed. However, nurses explained that it would be appropriate to re-insert the tube for the patient who continually required boluses.
Oliver explained ‘bolus-exchange’:

...basically every portion of their meal...is um allocated a certain, you know, according to calories...allocated a certain volume of Ensure...For example a...bread serving, I can’t remember the exact figure but it might be equivalent to 65 mls of Ensure and so if they don’t have that or all of that during their meal then they get 65 mls of Ensure after their meal to make up for that and that is explained to them pretty clearly and they mostly understand that (Oliver²).

Mandy provided additional information by adding that the boluses were generally a higher concentration in comparison to the overnight feeds that some patients had as part of their meal plan. Therefore the boluses were ‘Ensure Plus’ 1.5 concentrate while the overnight feeds were ‘Ensure’ 1.0 concentrate (see Appendix N6).

The adolescents also discussed that as part of the program they were required to have half an hour of ‘bed rest’ following all main meals (breakfast, lunch and dinner). The adolescents described how they sat on lounge chairs positioned near the nurses’ desk. Nurses called this area “the departure lounge” or “transit area”. Donna, a nurse, explained that the reason they sat near the desk was “so all the nurses can keep an eye on them”. Oliver reported that ‘bed rest’ used to take place on their beds but “on this ward it is physically quite difficult to see each bed and so they sit in an area near the desk”. While on ‘bed rest’ the adolescents reported they would read, knit, do craft, watch a movie or talk with each other or talk about the nurses.

Nurses and patients alike explained the main reason behind ‘bed rest’ was to prevent patients from purging or vomiting in the bathroom straight after main meals and to allow time for the food to digest. Zoe explained that “a lot of girls would go and you know syringe out their tube”. Some of the adolescents also felt ‘bed rest’ was a deterrent for exercise as some adolescents “would just walk around until they burnt off or imagined they were burning off whatever they were eating” or they would be “running it off” if they had the opportunity.

Six of the adolescents felt that ‘bed rest’ had some positives including preventing those patients that were anxious about just having eaten from vomiting, purging or exercising. They thought that it definitely had a place for the patients diagnosed with bulimia nervosa.
Zoe explained:

So after meals I think it is good having ‘bed rest’ because you...have to do something to preoccupy yourself and if you were allowed to go straight to bed you might be thinking like, Should I, you know, do something?. Whereas if you obviously can’t, then you sort of accept that you can’t and then you just think: Oh well I will just read or something (Zoe).

Three of the above six adolescents also thought it had its negatives and agreed with the other four adolescents that ‘bed rest’ was “not necessary” for everyone, “a waste of time” for some people, “annoying” or “pretty boring”. It was something that Sara thought “normal people wouldn’t do” after eating.

So like the prison inmate, the adolescent with anorexia had to quickly ‘learn the ropes’ in order to ‘survive’ within this ‘system’. They learnt that there were rules, regulations and a set timetable that needed to be followed if they were to be successful within the program. Success was measured by “getting better” and “getting out”. They learnt that their actions and their behaviour while on the ward would determine how long they remained an inpatient. Similar to an inmate whose actions and behaviour while in prison may determine whether he receives an early ‘parole’ (Ellis & Marshall, 2000) (see Appendix N7).

5.3 LIFE WITHIN THE SYSTEM

5.3.1 ‘DOING TIME’

According to Tupper and Wortley’s (1990b, p. 3) glossary of Australian prison slang, ‘doing time’ means “serving a sentence” and they described how the phrase encapsulates “the sense of futility and waste that is a prison sentence”. For a few of the adolescents with anorexia, the multiple, lengthy admissions to hospital were eventually seen in this same light. The impetus for recovery, as discussed later, for these adolescents was a realisation that they did not want to spend the rest of their life in hospital.

The adolescents reported very similar reactions and feelings the first time they discovered that they would be ‘doing time’ in hospital. Many were “frustrated”, in “shock”, “depressed”, “angry”, “on the brink of tears” and most of all “scared” of the thought of being hospitalised. Most reported that their initial reactions were a consequence of not fully
understanding what was going on when they arrived to the ward. That is, they were unaware their behaviours were ‘deviant’ and were unaware of societal views on what constituted ‘normality’. The adolescents described how when they arrived they had been placed on Level One or Level Two of the program depending on their medical stability. Most, but not all patients, were given a copy of the ward program on arrival but this did not seem to ease their anxiety and fear of being in hospital and on this program.

Danielle¹ explained:

_It was kind of hard because it was just the whole hospital fact that you’re scared of. It’s just that you don’t know what’s going on…I mean they have the Program all set out. But I’ve seen some patients don’t get that and it would be good when you first come in, you get everything set out, what’s going to happen, so you’re not too scared. I remember I got that, but I was scared by that. So really, it’s just the whole hospital thing. But you can’t really change that (Danielle¹)._ 

Most of the adolescents reported that they came into the system on Level One. As described earlier, this is ‘bed rest’ with or without toilet privileges. Josephine¹ was not allowed toilet privileges when she first entered the program and she felt quite frustrated by the fact that “the bathroom was right next to you”. The time spent on ‘bed rest’ was quite “boring” for many who remained on that restriction for as long as a week. Amber¹ explained that she was “pretty sick” when she came in and had “no energy” and so did not really care that she “wasn’t…allowed to do anything that required [her] leaving bed”. But by the third day she was “so bored”. It was difficult for Cameron¹ to remain on ‘bed rest’ because he was “so used to…running around and stuff”. He also reported that the days he spent on bed rest were “really boring” and that more or less it was just “nurses coming in all the time checking your blood pressure and your pulse and giving you your meds and everything like that”.

Zoe¹, on the other hand, had been admitted to the ward on Level Two on a Friday afternoon. She said, “I didn’t understand why I wasn’t allowed off the ward with my parents”. She did not get to see the doctors at all on the Friday and then no-one came to see her over the weekend. She also reported that “the nurses had explained it [the program] to us but I don’t know, you just didn’t really understand why you weren’t allowed off the ward and my parents couldn’t understand that [either]”. 

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Danielle¹ felt that with each subsequent admission it became easier for her because she knew the environment and the nurses within this environment. She stated, “you feel a bit more comfortable than when you first came in. You had all these strangers…” For Megan¹ it was a different story. She found it more difficult to follow the program and wanted greater independence than what the program provided her. Again, these sentiments are reminiscent of the prison inmate who might be settling in and may be “doing it easy” or who might be struggling and “doing it hard” (Tupper & Wortley, 1990b, p. 2). This depiction was confirmed in Easteal’s (2001, p. 95) study of female inmates in Australia, which described how “the ‘easy time’ prisoner learns quickly to respond in an appropriately deferential tone when spoken to”.

Megan¹ explained her dilemma below:

> I think it got tougher as it went along. First time it was kinda easier I think, because I didn’t really know what was happening, so I just kinda went with it and then the more times I was admitted I think the harder it got, because I wanted to be more independent… (Megan¹).

Most of the adolescents on first arrival expected that their stay in hospital would be a short one. They did not expect that the duration would be many weeks to months. Melinda¹ who was disgruntled by the amount of time she had spent in hospital, felt that she did not need to be here any more. She believed the doctors “keep you here for so long” because they do not think you can continue gaining weight at home. Obviously, as stated earlier, these adolescents were not free to discharge themselves but Melinda¹ felt that she should be given a chance and if she failed, she accepted that she might need to be re-admitted.

Melinda¹ explained her current predicament:

> …I don’t think I need to be here anymore and I think they’ve kept me for too long…They don’t think that I can put the weight on at home. Because that’s the only reason I’m here now, is just to gain weight. But I think they should let me have a chance at least and like say, Okay if you can’t gain a certain amount in a week, then you have to come back in. Something like that (Melinda¹).
From arrival to the ward to final discharge the time spent as an inpatient with anorexia can be a lengthy one from many weeks to months, depending on the severity of their medical condition.

5.3.2 ‘LAW ENFORCEMENT’

As nurses were the primary care-givers for adolescents with anorexia on the ward, it would seem that the time they spent together would be opportune for relationship formation to occur. Therapeutic relationships are well documented as being a vital element in assisting people along a path to recovery from anorexia nervosa (see Chapter 3). Yet nurses working within this particular treatment program were definitely fighting an ‘uphill battle’ because of ‘The Level System’ in which they worked and their role in implementing that program.

...if you are enforcing rules and regulations um they might not want to know you because you’re the awful person enforcing the law (Thomas²).

...having to enforce rules all the time...But when you have got to reinforce the rules, particularly to those who hate it, they are not very receptive of you...They don’t want to open up to you. They don’t want to talk to you. Which is part of building a relationship (Veronica²).

Most nurses saw themselves as enforcers of the program. Zac² described nurses as being the “front line for these kids”. He saw doctors as making most of the decisions yet nurses were enforcing those decisions and following through with the program and the doctor’s orders. In his eyes, nurses were “the face of the program”.

...we are the front line, we are the face, um, we are the ones that the kids look at as being the program...The face of their eating disorder program is us... (Zac²).

Oliver² described how ‘The Level System’ often placed nurses in a precarious and often confusing position for both themselves and the patients. He described the nurse’s role as taking on both an “observational” as well as a “disciplinary role”. He saw nurses as contradicting themselves by attempting to form a relationship with the young person and then being the ones to “catch them” out when they did something wrong thereby taking on...
a “policeman” type role. He envisaged that the nurses conflicting role was a by-product of the program.

“...we are not police officers but we are doing their job” (Mandy²).

Well I’m only saying police because technically what are we? What are nursing staff here for?...I mean technically we’re here [and we say], You’ve got to eat this now...You’re going to school now, You’re going to group now, We’re doing your obs now, You go to bed now. It’s sort of policing. I mean it’s not like a prison. You still get some freedom and liberty and that but technically you’re policing (laughs) (Riley²).

Nurses were expected to establish a rapport so that they could get close to patients and “offer support emotionally” and “be able to draw them out of themselves a bit and be part of their therapeutic management”. But this closeness was also a guise for uncovering information and then reporting that information back to the doctors. Oliver² saw nurses as “the eyes and the ears” for the medical team because nurses spent the greatest time with the adolescents with anorexia compared to other members of the health care team.

Nurses also had a duty to uphold the rules of the program. So nurses needed to be the disciplinarian if an adolescent did not comply with the program’s guidelines. Therefore the role of the nurse was perplexing not only for the adolescents but for the nurses as well. Explaining this conflictual role, Oliver² believed that it was simply “part of the burden of care in a nurse”.

“We are expected to be um setting ourselves up as some kind of confidante for them, not confidante so much as developing a rapport with them. But then at the same time we go off to a meal with them or catch them in the bathroom and suddenly we have to become the policeman for them. And I think it is a really confusing...role for the kids to see us taking and it is pretty confusing for us as well (Oliver²).

Nevertheless, Oliver² did believe strongly that the “emotional support” that nurses gave to these patients was “critical” to their recovery. He believed that he would attempt to provide this support whenever he cared for them rather than taking his job, as just a job. He attended to the physical tasks that needed to be done but also provided the young person with the appropriate psychological support. It is interesting to note, that in the quote below, Oliver² described adolescents with anorexia as “the eating disorders” (i.e a label).
...I think that, that emotional support of the eating disorders, is pretty critical as well. So that is something that I try and focus on when I've got them. Rather then just going in there, doing their obs, taking them for their meals and then ignoring them for the rest of the day (Oliver²).

Most of the nurses felt that the emotional support was critical for adolescents with anorexia. Even though they had to enforce the program and its guidelines, they saw themselves as a “support” person and “advocate” for the adolescent. Nurses saw their job as: “supporting them and explaining…what…their hospitalisation…is going to be like, what we are going to do for them, what their expectations can be from us, what we can expect from them and describe to them the program…”. They also believed that they were there to provide the adolescent with encouragement at the most difficult of times, that being the meal times. They described how an important part of their job was the supervisory role they played.

Paige² remarked that nurses played a myriad of roles when caring for adolescents with anorexia. She envisioned herself and others initially as ensuring medical stability through nutrition and the monitoring of vital signs. Thereby nurses were there to help them attain a healthy weight and to help them improve their eating habits so that they ate appropriately without for example pulling food apart. She also saw nurses as helping the adolescent to re-socialise with peers through attending and participating in the hospital school and group activity sessions each day. Again she believed the nurse’s most important job was to provide “emotional support” because she believed “the eating part is not going to work if the emotional part’s not there”.

Veronica², Riley² and Linda² took a more ‘clinical approach’ when they described their job. They described their role as following the program and its guidelines primarily by attending to physical care tasks. Note² that Veronica² and Riley² below both made what seem to be trivial references to the importance of “talking” and building up a “relationship” and Riley² felt that he was at times a “nurse-maid”. In the quote below, Veronica² has also labelled adolescents with anorexia by using the term “the anorexics”.

² Veronica² and Riley² were two of the nurses who later admitted that they did not like caring for the adolescents with anorexia.
...the anorexics here are put onto a level system and we just make sure they adhere to the specifications for that level um according to what the doctors want them put on. We also make sure that their observations are satisfactory—within normal limits and if they’re not then we notify the appropriate teams and do the required things to make those observations satisfactory. Um we watch them eat, um to make sure that they are having all their meal plan that they are supposed to have and if they don’t and they are on a ‘bolus-exchange’ program then we give them a bolus, if they don’t eat the required amount. Um, we just make sure that they’re psychologically OK as well—try to build up a relationship with them...and build up the trust so that you can have that relationship (Veronica²).

...I feel like all I’m really doing is watching them eat, doing obs [checking vital signs]...in regards to their physical status and then just keeping an eye on their weight. I mean yeah sure talking to them is fine but most of the other stuff is done by the doctors...So technically nurse-maid (Riley²).

Gabrielle² and Mandy², like the other nurses, were ‘enforcers’ of the program but they articulated the importance of building therapeutic relationships and trust formation with adolescents with anorexia. They saw positive relationships and building up a “rapport” as making it easier for the adolescent to come to them if they were having “any difficulties”. They both saw a positive relationship as being empowering for the adolescent. It gave “a bit of power back to them which often they have lost”. Mandy² also reported that it was very important for nurses to explain things in a clear and precise manner to the adolescent with anorexia. It was also vital that nurses provided the adolescent with rationales behind why certain things needed to be done. Mandy² felt that this helped her with her attempts to form trust with the adolescent with anorexia. But even though nurses expressed the importance of forming positive relationships with the adolescents with anorexia, this did not necessarily mean that these relationships developed effortlessly on the ward.

Gabrielle’s² explanation below of her role within this program demonstrated that through communication she attempted to form a positive relationship with the adolescent with anorexia. She insisted that “touching base” each day with the adolescent was important in order to ‘get to know’ them and establish a rapport. Nevertheless her description, like those of other nurses on the ward, alluded to the chief function of nurses as being one of implementing and carrying out the prescribed program guidelines. Her role included, “…being very strict with them on [the] guidelines and setting boundaries for these kids...”.

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...besides just talking to them and things...just each day I think touching base, finding out if they are struggling with anything. What you can do for them...Knowing that they have an avenue I guess in you...Then just the other nursing care I guess you have got and that is following through with the program and at times being very strict with them on their guidelines and setting boundaries for these kids and then sticking to those boundaries. So they know what they can expect and what is expected of them. So they understand exactly what is happening to them...Yeah carrying through on the program that we actually do have (Gabrielle²).

Even though Gabrielle² believed “touching base” was an important part of the nurse’s role within this program, Zac² revealed that he, and probably most nurses, did not actively “pursue these kids to talk to them”:

...with these kids ah we don’t, or I don’t pursue these kids to talk to them. I just think if they have a problem, they will come and see me. I don’t actually go out there and ask them, Is there anything troubling you today? (Zac²).

5.3.2.1 ‘Keeping A Watchful Eye’

The most time consuming job, not necessarily the most important, for the nurse caring for adolescents with anorexia within ‘The Level System’, was to supervise and observe the adolescents at mealtimes. Nurses used the terms “keep an eye on”, “monitor”, “supervise”, “observe” and “watch carefully” when they described their actions at the meal table.

I guess we are here principally, at least as nurses, to watch them eat and make sure that they eat the appropriate amounts of food (Linda²).

There were “six meals a day, three main meals and three snacks”. Zac² described how he “gather[ed] up the troops and head[ed] down to the kitchen” when it was time for a main meal or snack. He described how the nurses have a “meal plan folder which has all of their menus in it so [nurses] can check their meals off against the menus to make sure everything is there as it should be”.

Nurses needed to make sure that the adolescents “stick to the plan” with using the correct amount of toppings, eating within the correct time frame dependent on whether they were having a snack or main meal and making sure that their eating behaviour was appropriate.
Paige² added that nurses also chatted at mealtimes with the adolescents while observing them. She stated nurses, “make sure...they’re having the right portions of margarine as written in their meal plan, make sure they are drinking all their milk not leaving anything in the cup…and generally encouraging them to eat their food but at the same time talking about other things beside that”.

All the nurses explained their role at mealtimes in a very similar way and reported that they needed to “observe them” and “record” what had and had not been eaten “so that it can be reported to the appropriate people” or “if they are on the ‘bolus-exchange’ then you give them the exchange if they haven’t eaten their foods”.

Thomas² explained the usual mealtime practices on the ward for the adolescents with anorexia:

…they go down, escorted with a nurse, down to the recreation room. They get their trays, heat up whatever they have to heat up or get out of the fridge whatever they need to get out…and they sit down and they eat. Monitored by a nurse...half an hour for mains, twenty minutes for snacks (Thomas²).

Paige² felt, as did other nurses, that the supervision of the adolescents with anorexia at mealtimes was “probably not the most critical” part of her job but that it definitely required “the most attention”. The nurses felt that because of their illness these adolescents would use the time to manipulate by leaving things behind, concealing food items or by not using the correct portions of their spreads. Paige² believed nurses needed to have “a very keen eye to watch four girls at the same time at the table”.

The nurses described different types of interactions taking place when nurses and patients “all sit down at the kitchen table” together. Most revealed that the interactions that took place depended on the patients’ personalities or it depended on which nurse was caring for the adolescents that day.

Zac² explained that the interactions at the meal table depended on the patients that were on the ward at the time. He spoke of the two extremes of personality types that he had seen and he classified them as the “really combatant” patients and the “placid patients”. He felt that the “combatant” patients with anorexia were the ones that would “fight every
“last inch of the way to try and get away with something”. Riley\textsuperscript{2} described these particular patients as “hard core”, not unlike the label of “hard-man” that may be given to the very strong-willed and dominant inmate within the prison system (Tupper & Wortley, 1990b, p. 1). This meant that the nurses needed to be extra vigilant and needed to “watch them like hawks” at the meal table because “they will try every trick of the trade”. In these situations Zac\textsuperscript{2} felt that it became “a battle of power” and nurses needed to exercise their “authority over them” by maintaining their position as the nurse at the meal table.

On the other hand, Zac\textsuperscript{2} felt that other adolescents were “placid” in nature and “will eat everything and want more…in which case you have got to try and stop them (laughs)”. He believed these patients were subservient and would do exactly as they were supposed to and were “quite easy to deal with”. This classification of patients provided by nurses can be seen as similar to the classification of prison inmates noted by prison officers. Prison officers are usually aware of those inmates who are considered ‘deviant’ or are the ‘trouble-makers’ and those who are ‘compliant’ with the system’s rules and regulations:

...some patients, as I said, you can build up a better rapport with and you are...a lot less tough, not a lot less tough, that sounds terrible, that’ll do though (laughs). You are a lot weaker; I guess you could say, in regards to sticking with the rules. While others that are a bit obnoxious or stand offish, you’re more inclined to um be a bit harder on them (Riley\textsuperscript{2}).

Oliver\textsuperscript{2} instead believed that the interactions at the meal table depended on which nurse was caring for the adolescents with anorexia that day. He felt that there was a “real range” of interactions and that, “it is as different as…the staff”. He described three different styles of nursing practice. The first type of nurse was the one who had a balance between chatting and socialising with the adolescents about their interests but at the same time maintained “that…firm hand on the way things are conducted”. Then there were the nurses that “just growl and don’t really engage with the kids at all and the kids really respond very badly to that”. Lastly he described the nurses who were too flexible with the adolescents because they “don’t want to be too hard on them”. He felt these latter nurses would let patients get away with things that they should not be getting away with.

...I think it’s the way that you talk to them as well...If you are watching them eat and they didn’t have something, it’s the way that you tell them that they have got to have it...If you are abrupt and rude about it, then you are not going to build a relationship with them. But if you explain to them why and
Oliver² insisted there needed to be a “balance” otherwise it was “destructive” having “people who are growling and people who are saying do whatever you like”. The adolescents became confused and the “smarter ones take advantage of that and play staff off…and it just leads to longer admissions”. Oliver² understood why different nurses operated in different ways at different times and saw this as being a consequence of the same nurses looking after these particular patients day after day and being emotionally drained by the enormity of the task. However he believed, as other nurses did, that consistency was crucial when dealing with adolescents with anorexia.

So I understand why people who are given those patients day after day after day, by the third or fourth day, I can totally understand why they just throw their hands in the air a bit and go you know, I really can’t be bothered fighting with them about that again. Um so I understand why it is. At the same time I think that consistency is pretty critical because these kids…especially early on, when they are quite unwell, I don’t think they are really equipped to handle differences too well. I think they need firm consistency (Oliver²).

Most of the nurses described how talking at the kitchen table made the activity slightly “less stressful” for the adolescents. Talking also encouraged “normality” because as Linda² reported “most people talk around the dinner table when they are eating”. Again the nurses insisted that the amount of conversation depended greatly on the nurse or the patients and whether they were “vocal” people or not. It became difficult to engage with patients who were still “struggling” with their eating but Gabrielle² believed nurses needed to keep trying to interact with them to distract them so “they are not just focusing purely on their food”. Thomas² reported that he also tried not to be the “police person” at the meal table and wanted them to “get their minds off food” so he attempted to make the process quite “casual” with light conversation. However, sometimes it was very, very difficult. Thomas² reported that “if they don’t want to talk, I just sit there and um twiddle my thumbs for half an hour”.

While ‘keeping a watchful eye’, most of the nurses believed that it was healthier to avoid conversation directly about food. They believed for these adolescents “encouragement” was essential around the meal table but food conversation would only perpetuate their
obsessions about food and was “not normal”. It was believed, by all nurses with the exception of Donna², to be more productive for conversations to steer towards what happened on a ‘gate-pass’ or what music they liked or what pets they had at home even though “they loved talking about food” and calories. Donna² was the only nurse who felt that it was acceptable to talk about food with them “because they are so open about it and they know a lot about it”.

Mandy² additionally explained that sometimes these patients would compare what they were eating with the other girls and “if they are missing something they will always tell that person...Oh you have to have this. This is your meal plan...”, thus consciously is alerting the nurse to this.

If the adolescent looked like they were not going to finish their meal on time nurses would normally hand out “warnings” prior to the end of the meal just to let them know that they were “cutting it fine”. If they were genuinely attempting to finish the meal most nurses would grant a small extension of the time but “not much”. They would be encouraged to finish the meal fully. If they were only on a meal plan then what they did not eat stayed on the tray but if the adolescent was on a ‘bolus-exchange’ meal plan then nurses “gave them a bolus” after the meal.

…when they come in, they know the rules, they know that there is a set time, they’re aware of that so there’s no question of they didn’t know. So…if they look like they are cutting it fine, we’ll warn them a couple of times, we may even extend it a minute, if we feel that it is going to help them any. But if they just look like they are not going to get it done and they are not interested in getting it done, we’ll usually, if they are on a ‘bolus-exchange’, we will give them a bolus (Zac²).

…it depends how much they’ve left. We might give them a little bit of extra time, not much…and if they are looking like they are not going to finish, give them a bit of a warning that they are not going to. Otherwise a bolus… (Thomas²).

None of the nurses enjoyed “sitting and watching these kids eat” or being the ‘enforcer’ of the rules at the meal table. At first many nurses felt “awkward”, “out of place” or felt they were “intruding” on “something that is quite personal”. Zac² reported that if the adolescents were easy to get along with and they would converse with you then “the meal goes along as it should” and “you don’t feel like you are intruding”. But he stated there
would be times when the “kids…fight against you” and it became a “real battle” and as a nurse you just did not want to be there.

Oliver² felt “self-conscious” when he had to watch these adolescents eat. He did not like the feeling of having to tell the adolescents that they had to do something that they absolutely hated doing. He loathed being the ‘bad guy’ and he summed up his feelings and the feelings most nurses had about their role below. Engaging the adolescents in some conversation helped to make the situation less uncomfortable for him and the adolescents.

…I don’t especially like doing it. Because like everyone else…I don’t like that feeling that they’re developing a dislike for me through nothing that I have done…So that’s why I always try and engage them in some kind of conversation…and that kind of makes it easier. But it is not an experience I enjoy, saying to four young people who don’t want to eat, Come on. It’s time to go off and do something you hate. I don’t enjoy that. I don’t think anyone really enjoys it (Oliver²).

Thomas² reported similar feelings of being “uncomfortable” about being “the big brother looking over their shoulder” or the “policeman” checking that everything was by the book (see Appendix N8).

Paige² said that she tried to put herself “in their shoes”. She and Veronica², “would hate somebody watching [them] eat”. They tried not to make the adolescents feel like they were “staring at them” by using conversation at the table. Paige² saw the “importance” of the nurse’s presence at the table while Veronica² did not. Paige² described how the adolescents needed “guidance” and “encouragement” with their meals while Veronica² felt that “their weight” was the best indicator of how they were doing.

Veronica² explained this as follows:

…it should be known through their weight, when they are weighed twice a week, whether they are eating or not the right amounts…Whether we sit there or not is not going to stop them trying to sabotage the system (Veronica²).
Linda², Mandy² and Gabrielle² were a little “confronted” early on by the adolescents’ peculiar eating habits. Linda² laughed and said that sitting and watching the adolescents eat was “not one of her favourite tasks” because she felt like she was “knit-picking sometimes”. Mandy² was “frustrated” many times by their odd behaviour of cutting things up into minuscule pieces and eating one piece at a time. She understood that anorexia nervosa was a mental illness but she still could not comprehend why they cannot see that “you have to eat to survive”. It frustrated her to “see these girls sitting down there…cutting their meat, piece by piece…it’s not a healthy way to eat, to cut bits and pieces of food and…eating one piece at a time”. Gabrielle², like Linda², felt “a bit pathetic” when she had to correct the adolescents about the amount of butter they required on their bread serves.

Nevertheless, the nurses believed that ‘keeping a watchful eye’ while the adolescents ate was a necessity even though it was uncomfortable for all involved in the process (see Appendix N9).

...it is really confronting sitting there, especially when you see what they do…I guess the worst thing is with their breads…they have got to put a quarter of the butter on and actually being really strict that, that is a quarter and you feel a bit pathetic actually saying, No, look you have missed a tiny little bit of your butter…You see that it is such a struggle for a lot of them to eat, that I am sure we are making it harder for them with us there but unfortunately we can’t trust that they will eat…So even though it is uncomfortable, we still have to do it (Gabrielle²).

The reasoning behind why nurses had an obligation to monitor and ‘keep a watchful eye’ on these adolescents for meals was a result of the “nature of the illness”. The psychological component of anorexia nervosa made it difficult for nurses to believe everything the adolescent said to them especially when it came to food. The adolescents’ fear and trepidation around food and of eating food meant they could not be trusted in this respect. If they were not monitored, nurses believed that in most instances they would tell nurses that they have eaten, yet the nurse “can’t be 100% sure”. So as Zac² pointed out: “the best way of knowing the truth is seeing it for yourself…So to sit and watch them eat that meal rather than have them say they’ve eaten the meal”. Mandy² agreed with Zac². She felt if they were not observed at meals “they won’t eat”. 

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All in all it was the nurse’s “duty of care” to ensure that these adolescents while hospitalised “remain[ed] on track” to achieving medical stability and as a part of that nursing duty it was important that they supervised meals. Donna² reported that “if they feel they are not being watched or observed thoroughly then they will start to exercise in the night time and vomit...foods after they have eaten and...just things like that. So we are here to make sure that, that doesn’t happen and the only way we can do that is by observing them...”.

Riley² concurred and explained below in rather boorish language the point that eating is vital for survival. Nutrition is essential for the functioning of a healthy human body and without it a person could die. As nurses they had a duty to monitor the adolescent’s oral intake and medical condition. Interestingly Hillary Mantel (2004) also described similar sentiments, in a book called ‘Some girls want out’, where she commented about the pleasure and power the person with anorexia feels but which can eventually result in invalidity and death. Mantel (2004, p. 10), in a similar vein to Riley², commented “when you are isolated, your back to the social wall, control over your own ingestion and excretion is all you have left”. Additionally, Riley² believed that parents were given a reprieve from being the “physical ogres” when nurses adopted this supervisory role at mealtimes.

Technically as the saying goes, You don’t eat, you don’t shit, you don’t shit, you die! So really...that’s one reason. Although...I know it’s a bit brash but it seems to fit the bill. Um, mainly...poor nutrition, your body starts to waste away. So we need to keep an eye on maintaining everything else. So if you don’t eat, all of a sudden...heart rate starts slowing down, everything else starts slowing down. You have low potassium, you end up arresting. It’s...mostly medical reasons but also...it breaks away from their parents having to be...the physical ogres...[who] say, You gotta eat this now! (Riley²).

Thomas² mentioned “they’re sneaky” too and Gabrielle² verified that they can be “so manipulative compared to a lot of your other illnesses that you have in here...to be fair on them we have got to do it”. Gabrielle² believed that nurses needed to treat this disorder seriously and part of making sure that these adolescents did not get any sicker than they already were, meant “watching them”.

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I think also the program and the way we treat them is going to tell them how serious or not it is. If we are lenient and we laugh about it and, Oh yeah don’t tell anyone, you can do this. I think it shows to them, Hang on! I’m not really sick and yet…these kids can die just as easily as someone with cystic fibrosis (Gabrielle²).

The nurses spoke highly of the rules set within the program as they felt these assisted with maintaining a sense of consistency among differing staff members. Oliver² stated, “to have particular rules to work within helps with consistency”.

Oliver² maintained that his role in supervising meals was helping the adolescent to conquer the “two conflicting arguments within themselves”. He explained that for most, but not all, adolescents with anorexia, there were metaphorically speaking “two voices” in their head. The first ‘voice’ was saying, “I don’t want to eat that because I don’t want to put on weight”, while the second ‘voice’ was saying, “If you want to please the people that you care about then you will”. So he felt that they were “hinging on the balance” and it was not a “complete revulsion” of food. Therefore they would often “welcome that slight push over the edge” and the nurse being there “closely monitoring them is hopefully pushing them in a much quicker way towards some kind of healing”. Nurses saw their presence as being encouragement for the adolescent. According to Oliver², being firm and saying, “I need you to finish that” was not entirely unwelcomed by the adolescent.

Veronica², on the other hand, saw the practice of watching the adolescents at mealtimes as being a great disadvantage for the nurses who are trying to establish a positive relationship. The concept of monitoring meals she felt prevented the formation of trust between nurses and patients with anorexia nervosa. She felt that nurses were seen by the adolescents as taking on an “authoritarian” role that was not beneficial for therapeutic relationships. Veronica² was the nurse who earlier remarked that nurses should not supervise meals and that progress should be noted by weight gain each week.

I think that it’s quite difficult to build that relationship up, especially the trust section when you are made to sit down and watch them eat. You are seen as an authority figure and most people don’t really want to have trust or have relationships with an authority figure. So it is quite difficult to do… (Veronica²).
Donna², Mandy² and Gabrielle² all spoke of eating a meal with the adolescent as a way to minimise the awkwardness of the situation. Gabrielle² herself did not do this but thought it might be a good idea while Donna² and Mandy² did eat a meal with them on occasions. Donna² reported that she received a good response from the adolescents because she ate with them and believed that it “breaks the barrier” and “encouraged [them] to eat all their dinner”. Mandy² explained, “whenever I am looking after them I usually have something to eat so…I am becoming a part of them…”. Gabrielle² explained that it would probably make it harder for the nurse to actually watch them “like a hawk” at the table but that “in the long run” they would only be doing themselves a disservice if they cheated at the table.

Gabrielle’s² recommendation for making meals less uncomfortable:

…taking…a meal down with you and you eating as well with them, rather than them feeling so much on display. But then again it is hard to watch them. But at the same time I guess they need to have the responsibility. If they are going to manipulate things, well we are going to find out anyway in the long run. So, whether leaving eating with them and saying, Ok it is a normal thing to do and we are not going to watch you like a hawk. If we miss them putting butter under the table or anything, they’re the ones in the long run that can’t maintain their weight. So they are just going to end up back in here (Gabrielle²).

The nurses believed that ‘keeping a watchful eye’ at mealtimes ensured that the adolescents followed through with adhering to their meal plan and the rules of the program. Yet eight of the ten nurses admitted that they themselves did not always follow through with the “no swapping” of foods rule. They believed that “the whole system should work like a conveyor belt but it sort of breaks down in the middle somewhere” when it came to getting the correct meals sent up from the kitchen.

Zac’s² main difficulty was with the kitchen. The kitchen would sometimes send up varied portion sizes for each of the adolescents. He found it “hard to validate to a child on the eating disorder program why their one serve of rice looks like a Mount Everest one day whereas it looks like half a serve the next”. He would use his “own personal judgement” in these situations but on the whole he believed he did not “let swaps happen”. If it was “the kitchen’s mistake” and “they have gotten something up that they didn’t order” both Donna² and Gabrielle² would ring the kitchen and re-order their meal.
Paige², Oliver², Veronica², Mandy² and Riley² have all swapped items of food for patients because they did not see any “harm”. Even though Paige² emphasised, “…they are not supposed to. What comes up on their tray is exactly what they have to have. So if their meal plan says a bread portion and they get sent a crumpet, they can’t swap it for a piece of bread even though that’s also a bread portion. They have what comes up”. Yet Paige² confessed she normally permitted an adolescent to swap their apple juices for orange juices or their yoghurt for a different flavour. Paige² understood that the rule was there to ensure that the adolescents ate a variety of things rather than “a patient ordering ‘vita-weats’ for their bread portion for every single meal”. She rationalised her decision to allow swapping by saying: “Hey! If it’s a bread, for a bread portion…It is…you know…the same”. Veronica² agreed. She felt that the “no swapping rule” was “cruel”.

I think it’s cruel…Say if they want to swap a carbohydrate for a carbohydrate, I don’t see the problem in that. If there are no other effects from that, such as potatoes weighing them down or certain fruits may have a laxative effect or vegemite with salt in it…Then I don’t see a problem with it (Veronica²).

Riley² bent the occasional rule in regards to the meal plan too. If something was available on the ward then he would let them swap it for another equivalent. He decided that at least they would be eating it because they liked it rather than having to have a bolus for it because they did not like it. He would not allow a swap if the item was not readily available. Mandy² alternatively made her decision, depending on whether the adolescent always needed to have boluses or whether they always ate their food. So if they were usually compliant with their meal plan then she allowed a swap but if they were usually non-compliant then she would “stick” to the guidelines (see Appendix N10).

I bend occasional ones [rules], only in regards to meal plan. I look at it this way, if a patient is on a ‘bolus-exchange’ program and…it says that they’ve the choice between fruit or fruit juice…they get sent up a piece of fruit yet they prefer juice. If the juice is there, I’ll get it for them…If it’s not there, I won’t do it. But if we’ve got a certain item on the ward, Yes I’ll do it. That’s the only thing that I go against the program on…I see no harm in making certain changes if it doesn’t involve having to wait to get stuff from the kitchen…Because they’re still going to have it (Riley²).
Linda² and Thomas² were the only two nurses who reported that they stringently followed the “no swapping” rule at all times. Thomas² felt the swapping issue was “always a tricky one”. He did not see much difference between eating an apple and eating an orange yet he said, “I just go by the rules and don’t let them swap, honestly!” Yet Linda² felt very strongly that they should not swap at all.

...they have to either eat it or have the bolus...And they know that...if they want to swap an apple for an orange because they don’t like apples, then it’s like, Sorry you have got to eat the apple (Linda²).

Most of the nurses were satisfied with the meal plans that the adolescents were given as part of the program. As explained earlier when “they first come in, it is a lower calorie one and it builds up to about 3000 plus”. Most nurses felt the ‘bolus-exchange’ meal plans were a “good base”. They were “clear and concise” for the adolescents. Nurses felt the incremental increase in calories with each subsequent meal plan was a “stepping stone” for the adolescent to “focus on and achieve”. With the ‘bolus-exchange’ meal plan, the adolescents had a target amount of food that they needed to eat and they needed to do it within a certain amount of time otherwise they would get a bolus. Yet as Zac² stated, “some kids won’t need the ‘bolus-exchange’, others may require it”, so the meal plan was easily adaptable to individual patients. Those that required boluses and those that did not. Donna² had the only general complaint about the plans’ principles, noting that the meal plan for dinner did not allow for a drink. She saw the amount of food that they needed to eat as being quite large and she did not understand why they could not have a drink with their dinner if they wanted it. She stated that, “they can’t even have a glass of water, that’s not part of their program”. Donna² exclaimed that if she was the adolescent with anorexia she would “even go to the toilet and drink from the toilet tap (laughs)...I wouldn’t appreciate that”.

Similarly most nurses felt that the variety of foods that the adolescents could choose from was not too bad but after a few weeks as an inpatient it would probably be a bit monotonous. They all understood the reasoning behind why the adolescents were not as free as other patients on the ward were to choose from ‘special lists’ or ‘extras lists’ of food. The main reason was due to their disorder, their issues with control and food and the confusion and anxiety too many decisions can cause them. Yet Linda² felt it might be
a good idea to give the adolescent “the illusion of being able to make more choices even if…they are technically not making the choices”.

It was interesting to discover that the adolescents with anorexia saw the nurse’s role in a very similar light. Danielle¹ explained that the nurse’s job was to “look after us and make sure we eat”. She described how the nurses gave “medications” and checked that our “observations”, like temperature, blood pressure and pulse, were within limits. She reported that nurses were there to “make sure that we’re okay and not depressed or upset”, thereby confirming that emotional support that nurses themselves spoke about earlier. But of even greater interest she exclaimed, “they make sure that we’re not getting into any trouble outside of meal times”. Danielle¹ defined trouble as “some girls could be exercising, some could be throwing up…If the meal trolley is there, they could be tampering with that and changing around things”.

The adolescents explained that the nurse’s job mainly “revolve[d] around eating”. Generally they saw nurses as “checking” or “supervising” their eating and making “sure we are doing everything right”. Sara¹ reported they “make us kind of adapt to normal eating again”. They saw nurses as being a fairly good “support”. Although they disclosed that nurses were still spies for the doctors because they reported back to them in their nursing notes.

Amber¹ described nurses as people who “sort things out”, thereby communicating with the kitchen when wrong meals were sent or communicating with the doctors if a patient wanted to see someone. Chloe¹ said, “if they are nice to you, you can talk to them”. Cameron¹ described nurses as being there to “give you that extra push forward and help you progress” and Josephine¹ saw their role as following “the rules” of the program as well as being a support person and a “friend”.

Only Melinda¹ thought nurses had a good job. The rest of the adolescents felt that the job, in caring for adolescents with anorexia, would be “pretty tedious” because they have to do the same things each day and it would also be “annoying waiting around for people to finish eating”. Megan¹ explained it would be a difficult job because nurses needed to be “on [their] toes” all the time and she verified that it would be difficult to trust adolescents with anorexia around food.
I wouldn’t like to do it only because it would be pretty tedious day after day. It would be pretty hard too because you have always got to be on your toes and stuff...You can trust them to a certain degree...You can trust them as people and as friendly people but around food I don’t really think you can trust that much...So it would be pretty hard... (Megan¹).

Mealtimes were an “uncomfortable” experience for most of the adolescents especially “with nurses watching you and if it’s very silent”. They could either be bearable or “bad” depending on whether the nurse “just sits there and stares at you” or whether the nurse initiated some conversation at the table. Megan¹ revealed that she felt some nurses would be “genuinely interested” and would have a friendly conversation. However she thought some nurses were “interrogating” her. Generally most of the adolescents felt that the majority of nurses were “nice” however there were some that were “mean”, “unfriendly” and “unnecessarily strict” with them (see Appendix N11).

...some would talk. The ones who would talk and were like genuinely interested in a conversation that was good. Others...it more felt like they were interrogating you rather than conversation. That didn’t work because then everyone would just be like staring at each other, rolling their eyes going, God I can’t wait to get out of here...So the ones that were actually interested in, how you were, how you were going, that made it go so much easier and you probably wouldn’t concentrate on what you were eating... (Megan¹).

Well, some of them are a bit strict...they kind of stare at you...When I first came in, I suppose I’m a fast eater now, but I ate really slowly and kind of picky. And they’d just like, stare at you, and I was very uncomfortable and everything. Like, some of the nurses were nice and didn’t do that, but some of them do. And that was really uncomfortable and some of them are really strict, like, unnecessarily strict. Yeah, some of the nurses are fine, but just a couple... (Sara¹).

Danielle¹ felt that it was “not normal to have someone stare at you” and that staring actually did not help with getting the adolescents with anorexia into a “normal eating habit”. She explained this below:

I personally think it’s a bit uncomfortable and it’s not normal to have someone stare at you like that...You want to get into a normal eating habit and everything...It’s just not normal to have someone stare at you. I mean, they can watch you and talk to you and all that because I understand that’s what needs to be done. But the whole staring thing isn’t very comfortable (Danielle¹).
Everyone, except Josephine¹, felt that it was a good idea having all the adolescents with anorexia sitting at the table with a nurse for meals. Melinda¹ added, “but I also think that it would be good if, when you get higher up [the levels], you’re allowed to eat by yourself sort of thing. Yeah, have some freedom”. Josephine¹ reported that when she was a patient on the ward what really annoyed her was that the “eaters” and the “non-eaters” all sat at the table together for meals. Obviously “eaters” being those that ate their meals while “non-eaters” being those who refused to eat their meals and received boluses instead. She said, “it was bad for both sides”. If you were an “eater” it was uncomfortable because “you didn’t like to be watched by other people”. For her as a “non-eater”, it was “boring and just annoying that we had to watch the others and have to sit through it and suffer”. Some patients were very “slow eaters”. She felt that on these occasions, when there were two groups of patients, the “eaters” and the “non-eaters”, mealtimes were made even worse. It was not just the nurse that glared intensely but also the other adolescents at the table would stare at each other.

Zoe¹ remembered her first admission and recalled that when she arrived to the ward she “just wanted to go home as fast as possible” so she ate everything. But then on second and subsequent admissions it “turned into a bit of a game…because everybody wanted you to eat and it was sort of…Well I am not going to. She said it became a bit of a “farce” where she would take down a puzzle with her to the meal table and the nurse would say, “You’re not allowed to do that. You have to eat” and she would blatantly refuse. She agreed with the other patients though that sometimes mealtimes were stressful because the nurse would be “sitting there….staring blankly at you”. Some nurses increased the stress at mealtimes because of the way they spoke to the adolescents. She reported that the nurse’s tone of voice and the way adolescents with anorexia were spoken to at the meal table made them feel “a bit threatened” and “nervous”. Comments at the table from the nurse that made the adolescents feel this way were mainly when the nurse checked that the adolescents were following the rules as set out in the program. That is, when nurses examined plates and containers and checked that the adolescents were using the correct portion of spreads and eating the correct amounts of food in an appropriate manner, according to the rules of the program.
...I think meal times were made more stressful by like people saying, Oh let me see your butter, like repeatedly...I think you should wait until they have finished buttering and then before they start eating and then say, Oh have you used all your butter?...and then saying, Oh could I please check your butter?, rather than saying, Have you used all your butter, let me see [rough tone of voice]...It makes you feel a bit threatened and I think sometimes you get nervous about meal times...just the whole thing...you know checking everything and not allowed to heat up, not allowed to do this and it sort of just makes it even more stressful than it already is. Which [it] is obviously going to be because you don’t want to eat... (Zoe).

Nonetheless, some nurses “were good” according to Zoe. They brought a magazine down to the table with them and did not make it as obvious that they were watching them. Others “chatted with you about other stuff while you were eating, like movies or what you did on ‘gate-pass’ and that sort of makes it easier”. She felt that conversation decreased the stress around eating and made it more “social”.

In hospital though, Zoe often felt that eating was “turned into an event” because of the “routine” nature of the way the program operated. There were set times for everything and nurses remained inflexible with those times. Zoe understood retrospectively that in this environment it had to happen and said, “sometimes I think you get angry at the nurses for being so picky about times and everything...then when you think about everything else that has to happen like...school or...‘gate-pass’...you sort of understand that the rigidity has to happen”.

5.3.2.2 ‘The Surveillance Continues...’

Paige clearly summed up the feelings of most nurses, in that it did seem like the adolescents with anorexia were under constant “surveillance”. But again this was because of their illness and because they were on ‘The Level System’ program. It was a crucial part of the nurse’s duty of care to make sure that these adolescents remained medically safe while they were in hospital. But it did leave many of the nurses drained and in a mindset of always “watching and wondering” what these adolescents were getting up to next (see Appendix N12).
The monitoring and observation permeated all aspects of ‘The Level System’ program. Surveillance by nurses was expected by the adolescent with anorexia. Not only were mealtimes supervised and monitored by nursing staff but after main meals nurses again monitored the adolescents while they sat on ‘bed rest’ for half an hour. Donna² reported, “it was a simple task” but a part of the routine for the care of the adolescent with anorexia. The adolescents sat in an area called the “Morrocan area”, also known as the “departure lounge” or “transit lounge”. It was near the nurses’ station desk obviously so that the adolescents “can be supervised by nursing staff to make sure they aren’t going to the bathroom or exercising or purging or doing any of those things…”. Oliver² revealed that nurses took this opportunity to attend to other work but usually there were “nurses sitting at the desk…keeping half an eye on them”.

...we will just go about our business on the ward and check in on them every time we pass the transit lounge (Zac²).

...most of the time, they just kind of keep an eye on us from the nurses’ desk (Isabel¹).

The reason why the adolescents were kept within close proximity of the nurses was because in the past there had been adolescents who would “vomit in the garbage bin when the nurses aren’t looking”, were “caught exercising” or were “in the bathroom” immediately after main meals. Those patients with a propensity to vomit would have “more supervision and longer ‘bed rest’” according to Thomas². ‘Bed rest’ would normally be an hour long for the adolescent with bulimia nervosa.

Amber¹ remembered an occasion when a nurse was particularly pedantic about the half an hour for ‘bed rest’. This nurse punished the adolescents for leaving the ‘bed rest’ area five minutes early. As punishment, the nurse made them endure another half an hour of ‘bed rest’.

...and once...We went off like five minutes early and one of the nurses got us to come back and have another half an hour—which is really, really annoying. We were so angry at her that day. I’m sure she knows who it is! (Amber¹).
Nurses were also expected to make sure that the adolescents with anorexia attended school each weekday. School was a time to catch up on regular school work from their home school. Cameron¹ explained, “You get some work done but it is nothing hard that’s going to make you stress out”. The hours were shorter to normal school and the work was considered by patients to be “low key”.

…it’s also about all those in between times. What activities are they doing in between meals and snacks? So, are they going to school as they should and returning to the ward as they should? (Zac²).

In the afternoons the adolescents were also expected to attend the group sessions which were usually “art and craft” activities. Paige² remarked, “a program [for group activities are] displayed at the beginning of each week” on the ward. The adolescents reported that both school and group were a “good distraction”. On some days (usually meeting days or if school exams nearing) they did not “feel like” group. The older adolescents, especially those in Years 10, 11 and 12, who had a lot of school work and major exams nearing, explained that they wished they had a choice of whether or not they went to group. As Megan¹ explained, “if you didn’t want to be there, you still had to be there. So that was a bit of a pain”. Danielle¹ agreed. She asked if she could have a couple of days where she did not go to group and stayed on the ward to catch up on school work but she said: “They [the doctors] said, No! Because if they were flexible for one person, then everyone would want to not go to group”.

Amber¹ agreed and felt that group should not be “compulsory” on Tuesdays and Fridays because these were the days of the meetings and they found out “the news” either good or bad from the doctors about their Level and the privileges to be bestowed. She said it was horrible going to group after ‘the verdict’ had been handed down because “you have to sit on the couch crying and you just want to be alone in your room…in your little comfort zone and…you don’t want people in group…seeing you crying and stuff”.

As is usual within the prison system there were also restrictions placed on who may visit the adolescents with anorexia and for how long (Easteal, 2001). For Levels One and Two it was immediate family only for two hours on weekdays and three hours on weekends. On Level Three and Four the patients could introduce one other relative. The nurses reported that most parents followed the visiting rules of the program and there were not
too many problems with enforcing this aspect of the program. However Zac² explained that it was very difficult to “police” the visiting restrictions.

It was extremely difficult for nurses to turn away grandparents and sometimes people would just “slip in” too easily. Zac² described how the restrictions would be easier to monitor on a “lock up ward” but on an adolescent ward like this it was too difficult for nursing staff to monitor. With other patients being allowed to have their visitors stay for an unlimited time, nurses felt it was sometimes cruel to ask parents to leave after the allocated time period. If their presence was “not causing any harm” and did not interfere with the program they would “tend to pull a blind eye” if parents overstayed. This was “as long as it [wasn’t] the whole day”. They understood that it would be very difficult for the adolescent to understand why “they are not allowed to have the people who are closest to them with them” but for many adolescents with anorexia the nurses believed that if it was pressure from the “home environment [in the first place], then restricting their parents is not necessarily a bad thing”.

Gabrielle² argued that for some parents visiting needed to be compulsory. She felt for those she classed as “dysfunctional” families that are “having a nice life away from this poor child who is in hospital…those visiting hours should definitely be encouraged”. She reported that, “it is really important that not only do we say…they can only come in for this amount of time, they have to come in for this amount of time and spend time with their child”.

Linda² did not feel that “unlimited visiting” was necessarily helpful for the adolescent with anorexia. She thought that the restrictions were positive and nurses enforcing them allowed the adolescents to have the space they needed from their parents to work through their issues on their own. “But as they work their way up ‘The Level System’ and they head towards home I think seeing them [their parents] more and more would be a good thing”.

Melinda¹ was the only adolescent patient to report that her parents did not follow the visiting restrictions “and the nurses didn’t say anything”. The other patients’ feelings varied regarding the visiting rules of the program. Danielle¹ felt her day was “so full up” that there were only really a couple of free hours for visitors and so she thought that was “enough
time”. While Megan¹ thought it “really sucks” that she could not have her grandparents visit when her parents went away. She reported that it was at these times that she felt, “I am alone. There is no-one here for me”. She “never” really wanted her parents to go while she was on the program but in retrospect, she saw the time limit as being sufficient. Josephine¹ felt that the visiting restrictions of the program gave out “mixed messages about going home”. She felt that adolescents with anorexia needed the support as she personally was very, “very homesick”.

Most of the adolescents felt that parents should be able to visit “as long as they want because they’re more supportive” especially when they were on Level One of the program. Zoe¹ explained that being on Level One for the adolescent was distressing because you had “more time to yourself” and you got “more anxious” because you were “on your own and you can’t move around”. Sara¹ also exclaimed parents should visit for longer periods because “it’s really hard for us” and “it gets really lonely” in here.

All of the adolescents mentioned the fact that the program did not allow friends to visit. Isabel¹ remarked, “Well, at first I didn’t really like the fact that um friends couldn’t come and visit…I think they should be able to…It doesn’t really make sense to me that”. They felt that this was very “disappointing” as they saw no harm in it. Josephine¹ thought that it was “highly unlikely” that a friend would “scheme something to get them out”. Josephine’s¹ language here insinuated that being an adolescent with anorexia on this ward program felt like being in ‘prison’ and that it was unlikely that friends visiting adolescents with anorexia would scheme an escape plan to “get them out”.

Amber¹, in the quote below, described her intense annoyance because it had been over five weeks now and she had not seen her friends in these five weeks. She felt that because she spent a great deal of time with her friends and confided in her friends, they were probably a better support for her than her family. The adolescents believed that friends visiting them would help them to “get [their] mind off things” and “keeps [them] in contact” with what is happening in the ‘outside world’. Zoe¹ also added that it was “unfair” that the adolescents with anorexia could not have their friends in to visit while the other adolescents on the ward could. She could see the positive effect that friends had on other patients and said that friends “make them feel so much better”. She remarked that, “if you
are not allowed to see your friends and then you go back to school and no-one has seen you for...two months...it’s a shock for everybody”.

The adolescents’ comments seemed to exude this feeling of detachment from the ‘outside world’ as a consequence of spending time within ‘The Level System’. In many ways resembling the detachment or uneasiness some inmates may feel when they are released from a prison and then expected to resume normal roles in society again. Note Isabel’s¹ language below, which reinforces the earlier sentiments of adolescent’s feeling ‘locked up’ when on ‘The Level System’ program. She described leaving the program, as: “when you get out...”.

...you can’t have your friends see you and...some of my friends have been wanting to come and see me and I haven’t seen them for five weeks...It’s really bad because they’re not allowed to. It's just stupid! They should let...your friends...come and see you...within free time if it doesn’t...clash with school or group or meal times then they should be allowed to come in...Because well they’re the people that you spend most of your time with anyway and you’re in...a new environment and...you only see your family and it’s not like you hang out with your family anyway usually...Well you go out with your family but you don’t really hang out with them and talk to them that much (Amber¹).

...it would still be heaps better to see them [friends] um more often. So when you get out it is not like...I missed so much... (Isabel¹).

Along with having set time limits for visitation within the program, the adolescents with anorexia also had time limits set for showers and bathroom use. Showers were to be in the mornings and “it shouldn’t be more than ten minutes” each day. Nurses needed to keep an eye on the amount of time being spent in the bathroom as part of their role in the program. Time spent in the bathroom was to be kept to an absolute minimum as much as possible. Donna² explained, “they have got free use of the toilet as long as it is not straight after main meals...If they are a bit long I sort of check up on them and listen at the door and make sure they are not vomiting or anything...”.

Excessive bathroom use would necessitate the adolescent being placed on “toilet restrictions” by the doctors or nurses. This normally would be a maximum of two visits to the bathroom per shift and “they have to ask [nurses’] permission to go to the toilet”. Donna² explained that if an adolescent needed to go more than twice in a shift, she would
“let them go and...wait at the door” to make sure that “it is not more than a minute...and usually they make it very quick”. Some nurses felt they needed to be stricter with the rules for some adolescents who had “been caught a few times”, vomiting, purging or exercising in the bathroom. They reported that “if they were really, really busting, I would see no problem in giving them a bed pan...Pull the curtains and you can use a bed pan”.

Gabrielle² explained the nurse’s role in monitoring bathroom use:

...if we are noticing excessive use, if we are thinking they are vomiting or if they are losing weight or not maintaining...then we observe their toilet privileges...they may only have two toilet privileges a shift which means they can go to the toilet twice a shift...For some people probably that isn’t enough. For some people they won’t use that...Then also limited to 10 minute showers...We have to do that to try and stop their exercising and their vomiting and things. So...they are very much on display and yes when they have to ‘buzz’ and say, I am going to the bathroom now, I think is really hard for them...Not pleasant for them (Gabrielle²).

Excessive exercising in the bathroom or elsewhere would lead to the adolescent being placed on twenty four hour ‘bed rest’. Again this was at the discretion of the nurses or doctors. Nurses asserted that if the adolescent “has just done it once off, you may not put them on twenty four hour ‘bed rest’”. They would be warned that if they were “caught” again that this would happen. Paige² explained that nurses have the power to “put them on the equivalent of Level One for that twenty four hour period” and “we do have the support of the doctors to do that”.

Thomas² explained twenty-four hour ‘bed rest’:

...if there is a suspicion of them exercising, say if they have come out of the bathroom when they have said that they have been showering and there’s been no water running, you take their obs and their pulse is up and their resp rate is up and they are looking flushed...They might have a punishment like to be on ‘bed rest’ for twenty four hours or for the rest of the day if it is in the morning (Thomas²).

For those adolescents, who remained non-compliant and continued to ignore the rules of the program and the Level One restrictions that were imposed on them, or who were self-harming, the doctors requested that these adolescents be “specialled”. This meant they were usually placed in a single room on the ward and were allocated a nurse of their own, who kept “an eye on them” twenty four hours of every day until the specialling order was
removed. Zoe¹, one of the discharged patients, described a time, during her admissions, when she had been on “nurse watch” and this she explained was “when you are on twenty four hour-nurses watching you”. Zoe¹ remarked non-compliance with the program “discredits your whole reputation and so the treatment you get is often a lot more concentrated”. The use of ‘specialling’ on the ward for the adolescent with anorexia can be considered as being in some ways comparable to the use of seclusion or separate confinement for the ‘non-compliant’, ‘troublesome’ or suicidal prison inmate (“Department of Corrective Services”, 2003; Easteal, 2001; Walsh, 2006). Currently ‘specialling’ seldom occurs on this ward and is not a routine part of the program.

Mandy² further explained that the specialling orders were generally instigated because of relentless non-compliance and manipulation of the program from the adolescent with anorexia or it could be instigated when a patient was self-harming (i.e cutting or mutilating their body) in some way:

…at times we have specialled the anorexic kids because of the non compliance issues…one to one…just to keep an eye on them (Mandy²).

Finally, as part of the program, monitoring also included the monitoring of medical stability. All the adolescents with anorexia had their vitals signs (blood pressure, heart rate, respiration rate and temperature) monitored fourth hourly by nurses. These observations would be taken more frequently if they were on Level One of the program or connected to a cardiac monitor. This aspect of the nursing care was vital. Quite often an adolescent with anorexia dangerously dropped their temperature below 35.5º and their heart rate below 40 beats per minute on a night shift. In order to rectify this situation, nurses would often need to place extra blankets on the adolescent and an “overhead heater” over the adolescent’s bed at night time. The patient would be reviewed by the night doctors and nasogastric feeding would be commenced if not already in progress (see Appendix N13).
5.3.2.3 ‘No More Privacy’

As a consequence of the monitoring and surveillance, that became a part of the nurse’s role within this ‘Level System’, all of the interviewed nurses, except Riley², felt that they were constantly invading the adolescent’s privacy. The nurses insisted that they always warned the adolescent first before they invaded their privacy no matter what the circumstance. They explained that, “in nursing you always do it with due warning”. So Oliver² reported that if he felt the adolescent was spending a prolonged period in the bathroom, he would knock on the door first and inform them, “You have been spending a lot of time in the bathroom. Somebody is going to have to come in, if you don’t come out soon”. Oliver² always asked a female member of staff to go in if a female patient was in the bathroom. Donna² instead would look under the door and would see their feet moving and so she too would knock on the door and warn them to “get out” before she actually opened the door.

…when they are exercising in the bathroom, I have a look under the door, which has a little gap and you can see them, their little feet are going up and down, up and down, up and down (Both Laugh). And you knock on the door and you say, That’s enough. Get out! I can see what you are doing. I let them know that I can see…and they eventually stop and if they don’t get out, I say, I am counting to three and I am coming in. Because the doors are two way, you can open it from the outside…I let them count to three and if they are not out by then I just open the door and go in and get them if I have to (laughs). Which hasn’t happened to me yet but I did open the door… (Donna²).

The nurses believed, with these particular patients, sometimes “there does come a point where whether they are doing it deliberately or through some inability to…behave in a logical kind of way…there does come a point where you have to go past what you would consider normal or proper”. Invading someone’s privacy was something that they would not do routinely but these “kids have got to a point where they’re not really thinking particularly straight about that anyway so it has to be taken out of their hands to some extent….”. Again nurses described how it was not something that they wanted to do “willingly or voluntarily” but it was unfortunately something that they saw they had to do as part of their “job” (see Appendix N14). Thomas² believed the surveillance was there to ensure that they are not “doing anything that would be contraindicating [sic] to their plan”.

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Anyone coming into hospital would to a certain extent experience a loss of privacy and it was “one of the biggest drawbacks”. For the adolescents with anorexia this infringement on their privacy would “probably be slightly more than a normal patient given their condition” and ‘The Level System’ program. Melinda¹, a patient, acknowledged that on this program “you don’t really have very much privacy and they’re always wanting to know what you’re doing and why you’re doing it”. Nurses even disclosed that as part of their role in the program they would go through an adolescent with anorexia’s belongings and do “locker check ups” if they believed they were “storing supplements” such as laxatives or were eating or drinking prohibited food items such as sugar free chewing gums, sugar free soft drinks or concealing bottles of water. Nurses even described having “to check there is no syringe placed in the rubbish bin...in their room”³. The commonalities are clearly evident, between these locker and room searches, to the cell search or personal/strip search that may be conducted in a prison system (Easteal, 2001; “Just Oz”, 2004; Walsh, 2006), when prison officers are suspicious that contraband, such as cash or drugs, may be being concealed within an inmate’s clothing or in their cell.

...well it is an aspect of nursing that no matter what condition...you come into hospital and there is that barrier that nurses get to go past that regular people don’t. But with these girls...well girls and guys in particular...you get into very personal places...Sometimes you have to bust in on them in the bathroom if you feel that they’re breaking the rules of the program...you go through their stuff if you feel they are storing supplements...yes you go sit with them when they are being weighed, which is something that most people take as a very personal part of their life. They don’t like to share their weight and you stand there and measure it and judge it against the other days (Zac²).

Zoe¹ and Josephine¹, two of the discharged patients, reported that negative experiences for them when they were on the program, included nurses doing these locker searches and going through their belongings without their knowledge. This they felt was an immense invasion of their privacy.

³ Adolescents with anorexia have been known to take empty syringes out of bins, wash them and then use them to withdraw feeds from their nasogastric tubes.
Zoe¹ and Josephine¹ described their angering experiences below:

...gone through my stuff when I wasn't there, that really shitted me off...If I wasn't allowed in while they were doing that, then I should have been alerted to what was going on...I think patients should always be allowed to be there...because...I think that's...a bit dodgy. Yeah, so that's why I think you should always be given an option to be there. I mean some girls might not want to be there when they are going through their stuff but I think you should always be given the option and being alerted to what is going on and why... (Zoe¹).

Um well it used to annoy me how they used to search through my things. They would tell mum but they wouldn't tell me and I would just find them searching through my things when I got back from group (Josephine¹).

Melinda¹ recalled witnessing nurses checking through another patient’s belongings and drawers for the concealment of vomitus. At times nurses even checked this patient’s clothing in case she was secreting food.

[Patient’s name]...vomited in her drawers and they had to go through all of her stuff...So basically...she had to go out of the room and they just went through all of her stuff...They found the vomit in her drawers. And...sometimes they’d look under her shirt and stuff because she hides food under there... (Melinda¹).

The nurses described how the monitoring and the invasion of privacy were “the parts [of their job they] hated most”. Yet for nurses, to successfully implement ‘The Level System’ program, they needed to monitor anything and everything from their eating to their weight to their bathroom activities. Paige² explained that it made her feel like she was constantly telling them what to do a lot of the time by saying, “Don’t eat it like this, Don’t do that...Don’t have your curtains pulled”. Nurses loathed having to tell patients what to do all the time because it made the patients “angry” and made the nurses’ day “harder” and the patients’ day “less enjoyable”. They would much rather let them do what they wanted to do but their “conscience” told them “it needs to be done”.

...we do go and check them regularly whatever they are doing. When they are in the toilet we knock all the time. When they are in the shower we make sure they are not exercising. We weigh them in just underwear and gowns and for someone with a body image problem, to be seen in a gown walking around a hospital is just quite degrading...We have to have their curtains open and we touch them a lot...I think we breach it [privacy] quite a bit but I don’t know another way of going about it (Gabrielle³).
Megan¹, a patient, acknowledged that nurses did invade an adolescent’s privacy on this program, “but then…a lot of it was on the program for them to do. So it was really different for us compared to other patients”. She understood that even though it was their job to do these things, it did get “a bit annoying”. Some of the adolescents believed that it was necessary for some patients otherwise they would continue with dangerous weight loss practices. These adolescents felt, “they [nurses] only do it for your own good” and if they did not do their job then “there’s no point in being in hospital…because they’re [patients] just going to do the same as they did at home”.

The adolescents provided some examples of how nurses had violated someone’s personal space whilst on the program. In contrast to the nurses’ descriptions above, these adolescents suggested that nurses at times provided the patient with no visible warning.

Like if you had the curtains around your bed or something they would just walk straight in. It wouldn’t matter if you were like trying to get changed or something. That was a bit annoying (Megan¹).

…one girl…after her shower…she was putting on moisturiser and…[nurse’s name] just came over and opened the curtains and…[patient’s name] was like, Well you know you didn’t even say, Look I need to open the curtains….She just did it…She didn’t even warn her and I think you should (Zoe¹).

The process of inserting a nasogastric tube was seen by nurses as a “pretty invasive procedure”. This too was something that nurses had to do as part of their role and nurses justified themselves by saying, “I am doing this for the benefit of them” (see Appendix N15). It could be seen by the adolescent as a ‘bodily invasion of privacy’. A nasogastric tube was usually inserted on arrival to the ward. Most of the nurses described how it was an “unpleasant”, “pretty awful”, “uncomfortable” and “distressing” thing to have to do to a patient. Thomas² added, that if they have been in and out of hospital many times then “they know the drill” and it did not worry him as much. Donna² explained that sometimes a nurse needed to hold a patient’s hands “quite comfortably…for support” while another nurse inserted the tube. But on other occasions when a patient refused, nurses needed to “sort of hold them down and do it against their will”. Again, though, nurses declared “it needed to be done”. Both Donna² and Linda² described the nasogastric tube as “a necessary evil”.

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…if they are still and cooperative, it’s not a traumatic experience at all but if they are thrashing around and very uncooperative, I find it much more distressing as they do (Linda²).

We’re not doing it because we like to be cruel but we’re trying to help these kids. In many cases it is just the act of eating that food that can cause them the greatest grief. So ah sometimes they appreciate the NG tube just as much as it is needed (Zac²).

Oliver² agreed with the other nurses in that it was an unpleasant procedure to perform but it was “no worse” than “having to give a kid a needle for a premed”. He said that with most adolescents you can treat them as a “grown up” and explain things to them and if they want to refuse treatment then there is not much that can be done. However, he added, “with eating disorders, there is an element of not quite understanding why they are unwell and a bit of a loss of logic in that regard. So I think there comes a point where we have to hold them and do it…Which isn’t nice”.

A nasogastric tube could be used as a powerful “threat” or “punishment” for adolescents with anorexia. Oliver² hoped that no nurse on this ward did coerce an adolescent by portraying the nasogastric tube as a painful procedure but had seen nurses use it as a “veiled threat”. Mandy² commented that nurses, including herself, had used similar tactics, in particular the threat of sedation, doctors being called or being placed on twenty four hour ‘bed rest’, to frighten the adolescent into having their boluses when they had not eaten everything.

Oliver² and Mandy² explained their thought processes at this time:

I think some people see it almost as a punishment. Some nurses sort of say, If you don’t do this, then we are going to put a tube in and it’s almost said that way as well and so it is like, If you don’t then we will do this really unpleasant procedure to you. I feel uncomfortable about that. It’s no different from the one thing that paediatric nurses have been told never to do and that is threaten a kid with a needle. I think threatening a kid with a nasogastric tube is probably pretty close to that. Um but at the same time, they are old enough [and] as adolescents…they have to understand that certain behaviours may lead to certain things happening. I hope that no nurse here would use it as a threat in terms of, We are going to hurt you by sticking a tube up your nose. But it may be a veil threat in terms of, We are going to have to go to the next stage (Oliver²).

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...if they don't want to like have boluses or something and I said, Oh if you don't, they will have to sedate you. You know just to frighten them. Or, I will have to call the doctors...now and you will be on twenty four hour 'bed rest' (Mandy²).

Inserting a nasogastric tube can be a very distressing and traumatic experience not only for the patient but for the nurse as well. Mandy² recalled an instance when a patient with anorexia was so distressed that she needed “some sedation...to help her calm down”. The adolescent needed to have boluses and overnight feeds but she did not want to have a nasogastric tube. Mandy² explained that she too became distressed because she was “holding her down and giving her sedation and putting the NG tube in”. The adolescent “was very upset...crying very loudly” and was “looking up” at her with red, “swollen eyes”.

At that time, Mandy² remembered her feelings being “they are just kids”. It became a very difficult evening shift for her. Not long after inserting the tube, the adolescent vomited it out. Mandy² felt “hopeless” as though she had not achieved anything constructive or beneficial for the patient. She was also angry that the doctors were not there to help her. She said “they just give orders”. The doctor told her over the phone, “Don’t worry”. She felt it was not as easy as that when “they are fighting with you and you have to fight with them”. The doctor made the decision over the phone but he did not have to follow through with it. Mandy² related that at that particular moment she felt that what she was doing was unethical and believed that “until they are scheduled” nurses should not be “hold[ing] them down” because “they are not criminals”. But in retrospect, she believed that as nurses caring for adolescents with anorexia, “you have to do it”. Linda² was in agreement with Mandy’s² latter statement and reported in her interview, “it is just part of the job and there are parts of any job that people don’t like to do, but you’ve got to do it whether you like it or not...I see that as something that has to be done”.

5.3.3 ‘Awaiting the Verdict’

As an adolescent with anorexia gained weight, showed improvements in their eating habits as well as psychological and physical status, they moved up the levels of the program and thereby gained greater privileges. Sara¹ explained, “you get more privileges as you keep putting on weight”. The decision for someone to be moved up a Level was made at the twice weekly medical meetings which took place on Tuesday and Friday.
mornings. Although a number of the multidisciplinary team members attended these meetings, major decisions were still made by the treating doctor.

...these doctors...come around on the ward, they have made their decision and then they are the ones that deliver what the decisions are going to be… (Gabrielle²).

Early in the morning before breakfast on Tuesdays and Fridays, the patients were weighed after voiding in a bedpan (females) or urine bottle (males). They also had to wear a hospital gown. Chloe¹ explained that the bedpan was placed on a chair near the patient’s bedside and the curtains around the patient’s bed were closed. Patients were unable to use the toilet as they may be tempted to void in the bedpan and then “water load” creating a false weight. “Water loading” is achieved by drinking lots of water from the tap or other sources to increase weight.

Female patients preferred to have a female nurse on weigh days but said that “it didn’t really matter” either way. They understood the reasoning behind why they needed to void in a bedpan or urine bottle and why they needed to wear a gown. They understood that the nurses needed to confirm that there had been no “water loading” overnight by checking the concentration of the urine. The nurse measured the amount of urine voided as well as tested the urine with a dipstick for abnormalities. The adolescents were also aware that by wearing a hospital gown with only their underwear on allowed for greater accuracy with measuring the weight gained each week.

Some of the nurses, however, felt that wearing a hospital gown with “bare backs” and “walking out with your urine in the pan and putting it down” would be quite “humiliating” for the adolescent with anorexia. All the adolescents found weigh days to be “nerve wracking” and “scary” as well as “stressful”. Josephine¹ and Cameron¹ both felt that patients should not have to see their weight if they did not want to as this may reduce their anxiety around weigh day. Most felt the time that weights were done was too early in the morning but then appreciated that most other patients were not awake to see them in their gowns and to see them voiding behind their curtains. By communicating the latter, the adolescents themselves hinted that what they did on weigh day was for them somewhat humiliating and embarrassing.
Isabel¹, Melinda¹ and Sara¹ thought weigh days were “a good idea”. Isabel¹ stated, “I don’t really mind them…I look forward to them”. Weigh day meant it gave the adolescents an opportunity to move up a Level and gain more privileges. However, for these adolescents the stressful part was waiting for the doctors to hand down ‘their verdict’. Would they be ‘rewarded’ or ‘punished’ for their efforts this week? The news could be good but it could also be bad. For most adolescents the stress of a weigh day was two-fold; putting on weight was both good and bad. Good because it usually meant a “new chance to move up a Level” but bad because they felt they were getting “fat”. Losing weight meant a loss of privileges and punishment of some sort.

Amber¹ and Cameron¹ explained why adolescents with anorexia always worried about weigh days:

Oh, we always worry about them, because if we lose weight they find some sort of way to punish us. Put our meal plan up, move us back down a level or whatever. And if we put on weight, like we don’t want to put on weight, so we get upset about it. So it is pretty bad either way (Amber¹).

Um…you just get really anxious about them, you know, because you can’t tell what is happening, like you know, you want to put on weight but then you don’t because then you are going to think you are getting more fat. Yeah it’s just like a vicious cycle (Cameron¹).

Megan¹ did however like the idea of ‘The Level System’ in that you “got more freedom” as you moved higher up. For her and some of the other adolescents it gave them “something to work towards”. The adolescents felt that the “worst thing” that could happen following the medical meetings would be the doctors deciding that an adolescent needed to move down a level or would not be given leave from the hospital, known as a “gate-pass” over the weekend. Patients were allowed ‘gate-passes’ once they reached Level Three of the program.

Megan¹ explained that it really hurt when they were refused a ‘gate-pass’ because they had not gained weight and had remained stable. A ‘gate-pass’ was something that the adolescents really “look[ed] forward to”. It was in essence “freedom”. It was an opportunity to go home for a while or go out shopping with friends or family and a chance to return to “normality”.

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…it was like freedom for like two hours, maybe three and if someone cut it off you…even if it was just something like not losing weight but not putting on weight, just staying the same…That was kind of like, Come on!. That was…the worst thing… (Megan¹)

The nurses similarly explained that ‘gate-passes’ were a major “reward” for the adolescent with anorexia on this program. An internal ‘gate-pass’ meant that they could spend some time off the ward with family but needed to remain within the hospital. External ‘gate-pass’ meant they were able to leave the hospital for a specific period of time. ‘Gate-passes’ could be for a half-day or full-day depending on the decision made at the meeting. ‘Gate-pass’ was an opportunity for the adolescent to re-bond with family members and re-integrate back into the family dynamic. As a family they were able to partake in meals and then assess the success of these endeavours.

…if they’ve put on weight and haven’t had any real major problems through the week, they can get ‘gate-passes’ over the weekend, which allows them off the ward or out of the hospital for periods of time with their families…No kid likes to spend their weekends in hospital. So that’s quite a good reward for them (Zac²).

Zac² also added that a “reward” for the adolescent was greater “freedom” in the sense of doing normal things like using the bathroom “without being watched like a hawk”. Gabrielle² saw the “removal of the nasogastric tube” and the “freedom to walk around the hospital” as rewards for the adolescent with anorexia.

…there is also more freedom provided if they show that they can be trusted, they’ll get that freedom…given to them…They will be able to use the bathrooms without being watched like a hawk. Things like that…little things that are taken for granted. But for them it is a reward (Zac²).

Rewards and punishments went hand in hand with ‘The Level System’, as the program was based on “behaviour-modification” principles. Oliver² likened the learning principles used to ‘modify’ an adolescent with anorexia’s behaviour to that of “training dogs”. His reasoning bore a remarkable resemblance to early psychological research undertaken by Pavlov. Pavlov’s famous classical conditioning study showed how a dog could be conditioned to salivate at the sound of a tuning fork (see Feldman, 1996, 2002). Oliver² felt that two types of “negative reinforcement” existed for the adolescent with anorexia and these were the threat of a nasogastric tube and the hospital admission itself. The positive
reinforcements were again the privilege of getting “gate-pass on the weekends” and ultimately leaving the hospital and going home.

...you know there are two ways to train a dog. You can use negative reinforcement or you can use positive reinforcement and a similar kind of thing exists here I think...And obviously there comes a time when you have to use negative reinforcement and...whether you mean it to or not, the threat of an NG tube is a negative reinforcement to bad behaviour or can encourage them to behave well...behave is probably the wrong word to use, but push themselves harder to comply with what they know is expected of them...They want to go home because being in hospital is not a particularly pleasant experience...they want to have ‘gate-pass’ on the weekends...That’s all positive but...the actually being here is a negative in itself (Oliver²).

For Gabrielle², “withdrawing physio” from the adolescent with anorexia, was another “huge punishment” as many were “chronic exercisers”. She agreed with Oliver² that nasogastric feeding and “the whole admission to hospital is a punishment...[because] they have been bad”. She also felt that “restricting family visiting” would be a punishment for those who were very close to family members but would not be seen as a punishment by those who would be “quite happy to get rid of mum and dad and sister and who ever else”.

As described earlier another form of punishment that can be dealt to the adolescent was twenty four hour ‘bed rest’. This was generally used as a punishment for excessive exercising or unjustifiable use of the bathroom after several warnings had been issued.

Chloe¹, a patient, described how adolescents with anorexia could be ‘punished’ by the doctors dropping them down to Level One of the program or warning them that this would happen next time if an improvement was not imminent.

...well it depends but sometimes they get put on like Level One-‘bed rest’ and sometimes they just get a warning... (Chloe¹).

From the above discussion it can be seen that the most stressful days for the adolescents with anorexia were weigh days. After being weighed the adolescents ‘awaited the verdict’ from the doctors. Major decisions were made at these twice weekly meetings and it appeared the adolescent’s greatest reward whilst on the program was the opportunity to receive “gate-pass” on the weekend. This for the adolescents was “freedom”. It did not
matter whether the ‘gate-pass’ was only for a few hours, a whole day or overnight. The adolescents appreciated any time that they could have off the ward and away from the “controlled environment” into which they had been placed.

In some ways a ‘gate-pass’ was similar to the ‘exercise yard’ for the prison inmate. Time in the ‘exercise yard’ would be the inmate’s little piece of ‘freedom’. It is their only opportunity during the day to get some fresh air and exercise and have some time to themselves. However, unlike inmates who may still be under the constant glare of prison officers, the adolescents would not be under the constant watch of nurses. Parents would in some respects take on this responsibility. Additionally, for some inmates, the ‘exercise yard’ may be a feared place because of violence from other inmates. As Riley (2002) explained “prisoners live in almost constant fear of crime and firsthand accounts of prison life often describe strategies for avoiding victimization” (p. 457). For most adolescents with anorexia however, ‘gate-passes’ were welcomed and not feared. According to Tupper and Wortley’s (1990b, p. 1) glossary “pacing” is a common activity undertaken by prison inmates in the exercise yard, so named for its resemblance to “the behaviour of caged animals in a zoo”. Coincidentally, later an adolescent with anorexia actually remarks how she and others were made to feel like “zoo animals” on this program.

The only exception, to having this little ‘slice of freedom’, would be the prisoner that has been placed in ‘solitary confinement’. They would not have the privilege to go outside. This would in some ways be comparable to the adolescent placed on twenty four hour ‘bed rest’ or on Level One following non-compliance with the program; they too would not be “free” to leave the ward or their room. Cameron¹ reported that the confinement of Level One-‘bed rest’ got “quite annoying” because you were “stuck in [your] little room all day”. He suggested that Level One of the program should be modified to allow the person to “sit outside for maybe even half an hour or something to get a bit of fresh air...even if you were supervised”.

5.3.4 ‘LIFE AS THE PRISON OFFICER AND LIFE AS THE INMATE’

Nurses and doctors working within this program became in ways analogous to ‘prison officers’ in a prison system and similarly their charges became analogous to ‘inmates’. Leibling and Price (2001) have described the typical day for a prison officer in the United
Kingdom, as being routinised with regular duties that need to be attended to. Similar to prison officers working in a prison system, caring for adolescents with anorexia on this ward became a “very routine”, “automatic” and “monotonous” task for most nurses. Nearly all of the nurses described how they set themselves to “auto-pilot” because they “know the routine inside out”. The program for adolescents with anorexia was so rigid that nurses got “into a very automatic kind of mode”. But Oliver² believed that “monotony is a friend of nursing unfortunately”.

All the practical nursing tasks that the nurses performed, from checking meal trays, to taking their vital sign observations, to weighing them and testing urines, to making sure they adhered to bed rest or went to school, were all “just part of nursing”. It became “habitual” and “second nature” for nurses to make sure that these things happened at the same time each day. There was no variation from the set routine except a slight reprieve on “the weekends”. Once again this is similar to the routine in many Australian correctional centres with the timetable being strictly adhered to and the routine being slightly changed at weekends (“Just Oz”, 2004). Oliver² felt that nurses “go into [this] policeman mode” as a “self defence mechanism” otherwise they themselves would self-destruct from the strain of the job.

*I think that we get so caught up. It is a routine. So you go in there. You do what you have to do and you get out. And I mean that is partly because it is such a challenge I think sometimes to interact with them or get them to interact with you and build a rapport…Because you’re doing things to them that they are against and…so…you just get really blasé. You go in there. You do your job and you get out of the room…*(Gabrielle²).* 

Other nurses explained their everyday ‘life as the prison officer’ within this ‘Level System’ program (see Appendix N16 & N17):

…*it’s very sort of robotic…go do the meals, go do the obs, there’s the work done (Zac²).*

…I think it is also partly a self defence mechanism because…it is…a bit like a deputy head master of a school who walks around the school yard growling at kids, he is not even thinking about it anymore, it has just become habitual. Because if he thought about the things he was saying, it would become so jading and so destructive that he just wouldn’t do it anymore. And so I think…you kind of shut down a little bit and just go into policeman mode…*(Oliver²).*

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Nurses understood that “it must be very monotonous” for the adolescents as well. Some nurses became a little complacent “expecting them to know” what was expected of them when they were on the program. The nurses reported that this expectation of knowing the rules and following through with the rules of the program was mainly for those adolescents who had previously been on the program and had been re-admitted once again.

Caring for adolescents with anorexia was “a lot more demanding” and “frustrating” in comparison to caring for other adolescent patients. The main difference being that nurses physically saw a difference when they cared for other adolescents on the ward but with adolescents with anorexia, their improvement “move[d] like a glacier”. Improvements were not as apparent on a daily basis and nurses who had come back to work after days or even weeks off were likely to say, “Oh Crikey! Are they still here?”. Most found the work more “mentally draining…than physically draining”. Many admitted that they “just go in, do [their] job and go out” because for nurses it was sometimes difficult to “click” with these patients. Nurses also felt that the adolescents with anorexia “can’t necessarily see [nurses] as helping them” while other patients did and appreciated the help.

…these people, I think they can’t necessarily see us as helping them. Whereas other patients on the ward that have had a broken arm, they have had surgery or whatever, we are there and we help them. We take away their pain, we feed them, we get them things that they like, we comfort them… People with an eating disorder, we feed them, they don’t want to be fed…we don’t take away their pain, we can’t take away their pain…So it is very much different between the two (Gabrielle²).

Most expressed that they enjoyed caring for adolescents with anorexia “but in small doses” because “it can be exhausting”. Many believed looking after the adolescents a few days in a row was “draining” and this led to nurses not being as strict with the program. They understood that this inconsistency was not good for the patients or the staff and led to increased “manipulation” from the patients. They found that this type of nursing took “more emotional energy” because of its unpredictability.

I guess if you stop um engaging with those people that are manipulative then it takes you away from the manipulative cycle…so that you can’t be manipulated… (Veronica²).
Paige exclaimed that “the disciplining type stuff” that was part of the behaviour-modification program, was the hardest part of this job. This included all the “little arguments” that occurred at the dinner table as a result of nurses having to say, “Don’t do this! How much of that have you used? Why are you doing that? and You should have this according to the meal plan!” Paige did not enjoy having to do these things and felt like a “Food Nazi”. She always wondered at the back of her mind, “Am I just going to push it that little bit too far?”. Interestingly, Tupper and Wortley (1990b) explained that the term “Hitler” is often used by inmates to describe “an overbearing or officious warder” within the prison system (p. 3).

Veronica also found the “disciplining” difficult but additionally she also felt that she was not always supported by the doctors in regard to discipline. Veronica remembered a time when a young girl with anorexia had been exercising on the floor in the bathroom and developed a pressure area on her back which needed treating. Veronica felt that “she should have been put on strict ‘bed rest’ if she wasn’t going to comply to the rules”. However the doctors just told her not to do it again. Veronica was very disappointed and believed the doctors did not do enough to support her decision and remarked, “the rules are there for a reason. They expect us to stick to them but they don’t”. Zac found the constant repetition of program rules to be the most frustrating for him. They knew what the rules were but “continually push[ed] the limits” (see Appendix N18).

Some nurses explained that sometimes they “didn’t feel that they [we]re nursing” when they cared for the adolescents with anorexia and they had to remind themselves constantly that it was a “mental illness” and therefore a different type of care that they were providing these patients. They had to “keep on reminding” themselves that these adolescents were “just as sick as the next person in the bed”. Gabrielle revealed that sometimes these adolescents behaved quite irrationally and nurses would be quite frustrated with their behaviour. They can be “quite rude” and “quite abrupt” to staff because “they are not thinking clearly” and nurses “are doing things to them against their will”. The adolescents with anorexia, as described earlier, did not necessarily see nurses as helping them because many did not see themselves as sick in the first place. But, as Oliver described, a patient receiving antibiotics for “periorbital cellulitis” would see an obvious improvement “between the morning and afternoon shift”.

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Thomas\textsuperscript{2} sometimes felt frustrated when he was allocated to look after the adolescents with anorexia because as a senior nurse on the ward he felt that he should be doing more complicated work. He also remarked that when it was busy on the ward it frustrated him to “look down the corridor and see a nurse sitting there just watching these people and you think, Oh God! You could be getting that buzzer or emptying that pan. That’s frustrating!”.

Another frustration for nurses caring for adolescents with anorexia and perhaps the most significant one that was mentioned was the painstakingly slow progression towards ‘healing’ or ‘recovery’. Most nurses felt they were “banging [their] head against a wall” because they kept seeing “the same kids come back again and again”. Nurses wondered whether they were actually achieving anything because more often than not they would reach their “target weight”, go home then return a few weeks later.

\begin{quote}
Maybe we have, maybe we have achieved heaps, maybe something mental has improved but I think as nurses working in an acute setting we kind of get a bit frustrated that things aren’t happening faster (Oliver\textsuperscript{2}).
\end{quote}

\begin{quote}
…it’s disappointing to see when they come back in a worse state than what they left sometimes (Veronica\textsuperscript{2}).
\end{quote}

In the past Riley\textsuperscript{2} would get really frustrated with the adolescents with anorexia when they “manipulated” him and did not progress as quickly as other patients. Now he saw them as “the ones that suffer”. He believed that with ‘The Level System’ program the adolescents knew that they would either be ‘rewarded’ or ‘punished’ and there was “no use [for staff] going and getting all tied up in knots about it anymore”. Ultimately it all came down to what the “scales say”. If the scales say the adolescent has lost weight they get dropped down a level and if the adolescent remains constant or gains they go up a level and gain further privileges according to the program (see Appendix N19).

Interestingly two of the nurses Mandy\textsuperscript{2} and Veronica\textsuperscript{2} disclosed that they honestly did not enjoy caring for the adolescents with anorexia. While Riley\textsuperscript{2} admitted he “tolerated\textsuperscript{d} them”. Veronica\textsuperscript{2} continually emphasised her annoyance with the medical team for their lack of
support of nurses. She felt that nurses are kept ‘out of the loop’ a lot of the time. Psychologists and psychiatrists or therapists may see the adolescents but they did not communicate information back to the nursing staff or write in the progress notes. Veronica² saw the adolescents as “just…people in beds that we’ve got to look after” and she felt that it was too “hard to build…relationships up with them” and so she did not believe that nurses were providing them with that “emotional support” sometimes. Oliver², Thomas² and Linda² backed up Veronica’s² claims that nurses were not “privy” to a lot of information that would possibly make their job easier in establishing a positive relationship with these adolescents. Thomas² added that it was difficult because nurses did not want to say the wrong thing and make the patient uncomfortable and then “look like a bit of a goose” themselves because they did not know the full story behind the illness.

...this is something that some of us have rarely tried to remedy over the years and in the end some of us have just given up. I think that we as nursing staff, while we are expected to be involved in the care of these kids, we are not actually privy to what’s behind it. The medical guys, the psychologists, the social workers...they work out what the reason is, how it can best be handled, family therapy that kind of thing. Nursing staff aren’t made privy to that. For a while we tried to get involved and going to the meetings and um in the end we either were not invited to the meetings, they were held without our knowledge. I don’t know that the doctors necessarily valued our input. I know for a fact that in a number of instances they didn’t value it at all...and we just became too busy as well...But I find that frustrating that we’re...supposed to be pushing these kids in the right direction and helping them and being part of their treatment and yet we are not made privy... (Oliver²).

For Mandy² it was extremely difficult for her to look after adolescents with anorexia. She said sometimes she felt like holding them and shaking them and saying, “Eat!” She saw other chronically ill patients, such as the oncology and cystic fibrosis patients, as not having “a choice” while the adolescents with anorexia did. At times it frustrated her so much that she remarked, “I don’t want to acknowledge that they are there...just observe them and that’s all”. She believed that she did provide them with support, reassurance and care but covertly she felt that she was not as “compassionate towards” adolescents with anorexia. Gabrielle² also found it frustrating to see “a patient with an eating disorder...is choosing not to eat” and then there could be a “child that can’t eat and...is being tube fed”. But she however expressed she was “frustrated not only with them but with [herself]” because she kept forgetting that it was an “illness”. Nurses’ frustrations
tended to encourage a view of anorexia as not really a genuine illness or, at least, to allow these nurses to forget this fact.

A couple of nurses revealed they had a family member or relative who was going through the same issues and so they empathised with how the families must be feeling. They reported, “I just want to shake the kids at times and say, Look you don’t know what you’re doing to the family”.

It was evident that nurses found it extremely frustrating and emotionally challenging to care for an adolescent with anorexia. But how did the adolescents themselves feel? What was ‘life as an inmate’ like for them? Not surprisingly the adolescents with anorexia reported they were quite frustrated with some of the nurses and ‘The Level System’ program that was in place. Most of the adolescents thought the overall care they received from the majority of nurses was “quite good” even though ‘life within the system’ was very difficult. Most nurses, in their eyes, were competent in “[lay[ing] down the law” yet they were “nice” people. The adolescents acknowledged that “they’re just doing…what they’ve been told to do” and so did not take this against them personally. There were however some nurses that they felt were “mean”, “bad” and “unnecessarily strict” and these were the nurses they predominately focused on in the interviews. Perhaps this was so because these were the nurses that had made the most impact and had left a lasting impression, albeit negative, on them during their stay. These nurses appeared to have made their time on the program even more uncomfortable and arduous than it should have been.

Cameron¹ explained his experience of the nursing care:

…it is quite good. Yep…a lot of nurses were a lot more stricter than others. But you kind of need a little bit of strictness but you also want it to be…a little bit laid back too (Cameron¹).

All the adolescents with anorexia described how life on the ward was difficult for them. Being placed on the program meant that “normal activities”, like going to the bathroom, walking around or leaving the ward, became “privileges”. While for the other adolescents this was not the case. They spoke of a loss of “freedom” and a sense of ‘normality’ as a consequence of entering the program. Danielle¹ was frustrated because she was a “teenager” and “old enough” to do things for herself. She wanted “a bit of freedom” but

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could not have it because the program was “so tight on things”. Megan¹ reported that coming to hospital on a Friday and being placed on Level One was frustrating but finding out that no changes could be made until the doctors saw you made it even worse. The doctors would only come around on Tuesdays and Fridays because these were the days the medical meetings were held.

Many of the adolescents with anorexia communicated that they did not feel “normal” on this program. As the nurses assumed, many of the restrictions placed on them, like voiding in a bedpan behind their cubicle curtain on weigh days, were “humiliating” and “got everyone’s back up”. Earlier some of the adolescents had previously hinted at the humiliation of the early morning weigh day and not wanting other patients to see them. Amber¹ felt that walking past the nurses’ desk with a bedpan and in a gown made her feel inferior and “less than” the nurses. Sara¹ described, “we’re not all just like weird children” and nurses should not follow us around everywhere and watch us like a “hawk”.

_I think they shouldn’t follow you everywhere and kind of be…hawk-like and everything but I think they should be supportive and listen to what you say, not just jump to conclusions and stuff. So yeah and look out for you, but not follow you around everywhere. Because I think we should have a little bit of freedom (Sara¹)._

A couple of the adolescents revealed that they felt “lower than” most of the other inpatients because of their diagnosis. Josephine¹ explained she felt that there were other adolescents on the ward that were “more sick” than herself and seeing them made her feel that she “had done it to [herself]”. She also remarked that the other adolescents, like those with cystic fibrosis, “made us feel lower too”. Amber¹ agreed and she felt that having a nurse give you bolus feeds down a nasogastric tube “makes you feel like you’re lower than everyone else”.

Zoe¹ believed that “nasogastric feeding…should always be avoided”. She described how “it sort of sinks you down and makes you feel like you are anorexic” and when the tube was taken out, it made you feel “you’re not anymore”. Zoe¹ felt that not having a tube gave everyone the wrong impression because she did not want “people to think” that she was not “anorexic” when she still felt that she was. Cameron¹ at first felt a bit “demoted” and “embarrassed” about having a nasogastric tube. After a while, he realised that many of the adolescents on the ward were “anorexia patients” and many of the other patients he felt
understood that it was “an illness” and so he equated a nasogastric tube to “having one of those IV's in your arm”.

The nurses that enforced the rules stringently and were overly strict were the ones the adolescents “hated”. Sara¹ reported that there was one nurse in particular that was “really strict” and she “scared” her terribly by saying “unnecessary things”. Josephine¹ exclaimed, “it was a bit of over kill what they [nurses] did” and how they classed everything from “swinging on…tables” to “shaking our legs” to juggling as exercise. Melinda¹ hated how she was not treated as an individual and that “they never looked at me as being me”.

They, nurses and doctors, treated her “like everyone else” on the program and assumed that she would do the same manipulative things that others had done before her. She felt that some nurses were not “friendly” and acted as though they were “the boss”. She described how they came across to her as, “This is my job. This is what I’m here to do, and that’s it”. These nurses “didn’t…think about putting feelings into the equation”.

Many of the adolescents were under the impression that some nurses did not enjoy looking after them. These nurses made them feel uncomfortable by watching them constantly, would not interact or talk to them very much at mealtimes and made them feel they were “a waste of space” or “like crap” (see Appendix N20). They believed these nurses did “the bare minimum” and preferred to help the other nurses with their patients rather than look after them. Danielle¹ explained that some nurses showed their disinterest by forgetting mealtimes altogether. They would be sitting around and would not realise that it was a mealtime and this made the adolescents with anorexia feel that they did not care about them. Danielle¹ remarked that they were not “on the ball and thinking about our needs as well” (see Appendix N21).

Josephine¹ felt nurses “didn’t like the anorexics because we are not sort of sick”. Others believed that some nurses “didn’t mind” looking after the adolescents with anorexia because of the relatively “easy” nature of the work. They said, “it is not as if we are fully sick and need heaps of care” and “we are not too much of a trouble”. Josephine¹ concurred, “we were low maintenance really”. Josephine¹ also added that there were some nurses that were “really sarcastic” and this “was hurtful”. She explained, that during one of her very early admissions to the ward, a few nurses used to request a song called
“Eat It” by “Weird Al Yankovic” from the hospital’s radio station and then clandestinely made fun and teased them while the song played.

Josephine recalled this hurtful instance:

Um there were a few nurses who used to…there was this song called ‘Eat It’ from ‘Weird Al’ Yankovic and they used to…like put that on from…Radio Bedrock…and then they sort of made fun of stereotypical things that we would do…like exercising and throwing up um cutting our meal into small pieces and stuff (Josephine).

Zoe also reported a negative experience when a nurse made “personal comments” that really upset her for a very, very long time. A nurse told her that she was “just doing it for attention” and this she remarked was “the last thing that I want[ed]”. She found it very hurtful because she said, “I just want[ed] to melt away”. She explained that this nurse was way off the mark and nurses should not attempt to make assumptions about “why someone has anorexia or why someone chooses to do something”.

There were three types of nurses according to Josephine; the sarcastic nurses who did not like the “anorexics” at all and drew “the short straw” if they did have to look after them, the ones who tried to help you and “forced God on you and that was also bad” and then there were the nice, caring negotiable ones. Below Megan disclosed that when nurses displayed a negative attitude towards the adolescents with anorexia, this would then sometimes entice the adolescents to be ‘deviant’ or troublesome towards that particular nurse.

…it was like the short straw sort of thing because it wasn’t very interesting either-feeding people (laughs) (Josephine).

There were people who just didn’t want to deal with you and you knew that they didn’t want to deal with you. It was kind of like it was the ‘bum job’. It is like someone picked straws out of a hat and whoever got the shortest was stuck with us. And then they kind of reflect that attitude. Every time they would be like, Come on. Hurry up! and then automatically you would be like, Well they don’t care about us. We won’t care about you. So like you’d just annoy them or they’d annoy you and you wouldn’t eat this, you wouldn’t do that just in spite of them because of their attitude… (Megan).
Other nurses reflected their disinterest and boredom through tone of voice and attitude (see Appendix N22). The adolescents noticed nurses would never speak to the other adolescents on the ward in this same manner. For example, Zoe¹ believed that there were particular nurses that would “say the wrong things” and would make inappropriate comments about how much the adolescents with anorexia had to eat which was “not helpful” or would talk to them with disinterest (see Appendix N23). Other nurses she reported tried to “coax you into eating” by saying, “Oh please eat” which was not positive either and then there were others who would be “very…clinical” and say, “Okay. Are you eating?, No. Okay you’ll have your bolus? Yeah”.

...Oh come on. It’s meal time now. Like come on! I have got to get to dinner. Let’s feed you [disinterested tone of voice], you know that type of thing. Like because you wouldn’t say to…a CF [cystic fibrosis patient], Oh look...Can you get here so I can do it because I have got to go to lunch? [angry tone of voice], you know. You probably wouldn’t say that… (Zoe¹).

Amber¹ felt that sometimes nurses forgot they were human and did not “really treat us like…people”. Similarly, female inmates in Easteal’s (2001, p. 99) study also felt that there was a “general attitude displayed toward them that seemed to say that they were somehow less than human”. Amber¹ reported that she overheard a “nice nurse” saying, “Okay, I'm going to feed the ED [eating disorder] girls”. Amber¹ felt that the manner in which nurses sometimes spoke was inappropriate and “a bit demeaning”. Perhaps they did not mean to be that way but it came across to the adolescent very strongly. The adolescents often heard nurses labelling them as “anorexics” or “ED's” (Eating Disorders). It made the adolescents feel like they were being treated like “zoo animals”. It is interesting to note, that five of the ten nurses used the term “anorexics” at some point to describe the adolescents with anorexia nervosa during their interviews. Inmates, again in Easteal’s (2001, p. 93) study, held similar sentiments of feeling demeaned and having a ‘childlike dependence’ on prison officers. They too (grown women) were labelled as the “girls” (Easteal, 2001, p. 93). In fact, a Victorian inmate said, “You don’t get treated like anything...like an animal, like you’re in the zoo” (Easteal, 2001, p. 93).

...Well one of the nurses, she’s a nice nurse, but I heard her saying...Okay I’m going to feed the ED girls. It’s like we’re not zoo animals!...And once one of the nurses said to one of the [other] nurses, she said, Oh do you want me to help you watch them eat? It’s like...some of them don’t really treat us like we are people. It’s a bit demeaning (Amber¹).
Well instead of saying, Oh I’m going to go and feed the eating disorders or the anorexics or whatever. They could just say, Oh well I’m going to...take the girls to breakfast or whatever and stuff like that. Not call us under a classification like the ED’s… (Amber¹).

Zoe¹ also recalled a similar experience when adolescents with anorexia had been classified derogatorily by a nurse. A new admission had arrived to the ward and a nurse, that was considered by most to be “not very nice”, remarked brusquely to the other adolescents with anorexia: “Yes, she is one of your lot!”.

I am like, Oh does she have anorexia? Because she had the tube and everything and she was like, Yes, she is one of your lot! and I was sort of like, What do you mean by that? and she’s like, You know one of your lot! (Zoe¹).

Another disappointment for the adolescents on the program was that they felt ‘The Level System’; it set them up for failure in a way because they never reached “the top level”. Therefore there was “no point in trying”. They were usually discharged on earlier levels.

I don’t know sometimes Level Five is never really used. Level Four is probably never really used and I think if it is not used then it shouldn’t be there. Because some girls...when they first come in, Oh yeah I will get up to Level Five and then...you never get there. That’s a bit disgruntling, I think… (Zoe¹).

The program also placed nurses “in a hard position” because they had to enforce what was in the notes regarding levels and ‘gate-passes’. Zoe¹ stated that there was always poor communication between doctors and nurses. The doctors would tell patients something but then not communicate that to the nursing staff in the notes. She added that this mainly happened with ‘gate-passes’. On the weekend it was difficult to contact the doctors and patients would get really angry with the nurses but “it’s not really their fault” because “if...something’s not written there [in the notes] then they can’t do it”.

Josephine¹ recalled “MANY” bad experiences during her multiple admissions to the ward for anorexia nervosa. She remembered that one of the doctors promised her that she would be off bed rest the following week but this continued week after week. She said that she “finally got jack of it” and hit the doctor with a maths book. In retaliation the doctor decided she should be sedated. She remembered she was sedated with valium on the
ward to ensure that she remained compliant with the “Level One” orders that had been instated. She reported that she “felt trapped because...they put it [valium] down your tube and then you slowly get tired and there is nothing you can do about it”. The worst experience though was the time she spent in the Intensive Care Unit (ICU)⁴. She could not remember much of this time but described herself as being “drugged”, “tired” and “distressed”. She recollected that the feeds smelt horribly and they were definitely not “Ensure”. The feeds were something foreign to her. She also remembered that she would “dribble” because she remarked: “I couldn’t control anything”.

Amber⁴ also reported the sensation of feeling “trapped” on this program, especially when she received “bad news” from the doctors after a meeting. She felt like she was “never going to get out” (see Appendix N24).

Surprisingly, on the whole, the adolescents considered most nurses to be “nice”. As Zac², a nurse, pointed out, “I think it is more the action you take rather than the person you are that they don’t agree with”. Even though the adolescents focused on the negative aspects of their time on the ward in their interviews, they genuinely saw most nurses as encouraging them to do well in the program so that they could get better and go home. They described these nurses as talkative, supportive, caring and friendly. These nurses made them feel like they were “on the same level as them”. The adolescents remarked that they would talk about their families, “normal things” and it would make them “feel normal...not like an anorexic patient but kind of like their friend”. Their demeanour was different to the “bad” nurses in that they would be cheery and friendly when they spoke to the adolescents with anorexia. This allowed some adolescents to feel comfortable enough to talk to them if they had a serious problem. The adolescents felt strongly that the saying “you have to be cruel to be kind” has no standing when caring for adolescents with anorexia (see Appendix N25).

⁴ The adolescent in this instance was recalling an admission to the PICU (Paediatric Intensive Care Unit) that took place in 2002. This decision was made after numerous admissions to the inpatient ward setting, the adolescent’s complete refusal to eat and drink and non-compliance with the program resulted in persistent chronic weight loss. This patient had been scheduled under the Mental Health Act and with her family’s consent and support was sedated and fed continuously via a nasogastric tube in the Intensive Care Unit. This is a rare occurrence within the institution under study and the PICU setting has not been used since for the treatment of an adolescent with anorexia nervosa.
'The Level System' program and the nurse’s role within this program nevertheless created an apparent ‘us versus them’ mentality on the ward, where nurses and patients seemed to be at opposite ends of the spectrum in what they both were trying to achieve.

…their target is to stay thin and our target is to…get them back to a healthy weight. So they clash… (Zac²).

As the nurses had explained earlier, monitoring and surveillance of the adolescents with anorexia, was an important part of their job. The adolescents also felt that they were constantly being judged by the nursing and medical staff because of their illness. They felt that any other adolescent would not be treated the same way but they were treated in this way because they had a diagnosis of anorexia nervosa. Cameron¹ revealed that on the program “you can’t be yourself…you feel as if they are going to be judging you all the time”. He explained that he felt that he was being targeted a lot but was not sure whether this was his own imagination.

…maybe if you were um just walking past the nurses’ desk, they would watch where you were going, like seeing where you were walking…or if you’re going here, there (Cameron¹).

…like in between meal times, they always watch us more than they watch any other patient (Zoe¹).

…judging us on the way we are instead of what’s wrong with us…Like if a ‘normal’…if someone without it [an eating disorder] would do that, they probably wouldn’t judge them… (Chloe¹).

The nurses verified that they did tend to “look out for their behaviour” more than other adolescents with other conditions. They felt that they would probably accept anything that another adolescent did as just that; being “a teenager…they want their privacy, they are crying on the phone…having a tantrum…” and therefore they did not worry as much about this behaviour and took care of the medical or surgical aspects more. However with an adolescent with anorexia, Paige² felt that it was “almost like a reversal in terms of…observation”. She would look at that behaviour and wonder what was happening and why and have the medical aspects “in the back of [her] mind”.

Chapter Five: Results
As a consequence of this continual ‘us versus them’ or ‘prison officers versus inmates’ mentality the adolescents would frequently rebel against the conditions and the program that they were expected to conform to. The nurses and patients both described instances where adolescents with anorexia would ‘buck the system’; the system that was theoretical helping them to get better.

5.3.5 ‘BUCKING THE SYSTEM’

The adolescents were conscious of the fact that the doctors predominately held the power and control within this treatment program. They saw the doctors as controlling how much they ate, how much weight they had to put on, whether they could go out or have visitors. The doctors were the main decision-makers and therefore were seen as “in control of [their] lives” while in hospital. Doctors took away their “freedom” and were the bearers of “bad news”.

…the doctors like control our lives…which I hate…They are…fully in control of our lives and can…control what we do and stuff (Isabel¹).

Kind of makes you feel about this big [interviewee shows me her thumb and forefinger held 1cm apart]…like small. As if you’ve got no say…They’re [doctors] taking over (Danielle¹).

Nurses, however, were not too far behind the doctors because they were the ones who had the most contact with patients. Melinda¹ saw the team leader for the day as being in control of the ward because he or she would be in charge of allocating the staff to patients and would be the resource person for the day. In the day to day operation of the ward environment nurses made the decisions. However, patients saw that the ultimate decision in regards to meal plans, ‘gate-passes’ and levels was always the doctors. Megan¹ reported “there was always someone higher up” than the nurses and sometimes nurses became the “scape goat” for the doctors. Patients would be “frustrated” with the nurses but in actual fact it “wasn’t their fault” rather the doctor had made the decision.

…when it came to the program you could tell that the doctors were behind them [the nurses] telling them to do this and do that… (Megan¹).

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Isabel¹ acknowledged that most patients would “get pissed off” if the doctors decided that they would not be getting a ‘gate-pass’ for the weekend even though they felt they had tried their best for the week. This would often make patients who were looking forward to a day out think to themselves that the program was all a waste of time and resort to weight loss practices instead.

...you get like pissed off and think, Oh well what was the point of that and...try and lose weight or something… (Isabel¹).

The adolescents illustrated that “there were a billion, trillion” ways that they could ‘buck the system’ and lose weight and delay their progress (see Appendix N26 & N27). They explained that some patients would take some of the food off their tray prior to meals or tamper with the meal trolley. Some adolescents were “sneaky” during the meal and they would try to conceal food in their clothing or under the table. Some would scrape butter off their sandwiches or water down their milk. The most attempted tricks were exercising or vomiting in the bathroom. Other methods to ‘buck the system’ included syringing out feeds from their tubes, water loading prior to their weight being taken and tampering with their overnight feeds. The least common method was absconding from the ward. Absconding was attempted by some adolescents but happened infrequently.

Patients on the eating disorder program were usually all placed together “in a four bedded room” near the nurses’ desk. Melinda¹ provided an example of two girls in the four-bedded room where she slept who would compete with each other in doing sit-ups and other exercises most of the night. She found this annoying and asked to be moved out of the four-bedded girls’ room before she herself felt the compulsion to exercise as well.

...they used to sit up at night in bed, they used to do a thousand sit ups and a thousand leg things, a thousand back stretches and everything like that and then when a nurse would come in, they would just pretend they were pulling their sheets over... (Melinda¹).

Isabel¹ remarked that she knew that most adolescents had “many opportunities” to rebel against the system but she believed that she herself had not attempted anything “naughty” to date. She however was easily able to narrate a diverse range of activities that an adolescent with anorexia could engage in, if they wanted to, while in hospital and on the program.
...if you are really bad you can get up to so much…I have seen so many opportunities that I could have done something naughty but I haven’t… (Isabel¹).

...you can do heaps you can easily exercise in the bathroom um and you can even like…exercise in the room without them [nurses] seeing you…You could…vomit in the toilets um or like when you are brushing your teeth at night…if you were really like a pro at it [vomiting], then you could easily get away with doing it even with the door open…Um what else?...You could drink water before you got weighed or after you went in the bed pan…because then it wouldn’t show up or you could try and not go to the toilet and empty your bowels after weigh day…I think that is all (Isabel¹).

Initially it was “hard to break a habit” for most of the adolescents with anorexia and this was why they continued with their weight loss practices while in hospital. Some felt “naughty” or “bad” inside when they did do it but explained “you’ve just got the drive to do it”. Chloe¹ said that manipulation of the program “[made] them feel better” and Cameron¹ agreed that it made adolescents feel “a lot less anxious when you know you’ve done it”. Melinda¹ clarified that manipulation made the adolescents feel less guilty about having eaten “because their anorexia [wa]s telling them that…it [was] not good to eat all your food”. Overall, the adolescents believed that they resorted to the above practices because “they felt they were having too much…and they didn’t want to put on weight”.

Nurses would approach them in different ways depending on what they had done. Danielle¹ explained that if someone was suspected of exercising in the bathroom, the nicer nurses would “knock on the door” and then say something along the lines of “You’ve been in there for a while. Are you alright?”. Megan¹ agreed there were nice nurses who would “forget about” rather than “remind” an adolescent of the ‘punishment’ bestowed for ‘bad behaviour’. They gave them a clean slate and continued to treat them as normal and provided them with constant encouragement and support to do better. However, there were other nurses who would not be as kind and would say something like, “Get out now! You’ve been in there too long”. Melinda¹ agreed there were some nurses who were not as discrete as others were and would say things like, “Show me your pockets” if they suspected that you were hiding food at the meal table.

The adolescents confirmed what nurses had earlier reported, that the nice nurses handed out a warning for a ‘first offence’. Nurses would record the event in their notes and if it continued to happen then the doctors would impose greater restrictions. The restrictions
included things like the two toilet privileges per shift, ‘bed rest’ with no toilet privileges or in extreme circumstances twenty-four hour a day observation known as ‘specialling’, which were all mentioned earlier.

Most of the adolescents quickly realised that the only way to “get out” of the system was to be compliant and follow the rules. Therefore they learnt how to assimilate pretty quickly into their surroundings. This assimilation again is similar to the inmate’s in prison (Easteal, 2001). He quickly learns what he needs to do to get certain privileges of his own including an early parole hearing for good behaviour.

Yep some people tried to rebel a bit but then they found out…that the only way to do it, is to comply. So if you follow it [the program] you will get out quicker. So everyone kind of suited themselves in quickly (Megan¹).

…most of them do [follow the program]…because they want to get out of here (Chloe¹).

…we’ll get out in no time… (Sara¹).

While most of the adolescents reported that they did follow the program, the nurses on the other hand did not feel the same way. As Gabrielle² pointed out some of the adolescents ostensibly appeared to be doing everything they were supposed to be doing but in actuality they were not because they were losing weight.

…if you walk down the corridor, you can see out of the corner of your eye that they are doing something…They are often very, very sneaky in their behaviour. They hide a lot of things but at the same time…majority put on this front that everything is ok…Yes they are working really hard to get better and they’re eating well and they can’t understand why they are losing weight or anything else like that (Gabrielle²).

The nurses believed that most of the adolescents were “manipulative” and only some adhered “stringently” to the program guidelines. The more times they were admitted to the ward the greater the “manipulation”. Gabrielle² stated: “they are going to try as much as they can to get away with things” (see Appendix N28 & N29). Manipulation by inmates may also be seen within prisons. In Easteal’s (2001, p. 97) study, prison officers saw the women inmates as “devious” and “manipulative” especially in regards to drug trafficking.
Zac² described how the adolescents manipulated staff, the program and their progress in “many different ways”. He often saw the adolescents manipulating staff members by “being very friendly and building that rapport with them and in the meantime…doing little sneaky things under the table”. Some nurses noticed the adolescents were “very clever” at “getting very close emotionally” to those nurses “that tend to slack off a little bit in terms of enforcing the tough rules” (see Appendix N30 & N31). In these situations, these nurses felt that the befriending goes past that nurse-patient boundary. It then made it extremely difficult for the nurse to reprimand certain behaviours when they became aware of them.

…my suspicion is that there is a manipulation there because they try and ingratiate themselves to that person…and they form a closer friendship than they would with another nurse…It’s an assumption but I assume that it is…unconsciously or not, about developing a close enough relationship with that nurse, that things go more swimmingly in terms of what their treatment is…from their point of view (Oliver²).

Gabrielle² remarked that a common form of manipulation attempted by the adolescents with staff was the concealing, throwing away of food or saying: “I have not gotten this up. Can I have this instead?”. Things always seemed to disappear from the meal trolley and it was because “they beat you in there and take things off”. Nurses will not necessarily have the time to wait for the kitchen to resend an item because of the set time limit for meals. So the adolescent will normally be allowed to have something else instead. With the ward layout at present (see Chapter 2-Context for description) meal trolleys were placed opposite the nurses’ desk and therefore it has become a little more difficult for the adolescents to tamper with their meal trays without being seen.

…I think like manipulating their food, they manipulate your emotions and play on those as well. But I think the food thing is a big thing that I don’t think we realise how much they actually really do, do. They are very, very clever (Gabrielle²).

…at times when they are eating they might quickly throw something in the bin or put a bit of food under their plate or they might be fiddling with their feeds at night or exercising after dinner (Thomas²).

The nurses asserted strongly that adolescents with anorexia can and do “play one nurse off another”. Mandy² mentioned that she has been confronted many times by adolescents who have either said to her, “Oh she allows me to do this…Why are you not doing it?” or “Oh you’re so good. You let me do this. That nurse doesn’t let me do that”. The nurses
believed that the adolescents were very good at causing conflict between staff members within this program.

Mandy² also remembered an occasion when nurses had to do a room and locker search on a patient. This patient had been storing and drinking an unbelievable amount of “Pepsi Max” cans. Mandy² herself recalled that she “caught her” at the “vending machine” when she was supposed to be at school. As reported earlier, adolescents with anorexia were not supposed to have any food or drinks apart from those outlined on their meal plans and sent up by the kitchen. “Sugar free, diet drinks” were considered ‘contraband’ items for adolescents with anorexia on the program because they contain the ingredient phenylalanine, which in excess consumption has a laxative effect (see Appendix N32).

Riley² provided another example of how some of the adolescents manipulated staff and ‘bucked the system’ when they were restricted to “two toilet visits a shift”. He reported that they would tell their allocated nurse the first time that they needed to go to the bathroom but on subsequent visits they would ask another nurse and then another thereby “getting three or four visits a shift”. The allocated nurse may not be aware when the ward was busy and the information was not getting passed on.

…if they've been known to be exercisers, the doctors will say you can only have two toilet visits a shift, because that's where they usually get caught exercising. Usually they can manipulate by...going to one nurse and saying, I'm just going to the toilet now...that could be the nurse looking after them. But then the next time they ask another nurse to go and that nurse might not remember to tell the nurse that's actually looking after them. So they actually get maybe three or four visits a shift and get a bit of 'taebo' happening in the bathroom (Riley²).

Other adolescents would tell nurses they were having a shower but would be in the bathroom for longer than the allocated ten minutes. When this was realised by staff the adolescent’s pulse would be checked and in most cases their pulse would be extremely elevated indicating exertion of some sort.

…one will go in for their shower and 10, 20, 30 minutes later you realise they haven't come out. You take their pulse and you realise they are [in the] 150's. What have you been doing in there? Only having a shower...Not likely with a pulse that high (Gabrielle²).
Oliver² laughed as he retold stories of how adolescents have ‘bucked the system’ over the years by not following the program guidelines. He remembered one girl “cutting her tube” so that her feeds would leach out over night. He remembered another girl who crumbled her biscuits between her fingers as she ate and left half of them on the floor. He recalled another who would frantically move her legs in circular motions under the table as she ate as if on an “exercise bike” and the funniest was the girl he “found enshrouded in a curtain”. She had been doing “pull ups in the bathroom” using the shower rail until it broke and it fell to the ground with a loud crash. He investigated to find an embarrassed adolescent on the floor with the curtain and rail on top of her.

(Laughs)...the girl who liked to, when she ate her biscuits, she liked to crumble them between her fingers and lick up the crumbs but of course half the crumbs ended up on the floor or in her lap which she then brushed off. Um a girl who would get onto the exercise bike every time she went to a meal break and her legs would be going under the table...the girl doing pull ups in the bathroom until she pulled the curtain rail down on herself...Found herself enshrouded in a curtain (Oliver²).

The nurses believed the reasoning behind why they needed to manipulate varied. For some it was to “progress in the program without having to gain weight”. They falsified their weight and manipulated the program to “stay thin”. As “perfectionists” these adolescents were determined on “achieving” and being “successful” through their weight loss practices. Manipulation was for them “a victory”. Through manipulation, they were “spotting a weakness”, in the nurses or the program, that they could “exploit” in order to “get out of here”. They needed to make it appear that they were “progressing through the program” and attaining a healthy weight but in actual fact they were not (see Appendix N33).

A few nurses believed that manipulation was a part of adolescence and of being a “teenager”. Riley² believed “most teenagers” want to “buck the system” at some stage and these adolescents were placed in a position where they were being forced to do something that they did not like. However, as the adolescents themselves reported, nurses also believed they quickly learned that they needed to comply with the program “to get out of here” and so most did comply as “a means to an end”. Unfortunately many returned because they had not really been able to get out of the entangled trap of this “vicious circle”.

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It’s like most teenagers…they like to ‘buck the system’ and they…don’t like the fact that they have to put on weight, that they have to eat so, um…you end up in a vicious circle, where all of a sudden…they finally work out, after a few weeks, that if they want to get out of here they’ve got to eat…drink, be merry…get to the goal weight and then get out (Riley²).

Some nurses saw manipulation as part of the characteristic behaviour of “the illness” (see Appendix N34). It may not be as obvious at first, but their drive to hide from others what is happening to their bodies increases their manipulation and secrecy. For some they “don’t see that they need to be helped”. Their denial of any illness was so strong that they continued with their weight loss. Nurses, like Gabrielle², felt that the majority of adolescents may have been “forced to come in here” and “don’t want [their eating disorder] fixed right now”.

Paige² believed that as a nurse working with patients with eating disorders for a while now and “seeing quite some manipulative behaviour” she was a lot more attuned to and aware of manipulation and believed it was “normal”. Other nurses may not see it the same way because they all had different experiences and viewpoints. She believed that nurses “all come to work with…different back packs on…full of…past experiences…stereotypes and prejudice”.

Gabrielle² also was not personally affronted by the manipulation. She felt that it was good to see that they still had “a little bit of control”, “a little bit of fight” and a “little bit of spunk left before we actually kill it all off”. She saw the program as being necessary but acknowledged that it did invade their privacy and took a lot of control off them. Therefore she expected manipulation and would be concerned if she did not see any manipulation.

…um I think good on them a bit (laugh)…I think it is nice to see they still have got a little bit of control because I think they lack that when they come in…We invade their privacy…in a very big way and take everything off them, all their control…which is often part of the reason why they may have anorexia…being that they want to control something in their lives and we take that away… (Gabrielle²).

…when all the things are taken away from them, they just fight back. They just don’t want to do anything which is on the program at first… (Mandy²).
The manipulation was managed by nurses in various ways. Zac\textsuperscript{2} commented that if there was a suspicion of something going on, then the first thing nurses would do was inform each other of their suspicions. This enabled staff “to keep a closer eye on it”. The information then got passed on at the meetings for the doctors to decide what they wanted to do about it. Thomas\textsuperscript{2} felt that some nurses were more “supportive” than others when dealing with manipulation. He felt that some nurses were “overly strict” and immediately punished the adolescent with ‘bed rest’ for exercising. The more supportive nurses still followed the rules but would hand out a warning first before placing them on ‘bed rest’ and would sit down and talk to them to make sure “they understand they are not allowed to be doing what they are doing”.

Some of them...stick by the rules, like a policeman. Not just stick by the rules as a supportive person (Thomas\textsuperscript{2}).

...I sit down and talk to the kids and see if they understand they are not allowed to be doing what they are doing um and see what their understanding of it is before any sort of decision is made and then consult with the team leader that is on...If it is something that they do again or that was quite severe then they might get put on ‘bed rest’ for twenty four hours until medical review (Veronica\textsuperscript{2}).

Riley\textsuperscript{2} said it was “human nature” for the adolescents with anorexia to manipulate the staff, the program or their progress while in hospital and that nurses “just have to deal with it...before it gets out of hand”. But he believed, as most of the nurses did, that consistency among staff aided with preventing the escalation of manipulation.

...if you stick to your guns and make sure that they do the same thing all the time, um, they can manipulate all they want but it doesn’t mean they are going to get what they want (Riley\textsuperscript{2}).

Consistency with following the program was seen as vital for the staff and for the patients. However consistency was not always evident among the staff and this led to manipulation by patients and frustration for nurses. Not one of the nurses believed they were consistent in strictly following the program one hundred percent. They all described in their interviews, times when they had been “lenient” or given “leeway” or “made exceptions” to the rules.
...I sometimes let them out on their ‘gate-pass’ before morning tea instead of after morning tea. I pack their morning tea and then they can go and eat in the car kind of thing and... (laughs)... I let them swap foods sometimes... If everyone has gone out and there is... only one left, I actually let them have ‘bed rest’ in their bedroom with me and we will just talk instead of having it at the nurses’ desk (Donna²).

Sometimes the nursing staff let themselves down or they “were let down by medical staff” in terms of maintaining consistency. They did believe that the majority of the time they tried to stand firm with the program rules. Yet Zac² described how nurses were sometimes placed in a difficult position when for example a patient refused to eat and then refused their bolus as well. He said: “we can’t physically restrain them to do it [give a bolus] unless we’ve got permission from certain authorities and... it’s just too hard to chase that kind of thing up. So we will sometimes let it slide... pass it onto the people who need to know”.

On an evening shift or weekend the ‘doctor on call’ may not be from the eating disorder team and therefore may not know what to do in a difficult situation or decide that nothing should happen till the next day or Monday when someone from the team was available. This situation was very frustrating for the staff. On rare occasions, a patient would refuse meals or pull out their nasogastric tube or exercise while on ‘bed rest’ and other patients would also follow their ‘bad’ example because they could see no visible ramifications for a patient’s actions. Nurses would be left to deal with these unruly behaviours without the support of the medical people ‘after hours’.

You page the psych on call... and... they’re pretty useless because they are not willing to do anything. Just wait for the Consultant on Monday. But by Monday everything is finished and everything is right as rain. So we sort of have to deal with it on that day... (Donna²).

... and if one does it, then the other one says, Oh she got away with it. So I’ll do it too (Donna²).

Other times the doctors have undermined the nurses “authority and power” in enforcing ‘bed rest’. For example Zac² recalled an instance when nursing staff put a patient on ‘bed rest’ for excessive exercising and the team came along the next morning and let them have a ‘gate-pass’. This left the nurses feeling that they had lost their respect and reputation in the adolescent’s eyes.

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...other times...we are able to use a bit more authority and power on these kids and it's not followed through by the medical team...A child will be exercising...We have been told if they exercise to put them on 'bed rest'. We’ll do that and the next day the medical team says, What are you doing on bed rest? We will send you on a 'gate-pass' today. So that sort of undermines our authority and the kids no longer respect it...So we let ourselves down at times and other times we’re let down (Zac²).

Most of the nurses though expressed that staff should be consistent and show a united front when caring for adolescents with anorexia. They believed all nursing and medical staff should follow the program as much as 'humanly possible' and avoid making too many exceptions to the rule. They understood that this was an area that required much improvement on this ward. Many felt that the rules and regulations were there for a reason; to help the adolescent “get better”.

It was not fair on the adolescent when nurses were inconsistent with following the program or when nurses or doctors let patients get away with “not following that program”. Nurses believed, as adolescents did, there was no point being in hospital if they were allowed to get away with not following the program that was in place as its chief aim was to “help them start to get better”. Nurses felt that “weeks and weeks and weeks” can be wasted if people are too “lenient” on them or “not following the program”. The adolescents needed to gain a certain amount of weight before they were discharged and without nurses and other staff “sticking to that program” they would not be gaining any weight. Though, nurses did feel strongly that the adolescents should be in hospital for a minimal amount of time because it was such “an unrealistic environment”. The consequence of too prolonged a period in hospital meant their “home” life and “social” life suffered tremendously.

…it if we are not strict with it [the program] they won’t eat as much and they will exercise more…but we want to get them out of here as quick as we possibly can to give them a bit of normality. It is such an unrealistic environment in here. But...we do need to stick to it [the program] and also...be consistent. It is not fair for one person to have something carried through and one person not (Gabrielle²).
5.3.6 ‘WALKING A FINE BALANCE: BUILDING RELATIONSHIPS’

The formation of positive relationships between nurses and patients with anorexia was definitely not an easy task within ‘The Level System’ program. There were many obstacles which derived their source primarily from the program and the role nurses played within that program. In particular, the nurses’ observational role and the performance of certain unpleasant tasks as part of that role did not assist nurses with building strong relationships with patients with anorexia. Nurses were ‘walking a fine balance’ between trying to form potentially therapeutic relationships while still effectively doing the physical aspects of their job. Although overall the adolescents seemed content with the way the majority of nurses attempted to form relationships with them it was clearly evident that the relationships being formed were not ‘textbook’ therapeutic relationships as described in Chapter Three. Nevertheless these relationships possessed some therapeutic value for individual patients and nurses. Relationships reached a certain point but did not advance past this point.

…in the relationship…I think it’s always going to stay the way it is. They are not going to let you pass this point…Either they like you but they will not open up fully or they will talk to you and they will be nice as anything but…not going past that point (Donna²).

…I don’t think we help them as much as what we probably could if we could get them in a different kind of environment (Gabrielle²).

Nurses performed a job that required them to be vigilant and wary of their patients in their everyday nursing practices. The adolescents similarly were untrusting and suspicious of nurses and the duties they performed as part of their role in ‘The Level System’. Nurses, in particular, were ‘walking a fine balance’, as they attempted to form a solid relationship of therapeutic value while still doing the physical aspects of their job. They were confronted by their conflicting nursing duties and obligations to fulfill their role as the ‘enforcer’ of the program while simultaneously developing a rapport and trust (elements of a therapeutic relationship) with the adolescent. In fact trust, as described in Chapter Three, is a pivotal element required for a therapeutic relationship. Realistically though, genuine ‘textbook’ therapeutic relationships between the nurses and the patients with anorexia were highly unlikely within this milieu and within current circumstances.

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...some of my relationships with them have been really good and some of them have just been outright disasters (Linda²).

...it's a hard choice. You have to look after them regardless of whether you make a relationship or not (Mandy²).

Most of the adolescents described how they found that nurses who were strictly enforcing the guidelines of ‘The Level System’ program made it difficult for them to get close to and form a positive relationship with them. Danielle¹ felt that her illness made her see these nurses as “mean”. In retrospect though, many of the adolescents realised they were “just doing their job”. Performing their role within the program made adolescents with anorexia in some ways reluctant to approach these nurses if they were experiencing difficulties.

...because you don't like the strictness of it [the program] and your mental side of it doesn't want that...It's hard to form a connection. Like, they might be doing the right thing. They might be doing what their job is to do, sticking by the Program, but you might reject that and you think, Oh, she's being mean to me... (Danielle¹).

The adolescents’ greatest concern, within this program, was that nurses reported back to the doctors. They described “nurses [as] an extension of the doctors”. If they told the nurse something in confidence they believed that the nurse would immediately inform the doctors. They also did not trust the accuracy of the judgements nurses made and reported in their daily notes. Many felt that they could not trust nurses because of this lack of confidentiality. They were uncomfortable with being close to someone who they saw as making them do things that they did not want to do and therefore they preferred minimal contact (see Appendix N35).

I think a lot of the time they were someone that you wanted to like you because you thought they would treat you better...I thought some of them, I felt comfortable around but I never really felt that I could tell them much...I was always so scared that they would tell the doctors. I don't think I ever really confided in them much... (Zoe¹).

I didn’t really confide in them because I knew that they would always just write it down on the papers...I didn’t like that. I didn’t want it to be known... (Josephine¹).

...it feels harder because you feel that they’re judging you on what you are going to say and they might write it down straight in the notes, you know or tell it straight to the doctor and...they might kind of twist your words a bit or something like that (Cameron¹).
The sentiments described by the adolescents with anorexia regarding being wary of what nurses reported in their notes is similar to those of the prison inmate who, according to Morgan (1981, p. 266-267), “seeks to avoid a ticket, a disciplinary report, which could go on his…prison file…”.

The issue of nurses having to report to the doctors within this type of program was a major impediment to the formation of trust between the adolescent and the nurse. Each adolescent reported that the nurse’s role as a spy for the doctors made them wary of trusting nurses. Josephine¹ felt as though nursing staff had an ulterior motive when they talked to her. She felt that they were trying to interrogate her for information. Earlier Megan¹ had reported similar sentiments in that she felt that some nurses were interrogating her at meal times for information. Interestingly Zac², a nurse, admitted that he felt that some nurses’ attempts at forming a relationship were quite fraudulent while other nurses he felt were more genuine.

Zac² remarked:

*I guess it depends on the nurse and the patient. Some kids might see it as quite fraudulent in some aspects…Like they are just trying to trick them into thinking they care…Others it is just nurse-patient clicks and they…do get along and it is quite genuine. So you have your extremes or the ones where the nurses are quite fraudulent in their attempts and the kids can see that and then there are the other ones where the kids and nurse do get along (Zac²).*

All the adolescents reported in their interviews that nurses were difficult to trust because of their role within the program as spies for the doctors.

*…also knowing that they have to report back to the doctors, that’s totally hard to trust (Megan¹).*

*…Um cause like if you tell them something, they might just immediately go tell the doctor or something and you might not want them to know (Chloe¹).*

*…they are always suspicious and so they are probably planning to trick us to try and figure something out about us… (Josephine¹).*

*Um if they like run back and tell the doctors what we have said or they talk about it with other nurses or other patients even… (Isabel¹).*

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Some of the adolescents did disclose that they may open up to a more “lenient” nurse, if this nurse did not divulge or report things in the notes or to the doctors. Yet it was evident that this seldom happened on this program as not one adolescent was one hundred percent trusting of nurses.

...some others that you felt were a bit more lenient with the rules...then you kind of maybe would tell them something if you were really upset...If you found out that the doctors didn’t find out once you had told them something, then you are like, Oh they are not going to blab to the doctors every time. Maybe I can tell them a bit more... (Megan¹).

Cameron¹ described how “the nurse’s personality, how they are...whether they are male or female” also played a part in whether an adolescent felt comfortable in making a connection with them. As a male, Cameron¹ reported that he felt it was easier for him “to get along with male nurses more than the female nurses”. Sara¹ reported that she found that the “overly strict” nurses in her opinion did not understand what she was going through and therefore she felt terribly uncomfortable in confiding in them at all.

Zoe¹ summed up that nurses, within this program, had a difficult job in caring for adolescents with anorexia. She believed that most adolescents would not feel secure in connecting with nurses within this type of treatment program because of the role they played. She felt that nurses “walk a fine balance between being caring and connecting with you and doing their job”. It was difficult to do both these things at the same time. She did believe, though, that some nurses were better at ‘the balancing act’ than others because they remained “fair” but flexible. They knew what things “to push and what not to push” with the program.

...they are the ones telling you to eat, they are the ones that are watching you, making sure you eat, making sure you don’t do sneaky stuff and so often it is very difficult...I think they walk a fine balance between being caring and connecting with you and doing their job...I think sometimes the good ones know what to push and what not to push and they are still fair on everybody...If you don’t want to be treated, often it’s hard for you to trust someone that’s making you eat (Zoe¹).
A few adolescents remarked that “the best” nurses were sometimes the ones that were strict with following the rules. They were considered “nice people” and even though they were strict with following the program their personality compensated for this so these adolescents did not mind having them as a nurse.

…sometimes the nurses that are…the best are um really strict I guess…but it’s not as if they are my favourite because they are strict…um like I don’t really think about that. It’s because they are nice people (Isabel¹).

…some nurses can be strict but really nice at the same time (Chloe¹).

The nurses had similar sentiments to most of the adolescents in that their role in enforcing the program rules created conflict for potential relationships. Oliver² described articulately that nurses spent the majority of their time “observing behaviours and recording them empirically”, when caring for adolescents with anorexia. Their job, as it has been described throughout this chapter, was to be the “the eyes and the ears” for those who did not spend twenty four hours of each day with the adolescents. This enabled decisions to be made at meetings on whether progress had been made during the week. Nurses felt that they could influence decisions at meetings regarding whether a patient should be rewarded with a ‘gate-pass’ or whether they should go down a level because of these observations. In general they believed their opinions were taken into serious consideration by the doctors.

Gabrielle² explained this as follows:

…our main thing is…with this program is that it’s all observing and that is really all we do…The Level System’…they do see it as a reward or a punishment that…our observation impacts greatly…We have such control if we think about it. We can choose whether they go on ‘gate-passes’ or not…They may be doing something and we are very, very quick I think on judging their behaviour…whether that is necessarily a good thing or a bad thing for them to do. Then if we choose it to be a bad thing, then we choose to punish them…and…they go up or down the reward system…‘The Level System’…I could basically say you go into the meeting and if you say you don’t think they should go out on ‘gate-pass’, majority of the times they are not going to get ‘gate-passes’…and it is all by our observation…(Gabrielle²).
Veronica believed that she as a nurse was “always judging” patients whether they were a patient with an eating disorder or not. Nurses were in a position to make judgements about a patient’s mood and their behaviour. ‘The Level System’ provided nurses with guidelines to follow for the patient with an eating disorder and nurses had a job to fulfil in “making sure that [the adolescents] adhere to that level system that they’re put on”.

Mandy felt that the guidelines and levels helped her decide how much observation was necessary. She knew that if a patient was on Level One then the observation would be stricter because they were medically unstable. As their levels increased she felt nurses “relaxed” a little in their observation. Nurses, in this position of observing and making judgements, would find it difficult to gain the trust of adolescents with anorexia who would see them as their “enemy”.

Melinda, an adolescent, agreed with the nurses and explained below why adolescents with anorexia did not completely trust nurses.

_They don’t trust them because they’re the ones that make you eat. They’re the ones that stop you from exercising or stop you from throwing up. So they don’t really trust them. They see them as the enemy_ (Melinda).

The adolescents described how nurses were “always” suspicious of patients and similarly patients themselves were suspicious and mistrustful of most of the nurses. There were very few nurses that patients felt they could truly trust. Again Megan felt that this was because “they are following a procedure” and patients felt a “bit intimidated” by this. It made them feel that nurses did not “really care” about them. They felt disassociated rather than connected with nurses because they saw nurses as having a job to fulfil.

The adolescents themselves believed that most adolescents with anorexia would have great difficulty in trusting nurses because of “the illness”. The treatment revolved around food and adolescents with anorexia had difficulties with trusting people when it came to the area of food. Nurses, in this case, were the ones “trying to give [them] food” (see Appendix N36). The adolescents needed constant reassurance from nurses that they were having the correct amounts of food as indicated on their meal plan. They wanted no more than necessary and they expected all the adolescents to be treated equally and fairly when it came to the program (see Appendix N37). Yet this again was not always the case.
With the nasogastric feeds, patients were always worried that nurses would give them extra feeds or a stronger strength of formula. They felt that it was nice when a nurse offered them the opportunity to watch when they measured the feeds out. The adolescents felt this helped to increase the trust but this happened infrequently, if at all, on this program.

…They might tell you, You can come and watch me measure out this. Which is really good and then next time you might feel, No I trust you. Which is always nice… (Danielle¹).

…I remember I used to not trust them when they were getting my feeds ready…I didn’t trust that they would stop [them] when the dose finished…I always thought it doesn’t matter to them…an extra 10 mls…but it matters to me and so you think, Oh they won’t worry about it because they have got more important things (Zoe¹).

Zoe¹ in fact described another negative experience she had with a nurse who she felt was giving her an increased strength of formula for her overnight feeds. She recalled that she could tell that it was a more concentrated strength because it was “really dark”. She felt that the nurse was trying to deceive her because when she confronted the nurse about it, the nurse came back with the same formula in a bottle marked as though it was Ensure 1.0 Concentrate but Zoe¹ knew because of its colour that it was still Ensure 1.5 Concentrate from a can. Zoe¹ commented, “an anorexic person will never trust you if you don’t show them” (see Appendix N38).

If nurses showed patients, the bolus amounts before they syringed it down their tubes or showed the patients the overnight feeds being set up, they would perhaps trust them more than they currently did. They believed that when nurses did not show them these things it made them wonder: “If they are not allowing me to see, then they must be doing something that I won’t like”. They believed that it was the “anorexia” that did not trust the nurse and not that they did not trust the nurse as a person.

…I it’s actually really worrying me and it’s not that I don’t trust you as a person but my anorexia…won’t let me trust you… (Zoe¹).

Nurses on this program were always suspicious of patients. Megan¹ reported how she would close the curtains around her bed at night for privacy. For her shutting the curtains at night made her feel like she was “just shutting that world out” thereby leaving her to be
“alone and peaceful”. Some nurses did not trust her and “suspected” that she may be exercising at night and they “would always rip it open”. This really annoyed her. She said some nurses did trust her and “that was great”. Megan¹ felt strongly that all nurses should trust patients initially. If they were not progressing and gaining weight, then she suggested that they explain the situation and let them know the reason why the curtains would need to stay open at night.

The adolescents described nurses as being “really, really suspicious” especially when they suspected that an adolescent was exercising in the bathroom or in their room. Isabel¹ recalled an instance when she was lying on her bed and another girl was lying on the floor and they were talking to each other but the nurse thought they had been exercising and confronted them both about it. She said it was “really upsetting” when someone “accuses you of something which you know you haven’t been doing”. They believed that even the “nice” nurses did this. They would “put their ears up to the door” and listen or they would ask the other girls in the room, “How long have they been in there for?”. The not so nice nurses would open the door without warning. Even if the adolescent told the nurse that they had not been exercising, the adolescents sensed that the nurses did not believe them. The nurse’s observational role within this program made it difficult for nurses to be fully trusting of the adolescent with anorexia and vice-versa.

The adolescents explained their feelings of mutual mistrust and suspicion below:

…Because everyone thinks that all people um in for eating disorders…will try and be naughty and um get out of things and stuff…One nurse I can think of in particular…she is really nice and stuff but is just really suspicious…is always asking us…if we have been exercising or if we have been yeah trying to get away with stuff. Which I guess…would be…understandable but when they do it like all the time it gets annoying…They don’t trust us… (Isabel¹).

…some nurse might just walk past and then they will think, Oh hang on. They’re in the bathroom…I will just go and check…They will go and knock on the door, What are you doing in there? And it’s kind of like, What do you think I am doing in there?. I’m in the bathroom. Or you show them that your food is finished and then they will come over and re-check it kind of thing and you are like, Well I just showed you it was empty…Or maybe they will re-weigh you if they…thought that you might have just fidgeted around a bit then they will come back an hour later just to check that you didn’t do anything… (Megan¹).
...when people are exercising in the bathroom and stuff...they’ll just go and open the door and not knock or anything like that. If they suspect they are vomiting, then they’ll stand outside the door when they are in the bathroom… (Melinda¹).

...sometimes, you feel as if the nurses don’t trust you. Like with the exercising thing if you say ‘No’...You kind of feel as if they don’t believe you...you just feel straight away that you can’t trust that nurse (Cameron¹).

‘False’ accusations made patients unwilling to trust nurses or form a relationship. When Melinda¹ arrived to the ward, she reported that the nurses thought that she was concealing food and they would therefore check her pockets all the time. She said that this made her “not like” or “want to talk to” certain nurses. She believed that they treated her this way because of their belief that all patients with an eating disorder did these “naughty” things. For Cameron¹ nurses were always accusing him of exercising yet he could not prove otherwise in his position and felt “a bit stuck”. The nurses did not believe him and he reported that this situation could almost make you want to engage in these unhealthy practices. Similarly, Sara¹ reported a negative experience when two nurses opened the bathroom door on her because they thought she had been exercising. She, like the other adolescents, believed she was falsely accused.

A bit stuck, because I mean like I knew I wasn’t [exercising] but...you can’t really prove that in the position that you are in at that moment...But I mean it’s hard for the nurses too, to know what you’re doing. But you knowing that you haven’t done that thing and then them not believing you. At least you feel that they don’t believe you, is really hard and can almost make you think about it too much, to the extent, you actually might do it. Do you know what I mean? (Cameron¹).

When they accuse you of things, you don’t do. You just feel...you don’t want to talk to them. And usually they don’t...say, Oh sorry or anything like that. It is just like, That was my job and I suppose it is their job, but still. And you don’t feel very comfortable (Melinda¹).

...if they accuse them of something that they didn’t do – then they wouldn’t want to talk to that nurse (Amber¹).

...Well, once I was in the bathroom and I was taking ages because I couldn’t really go properly. And then they came in on me, like two of them, and they thought I’d been exercising and I felt really hurt because I knew I hadn’t (Sara¹).
At times a nurse spoke to other nurses or to the doctors about patients at the nurses’ desk and this was detrimental to ward nurse-patient relationships. Megan¹ felt that “if they are having a discussion about a patient”, nurses should “not do it at the front desk because…everyone can hear”. She said that hearing about “one of your friends…really hurts you because you are in the same boat as them”. When she heard nurses discussing patients she felt that maybe she could not trust them as much and it broke down her relationship with them. Amber¹ agreed that “if they’ve said something about another patient behind their back” it was difficult to trust that nurse. Thomas², a nurse himself, reported that he had actually seen “people…blurt things out like in front of everyone and its like, Oh”. Zoe¹ was always suspicious that “little conversations were going on between the doctors and the nurses”. These conversations she felt were not always accurate and it was therefore difficult for her to trust any nurse especially someone who was colluding with the doctors as well as enforcing the doctor’s orders.

Even though the adolescents did not completely trust the nurses or like the things nurses did, they believed that in some ways it needed to be done. Zoe¹ and Cameron¹ reported that they did not like nurses watching them at meals but felt that if the nurse was not there they would not eat at all. Zoe¹ also added that if the adolescent had some sort of rapport with the nurse, which would then lead into trust with the nurse, they would feel perhaps an obligation of sorts to eat in order to please that nurse. Conversely, Megan described how if a nurse was overbearing, the adolescents would sometimes refuse to eat on purpose.

…but then some nurses…if you get a good rapport with the nurse and you trust them…then when they have you…you feel like, Oh…you know it will make them look good if I eat…So it’s sort of like sometimes when the nurses are watching it helps…You might not like it but I know I wouldn’t eat if a nurse wasn’t watching. So it has to happen (Zoe¹).

It is annoying when it is happening. But now if I think back, it is a good thing that they are there…Otherwise…you wouldn’t eat it. So…you kind of need them there to…push you…that little bit forward…It’s kind of like a little bit of discipline…with them being there…You feel more pressured to eat it which is good because you actually do eat it (Cameron¹).

…sometimes I had to use them [boluses] when I got annoyed. Like if a nurse was being really pushy…I would be like, Screw it! I am not going to eat just for the sake of you having annoyed me…(Megan¹).

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Megan¹ earlier mentioned that “as people” you could trust adolescents with anorexia but “around food” you could not and that was why nurses needed “to be on [their] toes” when caring for adolescents with anorexia. It was not possible for an adolescent either to have full trust of the nurse. She believed that the relationship between a nurse and an adolescent with anorexia could only have a certain “level of trust”. This “level of trust” took a while to develop. She believed that when this occurred the adolescent felt some security in knowing that the nurse was “friendly” and was “not going to write this down or write that down about [them]” or “give [them] a bad report”. In this sort of positive relationship the nurse would be willing to find out about the adolescent and their passions and thereby their actions would reflect that “they are on [the adolescent’s] side”. Zoe¹ added that even if a patient mistrusted a nurse, this may not reflect the effort of the nurse in engaging in the relationship. She remarked: “Whether a patient trusts them or not doesn’t really always prove whether someone’s putting in a lot of effort…because over time…you do see that they are trying and that they do think that you are worth it. So I think it just takes a little while sometimes”.

I think by…actively showing them that you’re here for them, I think that is a really good way [to build trust] (Paige²).

All the adolescents constantly emphasised that a key part of the nurse’s “job” within this program was to be “suspicious”. The nicer nurses however would not confront them until they were absolutely certain. But the adolescents suggested that it would be nice if all the nurses gave the adolescents the benefit of the doubt the first time rather than automatically jumping to conclusions that something untoward was happening. This would possibly augment the therapeutic nature of current relationships between nurses and patients on the ward. Interestingly, Zoe¹ used language symbolic of that used within the legal system. She said even though adolescents with anorexia “don’t have a good track record (laughs)”, nurses should keep in mind that not unlike the “legal system” an adolescent on the program should be considered “innocent until proven guilty”.

They still have to be suspicious. That’s their job. Because they can’t just go around trusting you….If they are the nice ones, if they are a little bit suspicious…they won’t usually say it until they are absolutely sure. They don’t like accuse you outright (Amber¹).
...if you knew something was going on...like you knew someone had been in the bathroom...twenty minutes and they were obviously not having a shower or anything...They [nurses] check and you're thinking, Well that is pretty smart to check (Megan¹).

Well obviously if you take too long in the bathroom...it is kind of suspicious because people have been known to exercise in the bathrooms, to burn off calories that they've been eating...So, obviously if they take long, then they've got a right to be suspicious. But...I think they should give you a chance because half the time you're actually not (Sara¹).

The adolescents trusted a few nurses but not many who worked within this program. Melinda¹ said that adolescents trusted these few nurses because they were not only “nice” but “they know what they’re doing”. She said there was one nurse who had them quite often so she was aware of the rules and followed them. Sometimes, Melinda¹ remarked, “she makes exceptions because she can trust me” even though she knew this was not “really fair” for the other patients. She described this nurse as being supportive when she was upset. She felt comfortable in talking to her and she listened attentively. Melinda¹ believed that it was harder to trust a nurse who did not care for them very often. These nurses often did not know the rules well and “people get away with things, like not eating certain things” making it unfair for the other girls (see Appendix N39).

Apart from Melinda¹ and Amber¹ the other adolescents were not as keen to share confidential information with the nurse for fear of the doctors finding out or it being recorded in the notes for all to read. Cameron¹ believed that nurses “were trying to their potential” to form therapeutic relationships but he could not see the development of genuine trust ever happening in this type of setting or with this type of program. He said: “you can...gain a little bit of trust with them but not as much as a friend”. Cameron¹ believed that while adolescents with anorexia were in hospital they were always going to “feel as if the nurses are the ones...controlling everything”. This was very hard for someone who had been “used to controlling everything” outside of hospital. He believed “lots of them tried quite hard to establish good relationships” but he could “only find a few nurses” that he himself could “really trust”.

There were nurses that Cameron¹ did not get along with and so did not trust them from the outset and then those who might be nice but had been involved in something unpleasant like your first nasogastric tube and so “your brain just clicks to not liking that
*person because they have done this to you*. This left him with very few nurses that he could trust and this trust took a long, long time to develop.

...the one’s who you know, you don’t get along with, you can’t trust. So that wipes out half of them. And the other ones...when you first came...it could be a really nice nurse who put the NG tube in...your brain just clicks to not liking that person because they have done this to you... (Cameron¹).

The nurses, on the other hand, expressed that there were many, many obstacles to the formation and maintenance of therapeutic relationships while in hospital. They attempted to overcome these barriers to form some sort of relationship with the adolescents with anorexia. In general, the nurses commented that someone establishing a connection or positive relationship over time with an adolescent with anorexia was critical to their eventual recovery. However, Gabrielle² explained that even though nurses were in an ideal position, their attempts to form these positive relationships were hindered by many factors including the program that was in place.

...unless they have someone...that they have got a relationship with and it’s normally not mum or dad and it’s not the doctors, it’s got to be someone else who has got some knowledge. Well nurses are the best, they are 24-7 with them, so yeah I think it is really critical but I don’t think we’ve got the kind of setup that allows it to happen (Gabrielle²).

...If it was me being one of them and somebody was sitting there watching me eat and telling me what I can and can’t eat and what I can and can’t do then I wouldn’t really want to build a relationship with them either which is understandable. So it is very hard to break that barrier...That is the main challenge that I find in nursing the kids and I think that they need that element of trust and a relationship with the staff member that is here 24/7 (Veronica²).

The relationship with an adolescent with anorexia was “totally different” to any other patient. Nurses could “either love them or hate them as horrible as that sound[ed]”. The nurses believed that it was not a “free relationship” of trust. It was one in which nurses also described themselves as needing to “always...be on your toes”. As the adolescents described there was only a “level of trust” and the nurses agreed wholeheartedly with this statement. The nurses felt that a relationship of sorts did form but the relationship would not be truly therapeutic because nurses “call[ed] a lot of the shots”. Within the hospital setting the adolescents were going to see nurses “as baddies” and so the establishment

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of a rapport and authentic trust was going to be difficult until they reached “the recovery period”.

As previously described, the adolescents had difficulties trusting nurses with giving them their overnight or bolus feeds. The nurses similarly explained that they too did not trust the adolescents with the overnight feeds. They were mindful of manipulation of the feeds, the feed bag or line and would check on them “regularly” overnight. Many of them described how they would “tape” the top of the bag securely as well as the point where the nasogastric tube end joins up to the feed bag line. Others have connected the feed pump, the machine used to administer the feeds drop at a time, to a non-mobile pole at the head of their bed. This prevented the adolescent from getting up at night and going to the bathroom without notice. They would need to “buzz” for a nurse to be disconnected from the machine in order to use the bathroom (see Appendix N40). Many nurses also set the “volume limit” on the pump so that it made a sound when it had reached the limit and “if the feed has finished and the volume hasn’t been reached then we know they have manipulated”.

…I also tape the top down of the bag to make sure that, ah well to check that it has not been tampered with. They can still tamper with it but we will know then and I also tape it to the NG tube, so that I know they can’t disconnect…I hook it up to the bed for overnight feeds so that they can’t get up in the middle of the night and tamper (Zac²).

The nurses had seen too many adolescents with anorexia tamper with their feeds. As nurses, fulfilling their duties as part of this program, they could not ignore or not be suspicious of patients connected to feeds. Being suspicious was “the nature of the work”. They described how they would “look more closely” at the feeds if an adolescent was not putting on the correct amount of weight or was losing weight on weigh days. Veronica² remarked: “we have had kids disconnect the lines to the NG tube and put it in their bed or in a cup overnight…so that it looks like they are actually getting it but they are not…We have also had people tip some of the…Ensure out and add water to it so they are not getting the full calories” (see Appendix N41). The desperation of these adolescents to not put on weight meant that some would aspirate the feeds out of their nasogastric tubes with plastic syringes that they had procured from a dirty bin or they would get hold of “scissors or razor blades” to slit their tubes.
All of the nurses easily recalled instances when tampering with feeds had occurred on the ward. Some of these are illustrated below:

...let it [the feeds] siphon into a pillow case, into a blanket, into a towel or whatever they have got in the bed with them so you can see it running...They can take the feed to the bathroom and tip it out or siphon their NG tube themselves...or add water to their bags. So tip out a bit...of their feed and then add some water to it (Gabrielle²).

We have had girls who have got scissors or razor blades...and have slit along...the length of the tube and then held tissues to it and soaked up the Ensure into tissues and stuck it under their pillow...Or people who...scavenge through contaminated waste bins and take out syringes and use them to suck out the feed. Stuff that any well person would probably just not even consider doing or would...be repulsed by (Oliver²).

Sometimes they steal syringes that have been placed in the bin...obviously without the needles on them and they wash them out and they will use them and they will hide them somewhere behind the toilet... (Donna³).

We found one girl at three o'clock in the morning putting her feeds into her shampoo bottle (laughs) (Thomas²).

Oliver² described how he would initially “give them a bit of a chance” but if there had been prior “evidence” of tampering or a suspicion then he would tape the bag up and mark the tape with a pen-mark. Most nurses used their own code, be it a symbol like a red cross or their initials, which they placed inconspicuously across the top of the tape while taping the top of the feed bag. If the “pen mark” mysteriously moved position overnight then there was a high probability that the bag had been untaped and then retaped by the adolescent.

I personally don’t like to be suggesting implicitly that I don’t trust them to begin with. I like to suggest that there is some trust there...but I have been known to be sneaky and tape it up and then put a little pen mark across the end of the tape just to make sure that they are not actually untaping it and retaping it...And of course I do not tell them I am doing that (Oliver²).

...where I’ve taped it...I’ve got about two or three layers, I’ll actually put a line of pen through it. So then that way it’s to monitor whether or not they’ve been tampering with the feed (Riley²).

Unfortunately nurses had to “always keep a suspicion in the back of [their] mind...just to be on the safe side”. There were too many who would “swear blue in the face that they are not doing something when it is quite obvious that they are”. Their desperation to not
gain weight ensured that there would be some kind of manipulation of their progress, the program or the nurses. The nurses were assured that the adolescents would have the same kind of suspicion of them. They believed that this suspicion was a “safety net” for both of them rather than “to give in completely and trust someone wholly and solely”.

Nurses carrying out the program and being strict with the guidelines of the program led an adolescent to be mistrustful and vice-versa. The program itself hindered relationships immensely because these adolescents were “more restricted than the other patients”. In many cases, they did not want to be on the ward because they did not believe they were ill. They could see that they were not treated the same way as the other patients and had most choices and many things taken away while they were on the program. Zac\textsuperscript{2} remarked: “they can choose to eat the meal or they can choose not to…[but]…with choices you have consequences and they know the consequences of the choices they make”. Gabrielle\textsuperscript{2} believed that “the whole program” created an atmosphere of “non trust” for both sides. Nurses saw patients as “sneaky” and naturally patients felt that nurses were “sneaky” too. Nurses would wonder what they were getting up to if they were “talking together”. Similarly nurses believed that the patients probably felt the same way and wondered what nurses were up to when they were “talking outside their room”. The nurses reiterated that unfortunately this suspicion and mistrust would always be there within this type of setting, with this group of patients and with this type of treatment program and this could not be avoided.

\textit{I think nearly everything we do is seen as being sneaky and that doesn’t help the trust and same for them. I think anything that they are seen to do that we can’t see openly is actually seen as not being trustworthy (Gabrielle\textsuperscript{2}).}

Zac\textsuperscript{2} explained that nurses, including him, were “definitely suspicious if things don’t add up the way you think they should”. He provided an example that on weigh day, nurses had an idea of how much weight the adolescent should put on with the amount of food they were eating. When the figure did not match up to what they expected he said nurses would normally “jump to the conclusion that they’re either vomiting or exercising straight off the bat”. He insisted that the adolescents with anorexia would not “own up to” telling a nurse that they had been engaging in weight loss practices because “they know they are not supposed to” and admitting liability would “cause them to miss out on a benefit that they

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may get” from doing it. That is why it was imperative that nurses kept a “close eye” on them so that they did not engage in practices that were detrimental to their health.

Oliver² provided an example of a girl whose potassium levels were falling regardless of her oral intake. He reported that she was asked to return to ‘bed rest’ because staff had a serious suspicion that she had been vomiting frequently in the bathroom. The girl vehemently denied any wrong doing yet the nurse said that she had her own evidence and that was the blood results which showed her potassium levels had fallen into the two’s. Oliver² re-affirmed that the nurse’s role, within this program, was “to be on high alert for deviation from the program” for the adolescents own well-being, health and safety. It came naturally to those who had seen it all before-the “vomit in buckets” or drawers, “hearing noises” or the “kids running off to grab a book” before ‘bed rest’ and not returning for ten minutes.

Other difficulties for the formation of a relationship included the adolescents’ “lack of trust…of adults in general” (see Appendix N42). Linda² believed that they did not want “the adults in their life to help them gain weight” and this therefore created animosity because as nurses they were “effectively forcing them to eat”. However Linda² did not mind being the “enemy”. She replied: “I am paid to do a job, so I do it effectively”. Gabrielle² agreed that trust was difficult to obtain with these particular adolescents because they can be “so entrenched in their behaviours” that they “are not going to tell you the truth” and are going to effectively resist the help that nurses were trying to provide them. In comparison to other adolescents on the ward with other medical or surgical conditions, “these kids are not voluntary patients really…we are making them do things that they don’t want to do”.

Oliver² and Riley² thought that their gender at times was a barrier for them forming a relationship with these adolescents. They believed that being a male prevented them from connecting with some adolescents, both males and females, who “may have a real issue with men”. For Linda² she felt her age was a barrier. Linda² was one of the older members of staff. She said: “I think they do connect much more with younger people”. On a personal note, Oliver² remarked that having daughters of his own heading into adolescence, this type of work now made him “a little uncomfortable”. He said “my whole perception of what being an adolescent is like is being affected by the place I work”.

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For most of the nurses, they felt that making a connection and forming a positive relationship with an adolescent with anorexia had a lot to do with personality. There were some that they “immediately click[ed] with” while there were others they cared for in a professional way but did not like their personality very much. Thomas² believed, “some patients…they just seem to clash with the majority of…authority figures in their life”. This made it difficult for all nurses. Others nurses believed some of the adolescents were overtly “negative towards everything…the program and even…their parents”. Mandy² reported that sometimes it could be extremely difficult to get a conversation going because they would be so “shut down”. There was so much “blame” towards parents “for putting them here” and towards nurses for making them follow the program. They found it hard to comprehend that they were ill and “they [were] here to get better”.

The nurses explained their difficulties with forming therapeutic relationships as follows:

…At times I do yeah. When there is someone that clashes with your personality to such a degree, where you think, Arghhh, I just don’t want to talk to them or I don’t care about that person…I know it’s awful but it happens, not often (Thomas²).

…obviously some personalities you are going to connect with much easier than others…A patient that is much more suspicious, you are going to find much more difficult than one that is much more open. And that’s difficult considering they are anorexics and it’s based around secrecy to start with. But some are much more secretive than others (Linda²).

…some it is hard because…they feel like they are betrayed by their parents for bringing them in here and by the doctors for forcing them to eat and yeah so it can get a bit hard… (Donna²).

I guess it is a clash of personalities. We are not people who get along with each other initially…I don’t see any point in trying to fake that I like a person just the same as they don’t fake liking me. So I guess I just treat them like a person that I wouldn’t like and I do the job that I need to do and have as little interaction as required for them and me (laughs) (Zac²).

…if I like the patient…I’ll try to create a so called therapeutic relationship with that patient. If not…I’ll do what I need to with that child but that’s it. Do talk to them but probably not to the extent that I would with a patient that I have a rapport with (Riley²).
The ward environment and structure as well as staffing levels and patient acuity also impacted on relationship building. The current ward structure and its staffing levels meant that generally certain nurses looked after the adolescents with anorexia “five, six, seven shifts in a row”. In many cases these nurses were the “enrolled nurses” or the junior staff because of their skill level and the higher acuity of patients on the ward. If the ward was very busy and short-staffed a “pool nurse” may be sent to the ward and this nurse would usually be allocated the adolescents with anorexia because their care was “observational” in nature. “Pool nurses” did not regularly work on the same ward. These nurses were allocated to work on certain wards that were short-staffed for the day.

When nurses had “emotionally challenging kids like this everyday for six or seven days in a row” there was going to be a breaking point “where they just all became the same and you just sort of go through the motions and get your job done”. Oliver² suggested that if the ward made the effort to insist that everyone took their turn then the “united front” becomes a bit easier to maintain. It would be more difficult for the adolescents to have that “leverage” to ‘split staff’ if everyone on the ward followed the program consistently.

Oliver² explained the ward environment and its problems:

…at the moment we have a pretty high acuity of patients on the ward. Um and...if we are not getting pool staff we’re getting sometimes two enrolled nurses on a shift and when you have got other kids with TPN [total parenteral nutrition] and chemo [chemotherapy] and so forth um the obvious and simplest thing for the allocating team leader to do is to give the eating disorders to the enrolled nurses because the nature of their care really is...more observational rather than therapeutic in a physical, medical therapeutic sense. Um and so that’s the reason that they get them all the time…We have all been guilty…I mean a lot of people, and I try and do this when I can, try and find some sort of mix so that they can have other patients who don’t need that kind of high level of therapeutic intensive treatment. Just so that they get a break from having the eating disorders every shift. But yeah I think the main factor is yeah too many enrolled nurses and um higher acuity elsewhere on the ward (Oliver²).

As Zac² earlier described, there was at times a “pack mentality” among the adolescents with anorexia on the ward. He felt that the numbers of patients with anorexia on the ward at any one time can affect relationship building:
...they usually find a leader...the one that they all look up to and aspire to be like and ah I guess it all depends on, the kind of person that leader is. If they are quite difficult and confrontational that will make the others test your authority at the same time. So that can be quite difficult. When they are in a group they will usually work together as a group and when it is five on one [five patients against one nurse] it is quite hard (Zac²).

...it’s harder, if one nurse is looking after all five, to...police a lot of areas… like the meal times and that type of thing (Riley²).

There should be four patients with an eating disorder on the program at any point in time, yet often there were six. Mandy² and Riley² claimed that sometimes patients were discharged earlier in order to ‘get beds’. Sometimes the adolescents were deceptively admitted under a different diagnosis like depression, self-harm or failure to thrive yet they were all patients with an eating disorder. Not long after admission, their care would be transferred over to the Adolescent Team and they would be placed on the Eating Disorder Program (see Appendix N43).

Unfortunately the adolescents with anorexia sat on “a really low priority on people’s lists” due to the “busyness of the ward”. If there was a child in “respiratory distress” and a child with an eating disorder that was “a bit upset” then the nurses would prioritise and would definitely be spending most of their time with the child in respiratory distress. Chloe¹ concurred and said, “if there is like some really sick kids and stuff in...they’re the first priority”.

The assumption that the adolescent with anorexia’s care was fairly straightforward most of the time led to the same staff being allocated them time and time again. A quiet shift could easily be turned into a chaotic one, though this did not happen often, when the adolescent decided to abscond from the ward. When this did happen it usually required “police” involvement. For example, a decision may have been made at a meeting that the adolescent was unhappy or distressed about and so they decided to run away. When this did take place, according to Oliver², it occurred at the most difficult and inconvenient of times during the shift, especially after doctors have left the hospital for the day.

...it could be a Tuesday or a Friday and the doctor says, I am sorry we are putting you back a level or You thought you were going home in two weeks and now you are going home in four weeks or you know, Your dad has told us that this is what’s happening at home and we are not happy about that.
Suddenly they come back in tears. Next thing somebody has come in saying, So and so has run away. We can't find them and that usually happens on a Friday evening about 5:30pm (laughs) (Oliver²).

Honesty is an important aspect of a relationship and nurses believed that they did remain faithful to the adolescents with anorexia in this respect. They would always let them know what the “worst [case] scenario” would be or would find out something if they did not know the answer. Sometimes if a nurse did “mislead” an adolescent it was for “good reason”. This would usually be “a white lie rather than a flagrant lie”. From a “moral” and “conscience point of view” the nurses felt that they were honest because the adolescent had a right to know what was happening with their care. They may “sugar coat things to make something sound a bit better but…[they were] truthful”. On occasions, Oliver² admitted seeing nurses “making promises [they] [we]re not in a position to make” and he felt “that whole plan” was “fraught with disaster” and led to greater mistrust. Similar behaviours within prisons are reported by Easteal (2001), where promises may also be made but not kept. Paige² decided that some nurses may have held things back “in order to preserve the relationship”.

Maintaining power and control on the ward and within the program was something that could not be avoided and affected the nurse’s relationship with patients. Nurses were “in such a position of power” because they dictated most things with the patients with eating disorders. They took away a lot of the patient’s “autonomy”. As Gabrielle² pointed out: “they don’t get to choose when they eat breakfast, they don’t get to choose how long they take, they don’t get to choose when they go to the toilet, they have got to tell us everything…So I think there is a big power struggle”. The adolescents were used to being in control of “what goes in their mouth” and now nurses were trying to take that control away. Riley² stated that when the adolescent manipulated for control this made the adolescent feel as though they had won “the battle” but in actual fact he remarked they had lost “the war”. Nurses and doctors officially won all the time because of the “superior role” they maintained as the powerful and dominant stakeholders within this treatment program.

…Unfortunately nurses win all the time, because, otherwise if they don’t, then the kids are just in here longer and longer and longer or they get restricted more and more if they try and break out…challenge that power (Gabrielle²).
In the end they think they might win the battle but they lose the war so to speak (Riley²).

...there’s usually a bit of a tug and war... it’s trying to give them a little bit of control in their own care while maintaining most of it (Zac²).

However, many of the nurses commented that it was essential that they did take control away initially because their “disordered eating” was “out of control” and they required the program “to give them structure” in their life. Many felt that when it was feasible control should be slowly returned to the adolescent because they had to be able to continue the work when they got home. However this was difficult because ‘The Level System’ did not leave “a lot of room for movement”. The adolescents seemed to be given some choices and control over what they chose to eat because they filled out their own menu each day but even then there were “parameters” which were part of the program, around what they could choose. Oliver² hoped and believed “that what we are doing is getting these kids to think that they are gaining a bit more control in the things that are important while at the same time we are making sure that they are not making bad decisions”.

Nurses’ perceptions on the issues of ‘power and control’ within the program are described below:

...to resume a healthy eating pattern, to maintain a normal weight...We could control that but for them to take the initiative and to control it for themselves because they are going to be going home eventually and um yeah it definitely is important for them to be taking some control over their own lives… (Thomas²).

...I can’t say that it is always equally shared all the time [power and control]...I think a lot of people make a conscious effort to try and do that but once again within the program that we have there is not a lot of room for movement (Paige²).

Paige² explained that in the “day to day interactions” on the ward nurses held the power. But doctors held “the power largely” in the area of “decision making”. Nurses did have an “input” at the weekly meetings but “ultimately the doctor dictates the discharge dates and ‘gate-leaves’ and things like that”.

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As Veronica² pointed out earlier, another difficulty experienced with forming positive relationships stemmed from the fact that she believed that the doctors and psychologists did not give nurses any background information regarding the patient or the patient’s family situation that may have contributed to the onset of the disorder. She felt that nurses were often not made privy to this information. If nurses were aware of the issues affecting the patient they would be able to help them more and would be in her opinion more “compassionate” towards their situation. She said that she tried to be “compassionate” when she looked after them because it did not come naturally to her.

…itif we knew a bit more, what’s going on with them, then we might be a little bit more I guess, considerate and um compassionate, you might say (Veronica²).

I try to do that when I do look after them [be compassionate]…I shouldn’t have to try though. It should just come (laughs) (Veronica²).

For Oliver² and Donna² they felt that parents themselves hindered their ability to form a relationship with their child. Oliver² felt that sometimes “you get fairly hostile parents” who understand that there is something wrong with their child but when a nurse needs to tell them, “It’s time for you to go home now. That makes it very difficult”. He understood how they felt because he too would be angry as a parent about being asked to leave. However, he said it was difficult for nurses to get through to these parents “that them being removed from their kids might be helpful to their child”. Hostility erupted as nurses enforced the rules of the program and for some parents understanding the rationales behind the rules was “a painful thing for them to swallow emotionally”.

…it’s not really a matter of just saying, Your child has a chemical imbalance and we are going to treat it and you can hang around. It’s, Your child has an emotional imbalance or psychiatric imbalance or whatever and it’s quite possible that you as the parents are part of the problem (Oliver²).

…itif the parents are non-compliant with the program and they go against the nursing staff, it makes it impossible to look after the kids. Because the parents sort of support the anorexia and they don’t want us to enforce anything onto their kids because that’s their kid…So the parents are the main obstacle…that prevented me from caring (Donna²).
Oliver² remembered a particular patient whose mother literally “took an hour” to leave the ward. He recalled the difficulty in removing mother from daughter and the obvious “co-dependent” nature of their relationship. The mother “reading [the daughter] the riot act” was definitely destructive for her progress.

Oliver² explained the co-dependent nature of this mother-daughter relationship:

…She went to the door and there was this whole co-dependent… I love you, I love you too honey, I love you, come back, kissy, kissy, cuddle, cuddle. I have got to go now but I will be back tomorrow. And then she would be in the corner and she would be reading her the riot act about whatever…it literally sometimes took an hour to get rid of mum. Um but I mean that was pretty obvious that mum was very much part of the issue… (Oliver²).

Donna² explained that one of the very few times, when she could not form a positive relationship with a patient, was because this patient’s mother was not supportive of nurses or the program. An incident occurred when this patient requested to change plates at the meal table because she did not like the plate she was sent. Donna² allowed this the first time but noticed as she scraped her food from one plate to the other she left a lot behind and then left a lot on the plate while she was eating. The next day the patient requested to change plates again and Donna² refused and explained that yesterday she had left a lot of food behind. The patient had a tantrum at the table and Donna² informed her that she would be having a bolus tonight. Donna² remarked, “her mum came up and started yelling at me and saying, All she wanted to do was change her plates and I said, These are the rules of the program and I said, Everybody complies with it”. Donna² reported that she had to force the bolus in that night and the patient literally bit her on the hand and her mother watched on and said nothing. Donna² voiced it was difficult to form any relationship with a patient with anorexia when a parent was ‘off-side’ with the program and its rules. The patient had the support of their parent to continue their ‘destructive’ behaviours.

The one issue that kept re-emerging over and over again in the interviews was the issue of “inconsistency” with the implementation of the program. It was not only the inconsistency among nurses that prevented relationships from forming but it was also the inconsistency among the medical staff as well. Zac² described how his authority as a nurse was sometimes “contradicted” by the medical team. He might have told a patient that something would happen then the medical team decide that, “No. We are not doing it
...the ‘long termers’ they say...they tell you to your face, You’re the nicest nurse but you make us eat the most (laughs). So I feel like I am doing my job but I am also nice so it kind of makes you feel rewarded...And even if you feel like you have set your foot wrong with one new patient, then all the ‘older ones’ will tell her, No, she is the nice nurse. So the relationship turns and it sort of progresses. As long as there is one ‘old one’ she trains the others (Donna²).

It was apparent that forming ‘textbook’ therapeutic relationships or connections with adolescents with anorexia was arduous, challenging and at times incompatible with a behaviour-modification treatment program like ‘The Level System’. Yet most nurses believed they themselves never gave up trying. They believed and hoped that the
relationships that did form with adolescents with anorexia had some therapeutic value. As nurses, working within ‘The Level System’ program, they felt they would never be able to form a classic ‘textbook’ therapeutic relationship with adolescents with anorexia. Though, they did the best that they could do within the current circumstances.

…that’s the best we can do for the time being (Donna²).

5.3.6.1 ‘The Balancing Act’

During their interviews, the nurses provided subtle advice for others embarking on this perilous ‘balancing act’ of forming a relationship that has therapeutic value while carrying out the program guidelines. Zac² described this ‘balancing act’ as enforcing the rules while still remaining a supportive person. The nurses explored these elements while referring to their own and other colleagues’ nursing practice within this ward environment.

…it’s sort of balancing the two quite a lot. Making sure that they know that these are the rules, this is what I am going to tell you to do…At the same time, any problems, more than happy to discuss it. So balance between them definitely (Zac²)

Trust appeared to be a fundamental and recurring element that was necessary for a positive relationship. The nurses understood that they would never openly trust an adolescent with anorexia and vice-versa so there needed to be at least a “level of trust” between the two parties. This lack of trust was a key contributing factor to why relationships were not truly therapeutic. Gabrielle² remarked, “that’s I think why it [the therapeutic relationship] falls down a bit with our eating disorders”. They would initially give them the “benefit of the doubt” in most circumstances. However, as Veronica² pointed out, once this trust was broken then it was very difficult for nurses to trust or believe them in the future. Nurses also believed that there needed to be a “balance between firmness and rapport”. Ideally there should be an even balance though it was easy for nurses to “over-balance” one side or the other. At times, nurses in this study asserted that, some of their colleagues did ‘over-balance’ in the relationship. For the relationship to have therapeutic value, nurses believed that the adolescent needed to feel secure that the nurse was “on their side”.

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I think we do have to give them the benefit of the doubt when they first come in. But then you find them exercising and that is just part of them. They are not being naughty, they are not misbehaving, it’s just part of their behaviour that they don’t control. There is such pursuit and such one-minded...focus to not eat and to remain thin or lose weight that yeah that trust unfortunately you can’t have it with them (Gabrielle²).

...if you start showing that you distrust them then they probably don’t trust you either...You have got to give them the benefit of the doubt to begin with until they prove otherwise (laughs) and then you know that there is no trust there (laughs) (Veronica²).

The nurses believed that for any connection to form there needed to be an understanding of the disorder and acceptance of it as a “real issue”. On occasions there had been “poolies” [casual staff] who would work on the ward and would say, “Oh give me those eating disorders. I’ll sort them out”. The regular staff on the ward believed they understood the situation was a lot more serious because of the experience they have gained as a result of caring for adolescents with anorexia. However for many it still remained one of the most difficult illnesses for them to understand when they compared it to other conditions.

To understand their problem...I love my food and I am...not that fussed what my body size or weight is...and to try and get in the minds of them and try and work out why they are so obsessed with not wanting to eat or not wanting to put on weight or why they are not happy with themselves, yeah that is pretty hard (Thomas²).

I think that is the hardest illness that I try and grasp...to understand where they are coming from... (Gabrielle²).

...sort of realising what they’re going through. Half the time we never actually know the reason why they’ve developed what they have so that sometimes can help if we sort of realise that... (Riley²).

The nurses believed there needed to be “boundaries” when forming therapeutic relationships with adolescents with anorexia. They felt that developing a rapport was important but nurses needed to be aware that these adolescents “may be emotionally needy and...if they see someone showing interest in them...they may be a bit more inclined to make that into more than it should be”. Oliver² believed that without boundaries the relationship can be an “unhealthy” one and one of “co-dependency”. He admitted that he had seen this type of relationship form between nurses and patients during his nursing career.

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...but I think the eating disorder kids, often if they are emotionally a bit needy, they kind of grab on. I have seen this happen with some enrolled nurses who get them again and again and again, shift after shift… (Oliver²).

...with their anorexia, their secretive behaviour, they are very manipulative and that is just part of their eating disorder, as well as having…electrolytes and everything else imbalanced…So you do need to set yourself boundaries, otherwise you will be roped in and you will burn very, very quickly, I think with them. Because they can play you off beautifully. You need to set those boundaries right at the beginning and um everyone needs to have the same boundaries, whether it’s just the boundaries in the program, but also your personal boundaries (Gabrielle³).

All the nurses believed that “communication” and “conversation” were pivotal and without these elements there would be no opportunities for the development of positive nurse-patient relationships on the ward (see Appendix N44). The adolescent needed to feel “psychologically comfortable…to open up to” the nurse. Donna² felt that nurses should not “preach” to them but rather talk to them as a “friend”. Zac² believed that honesty needed to be part of the communication process. He believed that being upfront and “honest” with them would help with gaining their trust. He would tell them that there would be “consequences” to their actions if they were found doing anything that was against the program. He said this was better than “lying to them about the care” they would be receiving. Donna² agreed she would inform them of things including the “worst [case] scenario” such as “being sedated” while in hospital or the risks of “dying in your sleep” if medically unstable.

Finding a “common interest” and “spending time” with the adolescents helped with forming bonds. It became a starting point for conversation and a way to “engage” with the adolescent. Using “humour” and “being friendly” by saying “Good morning” or “Hello” each day also helped with connecting and showing them that a nurse cared. The nurses suggested that it was also important to keep the adolescent up to date by informing them of future plans and it was important to “touch base” with them each day to find out what they would like to put forth at meetings or to find out generally how they were feeling.

...um just touching base with them when you see them. Making sure you say, Hello...If you see them by themselves just saying, Are you ok?, Is there anything we can do for you?...If there is...a case conference or something coming up, going and saying, Oh look is there anything you want brought up?...Making sure that they know yeah there are people making
decisions, but people who want to make decisions to benefit them (Gabrielle²).

Empathy was seen as being an important element in relationship building by all the nurses except one. Zac² believed that an empathetic nurse would be a “good advocate” for the adolescents with anorexia. He believed that if nurses tried to understand what they are going through then they were better equipped to help them find ways to get through it. Nurses being there twenty four hours a day meant that they were technically “their voice” at the meetings and through empathy they may be able to “find better solutions for their care”.

…I believe you can’t look after them without being empathetic because um if you are not empathetic then obviously you are one of those ones that say, Oh it’s self inflicted. It’s a waste of time. I don’t want to look after them (Donna²).

Oliver² after attending a family meeting for one of the adolescents and seeing the family dynamics in action became more understanding of this patient’s family situation. He said it was not in any way easier for him to get along with this patient but after listening to the family situation it did allow him to have more empathy because he “was less likely to kind of jump to conclusions about her situation”.

Riley², on the other hand, was the only nurse who believed that he could not empathise with an adolescent with anorexia. He did not “sympathise” or “empathise” with the adolescent with anorexia. He said: “Well I can’t even go and say, Well I have some idea of what you’re going through because I wouldn’t have the foggiest”.

I can’t be empathetic…because in all honesty I think they are doing themselves a great injustice and have no real reason to do it (Riley²).

Consistency among staff was also extremely important to relationship building even though most nurses described this as being a particularly difficult area to manage over the years. There was great inconsistency among staff members day to day with following the program guidelines. Some nurses used the program as a “guideline” while others followed it “strictly”. Many felt that if nurses were more consistent perhaps “therapeutic relationships would happen a bit more”.

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whenever you are looking after these kids, you are having to repeat yourself and reaffirm your position on the rules and that is...every time you look after them. There has never been a time where you just sit down and they do as they do and you get on with it... (Zac²).

The rules and boundaries were considered by nurses to be “a sign of love”. It allowed the adolescent to know what they could and could not do. It was not “fair” on the adolescents or the staff to have some nurses allowing them to “swap” foods or “change” the way they did things while others did not. With greater consistency, nurses felt that adolescents would have more trust in nurses and would realise that the program was the same for all, rather than certain nurses were “bad” because they were too strict or certain nurses were “good” because they changed the rules.

I think if we...all put the same level of strictness on it and we all had the same ground rules, then maybe therapeutic relationships would happen a bit more. Because it is not good nurse, bad nurse. It is...all these nurses are treating us the same. Therefore, it must be the program. It is not these nurses have a problem with me. And I think that would actually help with trying to build a relationship with them (Gabrielle²).

Confidentiality of information would help with building trust with the adolescent. However within this type of program it was difficult to justify especially when the information shared impacted on the adolescent’s progress and health. Similarly a NSW ex-inmate in Easteal’s (2001) study reported, that prison officers have a duty to report any information if it potentially affects the prison and its workings. Nurses saw it as a “duty of care to report...things that have happened or that a patient has said to you in confidence”. The adolescent’s health was clearly more important than maintaining confidentiality in the relationship. If the information disclosed was not seen as harmful to the patient or others then it was usually kept confidential but if it was seen as being sensitive then the nurse would usually say, “You do realise that I am going to have to tell somebody else because I can’t help you the way that you need to be helped”.

...so I find if it’s appropriate, I will just keep it to myself and just go on with it. But...if it is really something that the doctors need to know I do inform them and I am honest with the person that told me the information and tell them that, Unfortunately I can’t keep it to myself. It’s for your own safety. I have to let them know (Donna²).

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So can we talk about who I can talk to about this…I don’t want to betray your trust…I guess then it becomes a matter of judging whether it was something that really needs to be passed on or was it something that you can just take… (Oliver²).

Nurses believed adequate supervision and debriefing sessions should be available for those caring for adolescents with anorexia. Without adequate support systems in place, the stress from this type of job and the ‘burn out’ will be additional factors inhibiting the development of positive relationships within ward-based programs. Some of the nurses in this study remarked earlier that they were emotionally ‘burnt-out’ and physically and mentally exhausted by this type of work because of the lack of support available to them on this ward. This ‘exhaustion’ would no doubt have a detrimental effect on the formation of therapeutic relationships.

…the same people seem to have to nurse them all the time and I think with our acuity lifting quite higher now in the ward…the same people will always get them…So people who get stuck with them, unfortunately will get burnt out (Gabrielle²).

Some nurses discussed that without adequate support systems nurses would cut their losses and give up sometimes with forming a relationship if they were confronted with a continually “hostile” or “defiant” patient that did not want to interact or engage with anyone no matter how hard they tried. Thomas² reported: “you might use all your charms and all your skills that would normally have a person talking to you…and they might be still telling you to bugger off basically”.

…if someone is difficult to have a conversation with or you’re finding that your every attempt is sort of being thrown back at you or you feel like you are getting nowhere…So there’s like this negativity or this…feeling that you’re not doing something right…It makes it really hard to pursue it [a relationship]…if there is no sort of positive reinforcement. There is no reason to keep at it…I mean that would make it very easy to sort of say put that patient in the ‘too hard basket’ (Paige²).

…there does come a point with hostility or just rudeness where after a while you go, Ahhh I have given this a pretty good go and I am not getting much back. So you just kind of cut your losses and give up I think (Oliver²).
Those nurses who were burnt-out, frustrated and stressed as a consequence of the adolescents’ behaviours on the ward and their role within the program were obviously seen as less supportive of the adolescents with anorexia. Some though were “fantastic” and were really supportive. On this ward some would “go out of their way to provide optimal care”, then there were “ones that don’t ever really want to look after them, couldn’t care what happens with them and…a lot of people in between the two”. Some nurses admitted that they did not go out of their way to form therapeutic relationships with adolescents with anorexia on this ward.

_I don’t specifically make any great efforts to do anything…I think the more you push a relationship with these adolescents the less likely you are to have a relationship_ (Linda²).

Nurses felt strongly that it was important, for those nurses attempting to form a connection with an adolescent with anorexia, to “treat them a bit human like” and not as though they were just a job. They were not an “object”. They were a “person” and “this place sort of becomes their home for a little while”. Unfortunately the patients in this study felt some nurses did exactly the opposite.

___they may not always like or be able to understand the type of care you are giving or why you are giving it. Why you’re seen to make them sit on their bed for half an hour after a meal, why you’re making them come to the table. Um I think that can be hard to then get a relationship out of that, that’s a good one (laughs)…It can be hard just because of what we have to do_ (Paige²).

Remaining professional was also seen as an important element of positive relationships. Unfortunately some nurses crossed the barrier of professionalism when they were “too friendly with them”. On occasions Thomas² recalled instances when nurses disclosed information to the patients about how particular nurses felt about other nurses on the ward, thereby providing the adolescents with anorexia with ammunition to use against these nurses at a later date. Therefore the final piece of advice from nurses, to others working with adolescents with anorexia, was to avoid talking negatively about other staff with patients with anorexia as it could come back to haunt you later.
In addition the nurses and patients in the study explained the chief qualities needed for an optimal relationship. They felt that patience was a virtue along with mutual respect. Oliver remarked that within a relationship there needed to be a “certain element of respect there” and when manipulation has occurred, the nurse needed to provide “advice in terms of your behaviour wasn’t ideal but I understand why it happened and let’s move together to remedy it”. Both nurses and patients needed to be willing to share information about themselves with each other. Nurses required professionalism and the ability to listen without providing advice. Both parties needed to be understanding of each other and the roles they played within this setting. Lastly, nurses needed to be supportive by validating the adolescent’s feelings and concerns as well as helping them to reach their goals while in hospital.

…need respect for respect (Veronica²).

Incidentally Donna was the only nurse in this study to feel that she had very little trouble with gaining an adolescent’s trust and building a relationship. She believed that adolescents with anorexia on the whole trusted her. She commented that she would be the first person they would ask to go through their belongings if a locker search was required and she felt they trusted her to correctly administer feeds. She reported that she had difficulties gaining the trust of about five percent of patients with anorexia nervosa⁵.

…the trust usually comes automatically with your communication…Trust has never been a big issue for me…Usually they do trust me even when it comes to looking through their draws and looking for sharp objects or anything like that. I am the first person that they want to look through their things instead of another person…Even with the overnight feeds they really…have to have trust in you when you are putting it up, make sure that you are actually putting the right amount in there. If there is no trust, in some cases, I actually show them the bottles and I just pour it in, in front of them…just to build that extra trust… (Donna²).

Alternatively, the rest of the nurses felt that the relationships they formed with adolescents with anorexia were not ‘textbook’ therapeutic relationships but as stated earlier they hoped they possessed some therapeutic value for their patients. The relationships that were established were a by-product of the nursing practices engaged in and expected of nurses as part of their role within ‘The Level System’.

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⁵ My observations, as researcher, corroborated this finding.
Nurses involved in the management of adolescents with anorexia within a behaviour-modification program such as ‘The Level System’ experienced many conflicts, challenges and obstacles when building therapeutic relationships. From this study, it was apparent that the program definitely did not help nurses with building up an authentic ‘therapeutic relationship’ because of its “set structure”. Nurses were the “people that carr[ied] out…the you do’s, you don'ts”. They believed “the situation changes a lot when you have actually got to enforce the rules and not just be a passer-by saying, Hello. How are you doing?”. The doctors did enforce the rules to an extent but nurses were in a position to be this “authority figure” everyday with the adolescents with anorexia. Unfortunately it made it extremely difficult for adolescents to feel comfortable in forming an irrefutable therapeutic relationship with someone in a position of power and control (see Appendix N45 & N46).

"I’m a nurse. I’ve got a job that I need to do and that authority comes with the position… (Zac²).

Most nurses believed that their role within this program was their greatest obstacle to their relationships with adolescents with anorexia and this caused much of their frustration and anguish. Nurses were “expected to do two things that are pretty much diametrically opposed”. As Oliver² described succinctly nurses were supposed to engage with the adolescents on a “personal supportive level” but then as part of their job they were “taking them down [for meals] and leaning on them to cooperate and do what they know is right”. Riley² did not want to be seen by the adolescents as the “evil clinician” or “Nurse Ratched…out of ‘One Flew Over Of The Cuckoo’s Nest’…just coming in, doing my work and going home” yet in essence this was what many of the emotionally burnt-out nurses were doing within ‘The Level System’ program.

"They get to the point where they don’t seem to want to care anymore and…they can act or talk quite rudely to the patient and be quite short tempered with them. Um, whether they notice that themselves…I don’t know. When you do see that, you think to yourself, Well blimey! That’s a pretty awful way to talk to someone and I am sure that the patients are picking that up too (Thomas²).

Even though the majority of nurses felt frustrated with being “the bad guy and the good guy all in one”, in the overall scheme of things, they felt that this was what the adolescent probably needed at this point in time because they were “teetering” on the edge of indecision. Without the set rules and the ‘gentle firmness’ on the part of nurses within this

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program, adolescents with anorexia would probably not eat or gain weight while in hospital and would continue with unhealthy weight loss practices and remain medically unstable. They stressed that they had an obligation and duty as a nurse to make sure that this did not happen.

…you are trying to be the bad guy and the good guy all in one. Um it’s very hard to say to an adolescent um, No you can’t go on ‘gate-pass’ this weekend, even though your best friend is having a party because the doctors have said, No or No your visiting hours are over. Your family will have to go home and then for the next minute to turn around and say, So how are you feeling you are going on the program? and expect them to want to talk to you about it. Um if that was me I would want to say, Well how do you think I feel? You are taking all my family away you know. Ah it is almost a conflict of interest I think. Mmmm although I suppose…if you are really good at it (laughs) um there are obviously ways… (Paige²).

For me I don’t think it is very easy because…you want to be their friend but at the same time you want to be very firm with them. You can’t do both…you know. It is very hard… (Mandy²).

5.4 ON PAROLE OR RELEASE

5.4.1 ‘DISCHARGE, RELAPSE AND RECOVERY’

The decision was made for an adolescent to be discharged from the ward when there was evidence of a change in psychological as well as physical health. The adolescent with anorexia realised that in order to go home and be ‘released’ they needed to be compliant with following the program and they needed to reach their goal weight. Recovery was described eloquently by Danielle¹ as “getting back into a normal life, without your eating disorder”. Danielle¹ described the journey as similar to traveling “quite a long road…which you have ups and downs before you actually reach the end of the road where you’re completely recovered”. There were many “hurdles” to conquer along the way. Many of the adolescents saw recovery as not just “putting on the weight” but saw it as a realisation that “who you are isn’t [dependent on] how much you weigh”. Zoe¹ described how an adolescent with anorexia was never “going to be 100%...better” and like “an alcoholic” could “get in a spiral again”. They believed that it took a long time to get better and not “feel guilty”. One hospital trip may not be enough. While for Sara¹, “recovery” meant being “normal” again.
The nurses had similar views on what recovery or being on the road to recovery meant to them. “At face value it means being discharged from hospital” and an “ultimate recovery” would be “no anorexic thoughts whatsoever”. They saw it as “compliance with the program” and a demonstration of “more…normal eating habits”. There was a definite change in “mind-set” and attitude towards food and life in general and an increase in their self-esteem. They were not so focused on the calories and how much exercise they needed to do to counteract the food they had eaten. They had “plans for the future”. Gabrielle² agreed with some of the adolescents and believed that it was a “return to as much of a normal life as possible” without the “fear” but believed that they never “get over anorexia”. So she believed they would always be “a recovering anorexic”. The “recovering anorexic” was able to cope within society.

…I don’t know if I would say recovery is [that they] ever get better or get over anorexia. I think you are always a recovering anorexic. I don’t think you are ever cured totally because I would say that there is always something that can happen that is going to un unstabilise you again, to push you back into that same pattern that you were in before. So…recovery to me is someone who is definitely not hospitalised that is actually…having what I would say would be normal, as much as normal could be, for an adolescent lifestyle (Gabrielle²).

…I say recovery is that they feel that they have…a bit more of a ‘voice’ and a bit more control in the choices they can make…above and beyond what they have on their dinner plate (Oliver²).

Discharge from the hospital program for the adolescent with anorexia can be seen as being similar to ‘release’ from prison for the prison inmate who has shown that he has been ‘rehabilitated’ or has served his ‘sentence’. The inmate may be someone that has remained on their best behaviour while in the prison system; not being involved in fights or disruptions. They would more than likely have an early parole hearing because of their overtly ‘clean slate’ while in prison.

However, once an adolescent had been discharged and was believed to be on track towards a healthier lifestyle they were expected to come in for weekly “check-ups” with the doctors in the Adolescent Medicine Unit (AMU). The check-ups were designed to monitor whether the adolescent was coping out in society with maintaining their weight and maintaining a healthy social life. Again, this can be considered comparable to the recently ‘paroled’ inmate, who may have to attend regular visits to the authorities, such as the
police or parole officers, who monitor their progress. Walsh (2006, p. 114) reported that “prisoners may be monitored in a number of ways while they progress to liberty; however, best practice suggests that they should be personally supervised by a community corrections officer, who also provides them with emotional and practical support”. Parole violations may necessitate re-entry to prison while for the adolescent with anorexia, an inability to maintain weight and progress on the ‘outside’ may necessitate re-admission.

*I don’t see any of the kids ever get cured from it. It is always something that they carry with them (Zac²).*

Unfortunately with some prison inmates the ‘institutionalisation’ process makes it very difficult for them to feel comfortable back in society. Many re-offend as a result of inadequately coping out in society. They may have been unable to find work, accommodation or the support they needed to re-start their lives and thus resort to old habits (Baldry, McDonnell, Maplestone & Peeters, 2006; Cameron, 2001; Roberts & Hough, 2005). Not unlike the high recidivism rates within Australian prison systems (Baldry et al., 2006; Cameron, 2001; Dubeki, 2003; Walsh, 2006), recidivism rates or relapse rates are also high among adolescents with anorexia (Russell et al., 1998). Some adolescents also felt they too were inadequately equipped with the skills to cope at home.

Many adolescents with anorexia were re-admitted to this ward numerous times. Zac² reported that for him recovery was “*the length of time between admissions or if they ever come back here again***. Zac² also added that “*sometimes they do fear going back into real society***”. Mandy² also remarked “*here they feel safe***” and that was why she found that some of the adolescents “*played up***” prior to discharge. Danielle¹, a patient, agreed and commented “*some girls don’t want to go home. They feel that they’re not ready***”.

*…some of them get used to being in here and they find a buffer and a comfort zone… (Riley²).*

*…only that they do end up coming back, usually (Zac²).*

*It’s difficult when you see them come in more than once, more than twice, and they say, This is it! I am never coming back and six months later they are back in, looking unwell (Thomas²).*

*Chapter Five: Results*
The nurses believed they would not always “sustain the weight gain when they get home”. The weight loss would normally be picked up at a clinic appointment and therefore the adolescent would be re-admitted that same day.

…every time they come back on a Friday afternoon, you know they have just gone for their check up at clinic and the doctors have said, You have lost some weight. You are going back into hospital and…of course they are in tears because they feel that they have taken a backward step. So if it is a subsequent admission then they really feel like they have failed in what they’ve achieved…It’s a long process. I mean the first time they’re here, they might be here for 3 weeks, 4 weeks, 5 weeks, 6 weeks whatever…and I am sure they must be warned by the doctor that there is every chance they may come back. But I am sure that when they leave they are pretty confident that they are not coming back… (Oliver²).

For Riley² it was a bad omen to think about how someone was going at home because they usually returned as an inpatient.

…you might not see them for two or three months…unless they come in for a clinic or something and you go, I wonder how they’re going? Usually that’s the kiss of death and they’ll usually come in as an inpatient… (Riley²).

Nonetheless, for many of the adolescents having a supportive relationship was imperative for their eventual healing or was the impetus for their recovery. This person needed to be someone, according to Melinda¹, who “listens to you and…takes everything that you have to say”. Some described how nurses, doctors and psychologists were somewhat helpful in encouraging them while they were on the program. Others described how family, the school or Church community, friends from school and their religion assisted them when they were discharged from the program.

The adolescents explained:

And a person that you can easily connect with. Even if it’s just a certain doctor or nurse or even one person from your family, like an aunty, that you can talk to, that you can express everything to…that you feel comfortable with (Danielle¹).

Um I suppose my close friends did. Holly for one she never mentioned it [the anorexia] really. She just treated me like I was a normal kid…She knew about it but um…she wouldn’t um try and force me to eat and everything. She just treated me normally (Josephine¹).
…my friends didn’t even mention it ever that I had an eating disorder. We didn’t even talk about it. But just being with them made me a 100% more normal… (Megan¹).

The adolescents also acknowledged the support they received from each other and this was believed to be both beneficial to the recovery process and assisted with their compliance with the program. Megan¹ felt that adolescents progressing together along the program at the same rate helped because each provided the other with support and encouragement along the way (See Appendix N47). For Isabel¹ it was great to know that the other adolescents with anorexia understood where she was coming from. They were an outlet for her to express her feelings and debrief. Similarly, in Wilson’s (2003, p. 419) study of young black men in prison, he described how “these young black men would look to each other as sources of comfort and support at times of crisis and conflict”.

We are like the main place that we get support. If you are… friends with all the other girls…you get support from [each other] (Amber¹).

For Amber¹ her first night on the ward was made bearable by the support and comfort given by the other adolescents with anorexia.

Amber¹ explained:

… on my first night…I didn’t eat all my dinner because I wasn’t expecting a meal that big…I had to get a bolus…the nurse is like, I’m sorry but I’ll have to give you a bolus and I was like, What’s that?…I was really scared but the other girls were really nice about it. They were like, Oh don’t worry, they just put the liquid down your tube and it’ll be fine…They were like nice…”.

The adolescents explained the development of comradeship between patients with anorexia on the ward and how for some these supportive friendships continued on the ‘outside’:

…plus I will have all the girls that I met in here which I will be able to talk to which is really good because even if people try to understand they can never like exactly know [what it’s like to have anorexia] so it will be really good. It’s been really good having…other people with the same thing [condition together] and knowing how you feel and stuff and being able to like share um like what we have been through and stuff (Isabel¹).
…we go through the same things and you become friendly with them [other adolescents with anorexia]…You just kind of develop strong friendships with them and you’re able to comfort them…You have that sort of closeness with them and that kind of bond…You can talk to them and they can talk to you about their problems…You kind of let it all out and express it to each other (Danielle¹).

…sometimes you make really strong friendships [with other adolescents with anorexia]…even though everybody’s experience is different…you have similar things…that occur…throughout your illness (Zoe¹).

5.5 REFORMING THE SYSTEM

5.5.1 ‘FINAL ADVICE FROM INMATES’

There was a plethora of advice given by the adolescents with anorexia in their interviews for ways that nursing staff, doctors and the overall program could be changed for the better. The main suggestions they provided during their interviews are summarised for ease below under the headings: nursing staff, doctors, program and recovery.

NURSING STAFF

The majority of adolescents believed that approximately seventy-five percent of nurses on the ward were “nice”. Yet even these seventy-five percent of nurses could still improve their approach to and management of patients with an eating disorder. Approximately twenty-five percent of nurses were described by the adolescents by terms such as “too strict”, “too pushy”, “overly suspicious”, “unfriendly” or “mean”. Generally the adolescents wanted nurses to greet them and smile at them and acknowledge them even if they were not eating. They wanted to feel like “a good cause”. They felt that if the nurse was having a bad day they should not take it out on them because they were overly sensitive to these issues (see Appendix N48 & N49). Their relationship with nurses was described by Megan¹ as “pretty close” with some while with others “it was never going to be close”. Male patients found it easier to bond with a male nurse and vice-versa for female patients.

…like most of the time everybody was really nice but then when I started like refusing boluses and pulling the tube out, it was sort of more like no one really wanted to be nice anymore and I think…just because you can’t
Unfortunately, many of the adolescents had very little trust in nurses and preferred to confide in parents or someone else rather than a nurse in many instances. Cameron¹ listed nurses as his third port of call after his mother and the registrar (doctor). For Sara¹ her first port of call was another patient with anorexia and nurses did not even make her list. Zoe¹ suggested nurses having a set of “confidentiality rules” stating “when you can talk to them and when they'll tell the doctors something and when they won't. Because often you don't want to tell them because you think it will instantly be written in the notes”. Zoe¹ added without a set of confidentiality rules, “if [adolescents] did want to talk about [things], like I am finding it really tough, then [they] wouldn't do it when a nurse was there necessarily”.

Some adolescents felt that nurses spent enough time with them while others would appreciate more time, including nurses visiting them in their room for a chat or to catch up with them. Danielle¹ suggested that there should be “a session that all the nurses attend and they like talk about ways to handle Eating Disorder Patients…in ways that they can be supportive and fair. Like…being cruel to be kind. They have their set rules that they can't bend on but again take a better approach to the way they do it and do it nicely”. Cameron¹ said sometimes nurses were “always in your face”. He commented, “…instead of just going…I am doing your blood pressure now...[saying instead]...Is it a good time for me to do your blood pressure?...”.

There was consensus among the adolescents that nurses needed to be familiar and up to date with ‘The Level System’ program guidelines, if they were looking after the adolescents with anorexia. The adolescents felt that non-regular nursing staff such as ‘pool staff’ [casual nurses] and ‘agency staff’ were not well equipped to undertake this job. Danielle¹ described, “we feel that we can get away with more with them and that’s kind of a downside for our health and it kind of sets us back”. They felt that these non-regular nurses, “they don’t know what they are doing and they ask you…questions which are really quite invasive but they don’t think they are. They are like, Oh so why did you stop eating?”. They believed that these nurses felt that they could cure them in one shift. Megan¹ called them “one shift cures” nurses. The adolescents preferred to be looked after by staff that were familiar with the program and rules and enjoyed looking after patients
with an eating disorder. They had greater trust in knowing that these nurses knew what they were doing.

...like one ‘poolie nurse’ brought down a stop watch...And she is like, Okay you have got half an hour! Let’s go!...Everyone was sort of like, Okay! [shocked tone of voice] (Zoe¹).

Josephine¹ described how some nurses and other patients on the ward, she felt, had an aversion towards patients with an eating disorder. She felt that these particular people (nurses) should care for the adolescents with anorexia or share a room with them (other patients) to learn more about them and become better acquainted and less offended. She described how some patients that did not have an eating disorder would be “teasing [them] or trying to help [playing God]” by giving their own advice and these people often made things worse.

...there is a noticeable fact that there is tension between the anorexics and the nurses and other patients because in a way they are not really sick. Perhaps those that are offended by anorexics must be put in the same bedrooms or made to nurse these patients in order for them to intermingle, sort problems out and mend the problems (Josephine¹).

On arrival to the ward, the adolescents felt that it may reduce a new patient’s anxiety and stress if a nurse sat down and explained the main elements of the program to them in uncomplicated terms. Zoe¹ suggested that nurses should explain to the adolescent that they are not going to put on too much weight, even though it may seem a lot to them, but enough to be a minimum healthy weight on the healthy weight chart. She felt that explaining the program in these terms made it a little easier for her. They even suggested the formulation of a simple ‘user-friendly’ reference guide that describes the program and its rationales for the adolescents on arrival and thereby assists them with their adjustment into their ‘new surroundings’ and its routine. For those patients placed on ‘bed rest’ they should have activities available for them to do to keep them occupied. Their fears should be allayed that it will not be long before they are off ‘bed rest’.

For those patients that require a nasogastric tube to be inserted the adolescents suggested that nurses should always provide a thorough explanation of the procedure first and acknowledge in their explanation that it may be uncomfortable and sore for a little while. Zoe¹ believed it felt like “when you get dunked in the water and you get that burning
feeling”. Cameron¹ suggested that a patient who has a tube in should explain what it is like having one put down and could be there for moral support while a new patient is having theirs put in.

Because a nurse saying it…it is good that they do say that, It’s not that bad…But it’s just not the same as…someone your own age, who has one in or has had one in, so… (Cameron¹).

There was also consensus among patients that staff should be encouraging and supportive at the meal table. Zoe¹ “never really felt” that she was supported by doctors or nurses when she was on the program. Away from the table they wanted nurses to be someone who listened to them, comforted them, gave them advice, was a friend, did not judge, stereotype or label them because of their diagnosis and treated them as a “normal” person. They did not want to hear nurses discussing their peers negatively at the front desk as this diminished trust within the relationship. They also wanted nurses to be upfront and honest with them about what they were doing. Sometimes they felt that they were not “openly honest” about things. They wanted nurses to talk about things other than the program and hospital. They all reiterated that trust with a nurse takes a long, long time to achieve but did want there to be greater trust within the nurse-patient relationship. They wanted nurses to be willing to give them a “clean slate” each day. They felt that even if they were correcting their eating habits they should, “say it nicely, kind of…have unconditional love”. Chloe¹ agreed, “some nurses can just…say it nicely but other nurses…they threaten you and stuff”.

The adolescents insisted that nurses making personal comments were unhelpful such as “just doing it for attention”. Zoe¹ believed nurses should not surmise why a person has anorexia as these comments made patients feel bad about their condition. They felt that they should not pry or assume but ask them nicely and politely, “What makes you want to lose weight so much?”. Isabel¹ agreed, she thought it was helpful when nurses “ask[ed] questions about ‘my story’”. Patients wanted nurses to be tolerant and to value them and accept that they do need to be in hospital and they are not taking up a bed for the fun of it. Zoe¹’s advice for nurses trying to establish a relationship is: “I think just pointing out to the patient, I can’t change what I have to do and then always try and think, Well how can I do what I have to do in the least destructive way? I think that is the only thing you can really do”. She also felt that building trust came from nurses acknowledging that it is “hard” for

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the adolescent and that they are not happy and they are not doing this because they want to. Nurses needed to understand that they were also frustrated with themselves and their actions.

...getting frustrated at me when I couldn’t stop exercising…I suppose that it is natural to get frustrated but…it frustrated me as well (Josephine¹).

Overall, the patients wanted nurses to be fair in their treatment of all patients with an eating disorder. They did not want nor expect too much flexibility with the program rules as this led to inconsistency. However, they felt that some flexibility was appropriate in certain circumstances. These circumstances included the kitchen delivering the incorrect meal and if a patient truly disliked what had been sent and wanted to swap one item for an equivalent item that was available on the ward. All in all though, they felt that the ‘no swapping rule’ was beneficial as it prevented ‘cheating’ occurring during mealtimes. The adolescents’ realised that in their present state “they don’t eat properly” and “they don’t know…what to eat…”. The adolescents also felt that nurses should be a little flexible with the start time for meals if there was an event on within the hospital. The half an hour time limit should start once the last person has finished toasting or heating up their meal. Zoe¹ disclosed that there was a “hierarchy” of sorts in terms of where people sat at the table and in what order people heated their food. This has parallels to the prison system where, according to Easteal (2001), an “informal hierarchical structure” may exist where an inmate may need to “fight in order to gain respect and her own place in the social order” (p. 98). Zoe¹ believed nurses should sit next to a different patient each mealtime as this would make eating more comfortable for everyone at the table. They even enjoyed opportunities to eat outside instead of in the kitchen all the time.

...at the time I thought that was really bad [no swapping rule] but it sort of makes sense because you always swap for less…So from the doctors’ point of view um it shouldn’t be allowed because it stops [you] getting better, putting on weight (Josephine¹).

All of the patients were resolute that nurses should engage in ‘normal’ conversation, be social and avoid staring at the meal table. Sara¹ advised that it was imperative to avoid “stony silence”. Conversation should revolve around personal interests, home life or school life as “it’s not…just about the eating”. Danielle¹ said that talking was a great distraction because it helped her and others not think about what they were actually doing.
Chloe¹ agreed, “it’s good when...the nurses talk to you and stuff and you can have a conversation while you are eating...It’s not nice if you can’t and...no-one’s talking and they are just staring at you eating”. Danielle¹, and many other adolescents, also added that they disliked nurses discussing their own diets, food or the program. Danielle¹ felt it was better to “steer the conversation away from that” as this reduced the adolescents’ own anxieties and worries. Finally, most adolescents did not want to receive the “third degree” about why they did not eat something. They wanted to be treated as an “equal” and be respected by the nurse whether or not they ate.

The adolescents felt that an inconspicuous check of what had been eaten during the meal or at the end of the meal was the best way to monitor food intake. Most of the adolescents appreciated nurses eating something with them even if it was just a snack. This assisted in making the mealtimes more “casual”. Except Megan¹ who felt that a nurse eating with them would not make the situation any less uncomfortable as she felt that patients would compare what they were eating to what the nurse was eating. For Megan¹ seeing other patients (eating or playing pool) in the kitchen area during a mealtime made the environment seem more ‘normal’ for her. For Zoe¹, when some nurses allowed other patients, like patients with cystic fibrosis, to eat their meals at the same table, it was seen as positive for her. She felt that seeing the huge, ‘scary’ meals of chips and crumbed chicken that they were sent up was a good influence and made them feel that their own meals were not “so big” or “scary”.

…it’s nice having people sitting around you that aren’t worried about what they are eating...(Zoe¹).

In regards to setting up nasogastric feeds for overnight administration the adolescents would like to be given the option to watch nurses measuring out the feeds. This they felt would gradually increase their trust in the nurse and reduce their anxieties, for a patient who was especially worried or untrusting that nurses were giving them more than what was required. The same was said about bolus feeds in that they preferred nurses who showed them the volume amounts on the syringe before they administered the bolus feeds through their nasogastric tube.
It was also considered better to approach an adolescent away from the other patients if they are suspected of suspicious behaviour (ie. exercising or vomiting or concealing food) rather than confronting them in front of other patients. It was also best to give the adolescent the ‘benefit of the doubt’ the first time and not to make false accusations but let them know that these things can happen. If the behaviour continues and the nurse needs to write their suspicions in the patient’s notes, Zoe¹ felt that they should approach the adolescent, let them know and talk about it. She commented they should say something like, “Look I feel you’re running in the bathroom. I feel that I have to put that in the notes and then just talk about that. Rather than just writing it down and the doctors coming in and saying, Down to Level Two”. She added, that a junior nurse should always consult with a more senior nurse if they do not know how to handle a situation and say to them, “Oh look should we apprehend them or do we just…you know…what’s the deal here?”. Lastly, Cameron¹ insisted nurses should not open the bathroom door but wait till the adolescent comes out and then check their pulse if they are concerned about exercising.

DOCTORS

Generally the adolescents felt that there was no real relationship between adolescents with anorexia and doctors because “no [adolescent] really liked them” as they were considered the bearers of bad tidings. The relationship was definitely one of authority and considered a professional “doctor-patient” relationship or “an us and them type [of relationship]”. They did however want greater negotiation to occur between themselves and the doctors without “compromising on health care but compromising on maybe exactly how things happen, the order things happen”. They wanted the doctors to allow them greater decision-making power while taking into account their age, level of maturity, thinking processes and medical stability. They wanted their ‘voice’ to be heard and acknowledged yet understood that sometimes this would be difficult because “anorexia takes over your mind”.

*I think doctors and anorexics just don’t mix… (Josephine¹).*

*…they’re a bit heartless… (Amber¹).*
The adolescents explained that they did not see the “two main doctors” often apart from twice a week on meeting days. Some of the adolescents described how they would sometimes talk together negatively about the doctors because they did not like the decisions they made. With the majority of patients being female they described the male doctors as not being as empathetic or supportive. Danielle¹ exclaimed, “say if you’re upset, they say, I know how you feel…and you kind of think well, You don’t know how I feel…It kind of feels like they’re not really supporting you. So if you’re upset they might just walk away and leave you or…they might just leave it up to the nurse to support you because that’s basically their job…The doctors are just there to tell you the news”. Megan¹ agreed she felt doctors had this attitude of, “this is it, gotta go, bye” (see Appendix N50 & N51).

Most of the adolescents wanted to see the doctors after every meeting even if no changes were taking place that week. They appreciated being given the opportunity twice a week to see them and get a personal update as it made them feel like “they hadn’t forgotten about you”. Some even suggested that on meeting days the doctors should come and talk to them prior to the meeting so the adolescent has the opportunity to make requests and voice concerns before decisions are made (see Appendix N52).

They felt that the doctor’s communication skills were good. However Josephine¹ and Zoe¹ would have liked them getting their consent rather than their mother’s before staff went through their belongings. Zoe¹ also added that it would be good to have clearer communication from doctors in the notes especially regarding ‘gate-passes’ (the type of ‘gate-pass’ and the length of time allowed out). The adolescents also suggested that it would be good if the doctors could organise one day a week where they catch up with family (in person or over the phone) to provide them with an update regarding their progress in the program. It was suggested that doctors avoid discussing a patient’s progress while they were on their beds in the four-bedded room. Even though the curtains were closed other patients with an eating disorder were able to hear confidential information and this made patient’s reluctant to express their own self-concerns and their issues. They also suggested that the number of doctors seeing them after a meeting should be kept to a minimum (1 or 2) as most disliked instances when groups of medical students crowded around their bed (see Appendix N53). Megan¹ explained for her, “it was
really scary, intimidating...having a team of students around...They just crowd around your bed and you can be like, Ok there is no escape!"

**PROGRAM**

Most of the adolescents were generally happy with the structure of ‘The Level System’ program that was in place. They liked that their days were structured with things to do and they were kept occupied. Some liked the levels because it encouraged them to do better in order to receive privileges. They believed that the structure ensured fair treatment and they knew what to expect if they were moved up or down a level (see Appendix N54 & N55). However, all nurses needed to be consistent with following the program. So Zoe¹ gave an example that with a full day ‘gate-pass’ patients needed to leave after breakfast and return before supper, however some nurses would let some patients leave before breakfast making it unfair for other patients on the ward. Similarly, if a patient on ‘bed rest’ was seen to be non-compliant by staff and other patients, yet there were no consequences for this patient, then the adolescents felt that this was also unfair treatment.

However, many felt that “the program is mainly just getting you in here and putting on the weight and sending you home”.

Danielle¹ explained:

_I don't like the fact that the Program is mainly just getting you in here and putting on the weight and sending you home. I reckon they should, at a stage when the patient is ready, do some more psychological side and have a psychologist and do sessions with the patient one-on-one. They might have sheets and stuff to do and self-talk kind of things. Just because it’s a bit hard when the patient still feels uncomfortable with eating, even if she's going home, because basically you have no choice in here and you just need that kind of help to think, that this is what needs to be done and like it's a normal thing, everyone eats....Just to make you feel more at ease and comfortable with eating (Danielle¹)._

The adolescents believed that more psychological therapy on a one-to-one basis was needed for all the adolescents with anorexia and not just those exhibiting a co-morbidity like obsessive-compulsive disorder. Many adolescents insisted that while they were on the program they did not receive any formal psychological therapy and this they felt was a
drawback for when they were discharged. They felt they had no choice but to eat while they were on the program but it was a different story when they got home. Many still felt uncomfortable about eating and they felt that they were not equipped with adequate coping skills. Without the appropriate supports in place at home, some adolescents resorted to their ‘old habits’ (see Appendix N56).

…but I thought sometimes there is not enough psychological help for us…Some girls probably don’t want it but I think it should always be offered and often it’s not unless you do exhibit…OCD [obsessive compulsive disorder] or something like that (Zoe¹).

I think they should look at the psychological part of getting better. Not just getting you to your minimum healthy weight and then off you go (Melinda¹).

Josephine¹ however, despised ‘The Level System’ of rewards and punishments. She preferred an ‘old system’ where adolescents were placed on ‘bed rest’ initially and then slowly worked their way up in a “step by step” fashion. This system did not have specific restrictions placed on visiting and the amount of weight needed per week. With ‘The Level System’ both Josephine¹ and Zoe¹ felt it was demoralising because they never reached the top level.

…‘The Level System’ does not work. It is emotionally detrimental and does not encourage I found (Josephine¹).

…some girls…when they first come in, Oh yeah I will get up to Level Five and then…you never get there. That’s a bit disgruntling I think, yeah (Zoe¹).

Many of the adolescents felt that the idea of overnight nasogastric feeds on arrival to the ward was an excellent idea as a way to “boost” weight and achieve medical stability “but if you didn’t have to have it, you definitely would not want it”. The adolescents believed that the initial overnight feeds allowed their stomachs to become accustomed to food again and it was good to have them overnight as “it’s not noticeable when you are sleeping”. However, once medically stable, most advised and insisted that nasogastric feeding (i.e boluses and/or overnight feeding) should be avoided at all costs. They felt that “it’s not normal to have something pushed down a tube” and it was better that the adolescent always be given the option to eat and drink normally first. The bolus feeds had advantages only when a person “felt really sick or really full” then bolus feeds became “easier” and “less stressful”. Josephine¹ commented nasogastric feeding is both positive

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and negative in that it was easier “…because you are not doing it to yourself. You are not making yourself put on weight. It is forced. But…it is stressful in another way because you can’t stop it…”.” Josephine felt that the ‘bolus-exchange’ meal plan was “unrewarding” because if you ate most of an item on the meal plan you still had to have the “full bolus” for the item because you did not eat it all. Zoe believed bolus feeds were “an easy way out” for the adolescents with anorexia because once they worked out the number of calories in the food and found that the bolus equivalent was less they would opt for the bolus. She said “…what’s meant to be a good system and meant to encourage you to eat turns out not to be that good”. By comparison they liked the idea of having individual meal plans and that the size of meal plans increased slowly over time.

All the adolescents were happy with the idea of ‘gate-passes’. Megan believed ‘gate-passes’ were good in that you “got to bond with your parents more. I suppose because, before you came in, you generally would always be fighting”. It was an opportunity to “test out your eating”. If you did not succeed at home, it did not matter because just being able to go home made Megan “feel…a bit more normal”. For Zoe, it made going home less of a shock. For many adolescents it was their slice of “freedom” from the hospital. For Melinda, it was a good “reward” for “doing the right thing”. Amber felt that internal ‘gate-passes’ were a waste of time because “if they don’t want you out of the hospital they shouldn’t really give you a ‘gate-pass’”.

…it is a good idea having ‘gate-passes’ because sometimes it kind of gives you something to like look forward to um and kind of um to work for…which…is pretty positive…It is…good to have a break…from the hospital and…to get out of the ward… (Isabel).

Most, as described earlier, were not pleased that friends could not visit them while they were on the program and could see no harm in letting one or two friends come to see them once a week. This aspect of the program was disappointing for them and they would like to see the introduction of friends into the program in the near future. If friends could visit it would be less of a shock for all when they returned to school.

…looking at other patients and their friends coming in, it makes them feel so much better and it sort of makes you feel unfair that your friends can’t come in (Zoe).
...it takes your mind off things heaps and...it can cheer you up and...it is good to know what is happening outside the hospital...It kind of...keeps you...in contact...Even if I talk to my friends on the phone and stuff, it would still be heaps better to see them um more often so when you get out it is not like...I missed so much... (Isabel¹).

School, group and physiotherapy were all generally seen in a positive light. Josephine¹ mentioned that when she was a patient they did journal writing every morning at school and she now finds that interesting to look back on. She also suggested that the adolescents should be taught about a few different conditions and illnesses including anorexia nervosa at school. Unfortunately for Amber¹ she recalled a negative experience with a teacher. The teacher assumed that she did not want to get her hands dirty while making short bread biscuits because she was afraid of absorbing calories from the butter. Amber¹ felt that the teacher had unfairly labelled her because of her condition in front of the other students (see Appendix N57).

As mentioned earlier, many of the adolescents believed the group activities were beneficial but should not be compulsory on meeting days. The adolescents felt that sometimes they were too upset to attend. They spent the whole time crying while other patients watched them. They felt they should be given the option of staying on the ward and writing in their diaries or having some “time out” to be by themselves. Danielle¹ wanted attendance at group to be optional for those adolescents who have major exams like the School Certificate and Higher School Certificate to study for and she felt that these adolescents should be able to use their ‘group time’ as ‘study time’ on the ward (see Appendix N58, N59, N60).

Group should not be forced. However diary entries every day would be better. They are great to look back on. Group is therapeutic only if the person is in the mood to do so. To be soothed (Josephine¹).

All the adolescents became accustomed to weigh days and the process involved with voiding in a pan or bottle and wearing a gown. It did not matter whether a male or female staff member looked after them on a weigh day. They thought perhaps nurses could wake them a little later but not too late as for other patients to see. Megan¹ suggested having random weigh days instead of set weigh days as a way to reduce the stress accompanied with this day (see Appendix N61). While Amber¹ suggested reducing weigh day to once a week instead of twice a week to reduce the pressure and stress of a weigh day.

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Josephine¹ and Cameron¹ suggested patients having the choice of whether they wanted to see their weight or not. Most adolescents were nervous on weigh day and some would attempt to manipulate their weight. There was also competition among the girls on weigh day especially if an adolescent did not gain as much weight but were then seen to have been given a “better reward” (see Appendix N62). Josephine¹ agreed sometimes some girls would be “playing little mind games” with one another and this was “awful” while other patients were supportive. Zoe¹ concurred that the support among adolescents with anorexia was sometimes not so positive when competition was rife on the ward and each would be thinking of the other, “Oh my God! Am I a better anorexic than her? Am I thinner than her?”.

As stated earlier, Josephine¹ felt that the visiting restrictions gave the adolescents “mixed messages about going home”. Josephine¹ felt that she really needed the support of her parents when she was an inpatient and was denied this support because they were limited by time frames due to the visiting restrictions of the program. Most of the other adolescents felt the restrictions were ‘okay’ except if someone was on ‘bed rest’ then they felt their parents should be allowed to stay longer if they liked. Cameron¹ additionally believed for those on Level One-‘bed rest’ they should be allowed to sit outside in the fresh air for half an hour each day even if they are supervised by a nurse during this time.

Interestingly many of the adolescents described rarely seeing the dieticians and suggested there should be greater contact throughout their admission until discharge (see Appendix N63). They described their relationship with dieticians as “fake”. Each did not know the other well and sometimes the adolescents would be nice to them in the hope of receiving a better meal plan. Chloe¹ and Amber¹ reported they had not seen a dietician to date (see Appendix N64). Melinda¹, on the other hand, saw three different dieticians and each kept changing the rules (see Appendix N65). Melinda¹ suggested that the meal plan should also “allow us to drink water and have salt on the food”. She mentioned if limits were set on the amount allowed each day this would prevent water-loading.

The most frequently cited advice from the adolescents was that nursing staff needed to be consistent and fair with following the rules of the program. There needed to be a balance between being strict (following the rules) and being fair. Josephine¹ suggested being “firm but negotiable” so that connection can still form between the nurse and patient. Zoe¹
remarked when she was on the program she disliked that some nurses would check certain patient’s containers after meals but in retrospect she thought that all nurses should check everyone’s containers, thereby making it fair for everyone.

...because then things work and then more negotiation can come which is important because there can be a lot of tension which makes nothing work... (Josephine¹).

The adolescents thought that an outing to have lunch out or see a movie or go shopping might be an idea while they are on the program as a means to release anxieties for those who have been in hospital for so long. It would also be an exercise in learning to eat “socially” with other people around. In hospital the adolescents are only eating with the nurse. Zoe¹ felt it would make them “appreciate what [they] could do almost everyday if [they] weren’t in hospital”. Isabel¹ suggested the introduction, into the program, of ‘going for a short walk’ with a nurse, to have a little time off the ward. While Melinda¹ suggested having some time outside in the courtyard. They also thought that having a “making your lunch class so you learn to do it right and not cheat at all” might also be a good thing to try on the ward. A reward for reaching a certain level in the program may be to choose something different to eat from an “extra’s list”, thereby increasing the adolescent’s choice of food. Zoe¹ suggested allowing the adolescent to choose steamed chicken instead of crumbed chicken as an option, which was to her far less scary. Megan¹ thought food challenges were a good idea during admission. She had seen this done at another facility. This meant challenging the adolescents to do something ‘scary’ when they got to a higher level. For example, they might be asked to try a piece of chocolate. If they cannot manage to ‘meet the challenge’ the adolescent receives a bolus equivalent to the chocolate everyone else tried. However, the idea is to encourage the person to try it and Megan¹ reported the adolescents normally talked about the challenge later. It made it easier for the adolescents to feel comfortable with trying things, like chocolate, when they went home (see Appendix N66).

Starting competitions like nurses versus patients at pool or board games may help build positive relationships on the ward. Some felt that formal ‘bed rest’ was not necessary for all patients with anorexia nervosa. Josephine¹ felt adolescents could be playing a game of pool instead of sitting down for half an hour in the lounge area. They just needed to be out of their room and away from their bathroom for this period of time as this was a “stressful
environment”. Nurses she felt could still keep an eye on them in the play room and other patients would also be in the play room. Zoe¹, on the other hand, suggested allowing the adolescents to watch television in the play room or allowing them to do sit down past-times in the playroom for half an hour (board game or puzzles), might be a better option than sitting in the Moroccan Area for ‘bed rest’.

…it is not like you are going to lose a bit of weight anyway just by walking around. So as long as they stay out of their rooms but go and be in the play room…I don’t think it [‘bed rest’] is necessary (Josephine¹).

RECOVERY

Most adolescents remarked that for recovery to occur there needed to be a smooth transition from the hospital to the home setting. Support systems and supportive family and friends were most commonly cited as aiding their recovery. Many who had seen Level Five wanted Level Five of the system to return. They believed that Level Five was an opportunity for the adolescents to take on the responsibility for eating. Josephine¹ mentioned Level Five was good because “it is up to them and if they go backwards then they see the nurse [so] it is sort of a penalty”. This allowed the adolescent to see how well they can handle things for themselves in terms of eating while still having support available. Level Five would distinguish those who were not ready for discharge from those who were ready. Overnight ‘gate-passes’ on the weekends were also seen positively as beneficial for the transition back to the home setting. It gave the adolescents the opportunity to test out their skills at home around the family dinner table. The regular hospital check-ups following discharge were also seen as positive however they needed to be tapered according to the individual patient’s progress and coping skills.

None of the adolescents really felt that nurses “fully understood” what they were going through. Megan¹ reported that nurses need to understand “that we can’t control it…If you are going to yell at us and tell us to eat something it is not going to make a difference…I mean…if we are going to eat, we are going to eat it….If we are not going to eat then there is no way you can really yell at us and persuade us to do it. It is just not going to happen and that it takes time. I mean, there is…no quick…cure. It is going to take time and [adolescents with anorexia] are going to fail at first definitely. Everyone always fails but
then after a while…it is going to be [their] own decision. No one is really going to cure [them]”.

…it’s not us that is controlling it (Chloe¹).

…just more tolerant and just see it as another disease because you can’t really understand… (Josephine¹).

…we can’t help it…(Josephine¹).

…it is my head…I can’t really help what I am doing or I don’t want to do…It’s like I can’t really help it. It is my head (Isabel¹).

Education for parents was also seen as deficient on discharge from the program. Many adolescents wanted their parents to understand what their role would be on discharge. They believed parents needed greater support and education in this respect. Some wanted their parents to see the serving sizes and types of meals that they were given in hospital so that they could now metaphorically take on the role of nurse in deciding what would be an appropriate meal. Some liked the idea of continuing with a similar meal plan when they left hospital until they felt comfortable with eating ‘normally’ again. Most did not see it as necessary for parents to be as strict as nurses needed to be with following the program and its specific rules for mealtimes but felt some ground rules needed to be negotiated at the start to reduce the fighting at home. They felt that if parents were “overly strict” they would “shut [themselves] off” and it would not be long before another admission would be necessary.

…it if they [parents] don’t understand what is happening, then it is not going to work. If they are kind of really, really strict, like I said in the hospital, if they are really, really strict then you are going to shut yourself off and if they’re the only one you are going to see every day then you are going to slip straight back down and end up being in here again. So they maybe need more education and more support from doctors or psychologists and stuff too (Megan¹).

…you sort of need to transfer like care over from the nurses to your family and sometimes the family doesn’t know what to do. So I think often you need to sit down when you get home and just say, What rules are we going to have? and you know, How are we going to do this together? (Zoe¹).
Hospitalisation was seen in retrospect as helpful including the work nurses did in “pushing you towards...your goal” and doctors “setting the weight”. Zoe¹ insisted that her experience of having anorexia made her a “stronger person”. Many found their close friends were excellent supports when they left hospital. These people talked to them, listened to them and never judged them. Others found family, religion, school and other patients with eating disorders who they had met helpful and someone they could place their trust in. These support structures provided the adolescents with the “will to get better”. For many their turning points were a realisation that they did not want to do this anymore and that they had other goals and aspirations in their sights. Some kept reassuring themselves that things were better when they did put on weight as they did not want to be sedated or to spend their whole life in hospital. Zoe¹ exclaimed, using prison terminology again, that it was “better being out than in”. This is similar to the feelings of inmates in Wilson’s (2003) study who described how “prison was not a good place, but a ‘pause’ in their lives that stopped them achieving what it was that they had wanted to achieve” (p. 422). Cameron¹ did a lot of ‘self-talk’ and said that sometimes “you just have to support yourself by yourself (laughs)…to get through it”.

Even though sometimes I think, Oh I really don’t want to put on weight but then you have just got to tell yourself...Everything is better when you do and that’s what you have got to keep reassuring yourself and that, It’s not going to lead you anywhere. Like, you are not going to get anywhere living in hospital (Zoe¹).

Lots of support, probably at least have...a friend who can understand what’s happening with you...So when you do leave you can always have that rebound friend...If you don’t talk to your friends about what’s wrong with you and stuff you feel a lot more pressure but if you just have one friend who understands the whole story properly then it can be a lot easier (Cameron¹).

Josephine¹ believed that once discharged from hospital it was best that people did not dwell on the problem. She hated people saying to her, “Oh, you are doing so well”. For her it made her feel that she was fat. Zoe¹ on the other hand did not want people to think, “Oh you’re all better” but to think, “Oh well you’re managing but that doesn’t mean that you’re better yet”. She felt it needed to be reinforced to the adolescent with anorexia that staff understood and acknowledged they were “still struggling” but were “not as acute” when they came back for check-ups.
5.5.2 ‘FINAL ADVICE FROM PRISON OFFICERS’

Nurses similarly provided suggestions for improving the care they gave as well as advice on improving the program. Again the advice is divided under the headings: nursing staff, doctors, program and recovery.

NURSING STAFF

Zac² believed it was “never” easy to form a positive connection with an adolescent with anorexia. However he suggested being “firm but fair” with them and showing no “favouritism”. He felt that confrontation should be avoided and instead advocated discussion. By involving the adolescent he believed they would benefit from greater autonomy over decisions (whether good or bad) and achieve a little more control. Thomas² felt nurses needed to “stick by the rules as a supportive person” not as “a policeman”. Nurses needed to be “upfront” yet “approachable” and “available” to the adolescents for a relationship to flourish. Donna² advised that nurses needed to be honest with these adolescents and to acknowledge it as a serious and genuine illness rather than a “spoilt brat kind of thing” if they wanted to form a relationship. Gabrielle² added, “these kids can die just as easily as someone with cystic fibrosis”.

Oliver² also insisted that it was important to be honest and respectful towards the adolescent. As with the adolescents above, the nurses felt that finding a common interest and establishing a rapport was important in forming a bond. Most nurses strongly believed that forming positive relationships or connections with adolescents with anorexia was a fundamental part of their care and recovery even though these were difficult to build within the current environment because of the role nurses played within the program. As Gabrielle² pointed out, caring for adolescents with anorexia is “worth all the fight that you possibly can do”. Nurses felt that perhaps the long-term, readmitted patients appreciated and trusted nurses a little more than others would because they have had the time to really get to know them. Veronica² was the only nurse to suggest that nurses not watch the adolescents eating, as this she felt prevented therapeutic relationships flourishing. She felt progress should be determined by weight gain. But if nurses did continue to watch them eat as per ‘The Level System’ then the way a nurse communicated was especially important.
Paige² suggested the program being a little “more relaxed” on weekends and allowing the adolescents to have “breaky in bed (laughs)…”. But then added, “if they don’t gain weight or they lose weight or they are going backwards then obviously that wasn’t working…that’s not helping. We need to do something else…”. But she believed that the nurses needed to trial something different in terms of the way mealtimes are done. She felt that nurses did spend enough time with patients but this time needed to be more productive and constructive. Similar to the adolescents, she even suggested that the nurse take the patients off the ward to sit somewhere different to have their meals or they be allowed to have one meal from home occasionally. Likewise, Paige² also believed that the time they spent on ‘bed rest’ could be better utilised with the nurse in charge of them interacting with them in some kind of activity for half an hour when the ward is not too busy (see Appendix N67). She was the only nurse to suggest the possibility of a “nurse-led program” with nurses deciding on ‘gate-passes’ and levels and doctors attending to the medical aspects, including the ordering of feeds with dieticians, ordering blood tests and medications.

Again inconsistency was seen as a major issue. Nurses were inconsistent with following the program on a day to day basis. Inconsistency occurred between different staff members, the same staff member depending on their mood that day and depending on what the staff member saw as a high priority within the program. A similar type of inconsistency among different prison officers and the rules was reported by inmates in Easteal’s (2001, p. 100) study, with interviewees commenting: “One will tell you one thing; another will tell you the opposite”.

…it does take emotional strength…It is easy to go and fix a drip, press a few buttons whether you are happy, sad, exhausted or not. It’s not so easy to go in and try to get a rapport with someone and find out how they’re feeling when your feeling tired…So when you are dealing with human nature stuff…it’s a lot harder (Paige²).

Zac² advised it was “best to be consistent across the board. If the kids see that everything is done exactly the same they will give up trying to manipulate staff and that will take out some of the anxiety we are carrying for these kids. Because they’ll say, No leeway is given no matter who is looking after you”. Gabrielle² agreed that there was no point having a program if nurses were inconsistent with following it as both the patient and nurse suffered. She said: “if we are not sticking to that program, they’re not going to be gaining

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weight. Because that program is the only way really I can see that they are going to eat more than what they expend out. If we are not strict with it, they won’t eat as much and they will exercise more”. However Paige² did not believe that with this program “that [consistency] can ever happen 100%. So as long as that doesn’t happen 100%, then you are always going to get the patients saying, Oh such and such does it this way or that way”.

…they do compare each other and they do talk a lot so there needs to be that consistency not only with the program but with us…with staffing actually dealing with them because that inconsistency is also not fair on them (Gabrielle²).

Gabrielle² suggested “they sign a contract” which could delineate what is going to happen while they are on the program and what they can expect from nurses thereby “putting a bit of an onus” on the nursing staff in that they have got to fulfil something for the adolescents. At the same time the adolescents have got to fulfil objectives for the nurses. She felt that this “consistency then means they can’t manipulate [the program]”.

Nurses believed having the same rules for all avoided conflict on the ward. Too much flexibility leads to things getting out of hand. However they believed in some flexibility, like the patients did, when the kitchen had made the mistake or if a patient genuinely disliked what had been sent and an equivalent item was available on the ward. The majority of nurses felt, though, that the ‘no swapping rule’ was a good rule in theory and should not be broken too often by nurses in practice otherwise confusion reigns supreme.

Some people get a bit too fixated on actual rules. I mean…rules are there, not to be broken, some are, but mostly, why can’t you bend them a little. There’s no reason why you can’t bend them a little (Riley²).

…some nurses do let them swap, some don’t. It can get very confusing to the kids…The rules are there for a reason…The kids know the rules so it is not as though…they are going into it blind… (Veronica²).

Zac² described how seeing these adolescents’ names next to his own in the ward allocation book made him a little nervous sometimes. He said: “I have a little bit of a palpitation…every time…their names are next to mine (laughs)”. Changes were frequently made by dieticians in regards to spreads or what the adolescents are allowed to have and Zac² described, “I have trouble keeping up with the rules of the day because dieticians will
change what they are allowed to have. So often I just feel a bit nervous going in there and having things changed since the last time I did it. So I don’t know whether they’re pulling my leg or it is a new rule….”. Nurses suggested that all members of the multidisciplinary team needed to keep everyone up to date by informing all nursing staff of changes to the program.

Many nurses suggested that care needed to be rotated among staff to decrease burnout as the work and patients were demanding especially on an emotional level. Currently the care of the adolescent with anorexia has “become the domain of the enrolled nurse and the casual nurse exclusively” because of the skill mix of nurses and the patient acuity on the ward. Oliver² suggested therapeutic relationships on the ward might improve if “everybody gets a go”. Nurses would then not be as exhausted and they would therefore not feel the need to just “go through the motions” to “get…[their] job done”. He felt that, “if you have more people doing the job…then that whole kind of united front thing becomes a bit easier to maintain”. Paige² believed, “you need to have a break from them. Like maybe not even have them two days in a row. So that each time you are caring for them…you’re ready to um put all your effort into making a relationship with them”. However Linda² reported that, “given the staffing levels that we have, it’s running the best it possibly can”.

I think there has been a long tradition of…giving the eating disorders to the casual because they are not the sick ones. But in actual fact they probably need consistency more than anyone else in that regard (Oliver²).

I think rotating the work load, I mean there is only so many times that you can look after the eating disorder patients in a week and not be a bit frustrated yourself. So yeah just rotation (Thomas²).

…it is not always good to look after eating disorder patients every day. You need to have a break because otherwise you will lose [your] patience with them (Mandy²).

I think much more sharing would be good. But given the allocation load of the ward, I don’t know that that’s always possible (Linda²).

Donna² provided similar advice to that given by Josephine¹ earlier regarding nursing staff. Donna² mentioned that “the nurses that don’t really want to look after them [should be] encourage[d]…to look after them for a little while and to interact with them and get to know them…so that they have an idea of how it is to look after them”. Nurses also felt that the way a task or activity was performed by a nurse impacted on whether the adolescent

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wanted to form a relationship with that nurse. Nurses suggested that the nurse’s attitude when caring for adolescents with anorexia needed to be both positive and professional for a connection to establish.

An invaluable skill that nursing staff required was education in counselling methods so as to learn “the skills to know how to talk to these kids and try and get them to open up”. They did not want to be professional therapists and felt this work should be left to the professional psychologists and psychiatrists but believed learning skills may make the formation of therapeutic relationships on the ward easier. Paige suggested that not having these skills “might be what stops people from starting a conversation and a relationship. Not knowing the right things to say”. Patients would benefit more if nurses had the proper training and would perhaps feel more at ease with coming to a nurse for support when they needed to talk to someone. Veronica reported nurses were probably not as supportive and responsive to the needs of adolescents with anorexia “as what they could be”. At the moment, it was as Donna described, “on the job training (laughs)”. Linda felt that perhaps ‘the system’ as a whole did not want nurses to gain these skills because it would threaten the position of other members of the team.

…I think we support each other more than we support the patients (laughs) (Zac).

…some um training on counselling skills…possibly for the staff. Don’t think that is a skill many people have developed um through courses and that… (Thomas).

The system can be changed to incorporate nurses into doing it [gaining counselling skills] but I don’t know that this particular hospital wants to take that step (Linda).

Gabrielle felt that nurses were trying to form therapeutic relationships but patients would see that they were “not very good at it”. She agreed and felt that nurses really were not very good at this, on account of variables such as time constraints, patient loads, the busyness of the ward and because of the authoritarian role they played as the main enforcers of this program. She felt that nurses did need education in counselling methods so they know what to say to a ‘fragile’ adolescent. They also needed to obtain the skills to understand what a therapeutic relationship is and how to build a proper one while still

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being firm and fair and maintaining that all important consistency with following program rules (see Appendix N68).

Gabrielle² suggested that perhaps there needed to be a “dedicated nurse” that has the skills to know how to respond to certain questions and who can explain the impact this illness has on their bodies. She explained that they have very poor insight into their disease. Even though “they can count calories, they can count fat content and things like that” their insight into their disease itself is very poor so they need education about some of the side-effects of the illness such as osteoporosis. They therefore needed someone who can “befriend them, spend time with them, talk to them, go through cooking classes…teach them…about their disease” but who does not nurse them on a daily basis. She remarked as nurses this was probably what some nurses did do to an extent, but in retrospect they did it poorly because they either did not have the time or proper skills or were seen as a “threatening figure” by the adolescents.

…the counselling kind of role of our job…We don’t get time for it. Unfortunately, when you are busy that is one of the first things that goes (Gabrielle²).

I think there is a great need whether it is a CNC [clinical nurse consultant] or a CNS [clinical nurse specialist] purely for eating disorders that can touch base with them (Gabrielle²).

I think they need to start looking at cooking and touching food and eating what they cook (Gabrielle²).

DOCTORS

The main issue with doctors was their communication with nursing staff. Many felt that they were “left out of the loop” in terms of understanding the care that was being provided by other health care workers in the team and most importantly in understanding the background to the illness for each adolescent. Oliver² described there being “a bit of discomfiture between medical staff and nursing staff”. He felt that the transformation of nursing into a profession of its own and in its own right has perhaps left the medical fraternity in a position of unease because nurses are moving away from that traditional role of being “in the servitude of the doctors”. Some doctors he felt have embraced this move and appreciated what nurses had to say and listened to their advice while others
were still resistant to change and felt that management issues should still primarily be the
domain of the medical staff only.

...you actually find out more when a doctor’s seen a patient from asking the
parents or the patient themselves rather than seeing the doctors because
half the time they’ll sort of just fob you off and you don’t know anything…
(Riley²).

Documentation and also verbal communication once they have seen them
(Veronica³).

...half the time we never actually know the reason why they’ve developed
what they have so that sometimes can help if we sort of realise that…
(Riley²).

I see it as an area that should be a necessity not something that should be
not discussed. If they want us to care for the kids then I don’t see how they
expect us to care for the kids properly, if they don’t tell us everything that is
going on (Veronica³).

...but also I think we’re coming from an experience point of view that can
often threaten I think your residents and registrars that come through,
because we are the only ward really that deals with the eating disorders…
(Gabrielle²).

...besides the basics, we are given no information about these girls at all
and I think that’s to our detriment. I think it is important that we have as
much information on these girls as we could possibly get. We need to know
where they’re coming from to be able to help them to move forward…You
could say something inadvertently and really upset one of these kids and
not know why…I think we cannot give holistic care if we don’t have all the
information available (Linda²).

Depending on the doctor being spoken to, some nurses felt their opinions and advice
would sometimes “go in one ear and out the other”. Similarly the support given by the
doctors to nursing staff again depended on the doctor. Gabrielle² believed that it was “not
so much the consultants” but “more the medical team that deal with them…the residents
and registrars and the psychological team”. Some doctors provided nurses with excellent
support while others did not and this had repercussions for the formation of positive
relationships between nurses and patients.
Zac² and Veronica² both described this below:

...we need to be able to tell the kids...that when they don’t do something, this is the consequence and have that followed through. Sometimes we will tell them something and...it is not followed through and then they sort of lose that little bit of respect for us...as if we are all just hot air...And in losing that respect they try and push the limits a bit further and a bit further which strains any relationship you had formed with them initially...So support [from] the medical staff definitely (Zac²).

I don’t feel as though we get enough support from the medical team um as nurses. I don’t...They get seen by psychologists etc but nothing is written in the notes...so we wouldn’t even know [what’s happening]. I don’t think that there is enough communication there...It’s just so hard to build those relationships up with them. So um they’re not getting the emotional support either. They are mainly getting it from each other rather than staff members (Veronica²).

Nurses appreciated when doctors acknowledged and validated their concerns and their input into the management of patients with eating disorders. They wanted doctors to value what they had to say because they spent twenty four hours of each day with these adolescents and they felt they knew “their attitudes and...how they [we]re thinking” and whether they should be rewarded for their efforts or not. They wanted doctors to read the nursing notes and if the notes reported that a patient had been misbehaving all weekend they needed to consider those issues at the meeting. Veronica² felt that, when doctors did not acknowledge nurses’ contributions or their concerns, it was a “sign of disrespect for what we do”.

I would feel a lot more comfortable with knowing that we’ve got...greater input. Rather than feeling abandoned whenever we speak up about an issue (Zac²).

...but the doctors don’t seem to want to know. That’s how I feel...They don’t want to know...about how we feel. It’s their program and we just comply with their program. That’s how I feel that they are treating us (Donna²).

...doctors do their doctor thing, nurses do their nurse thing. But what they [doctors] seem to forget is that nurses are pretty much with the patient 24/7 and we do most of the cares yet...have minimal say especially in regards to the eating disorders... (Riley²).
I don’t feel as though we get enough information about the um kids and they [doctors] don’t communicate with us enough…I don’t think they read what we write in the notes either…I see that as a sign of disrespect for what we do…Which makes me not have much respect for them (Veronica²).

...having the doctor support with whatever we do. Being heard when we say, This is not working, they’re not happy or they’re manipulating it…This person is doing really, really well. You can’t see it. She is not really gaining that much weight but she is doing really, really well. Can we reward her? (Gabrielle²).

The other issue was with doctors themselves not being consistent with following the program. In certain instances placing a child on Level One but allowing them to “get up and walk around the ward and go on gate-passes” which is not Level One. They accepted some adaptation occurring with the program but for “special needs” only but felt that all staff needed to “stick to [their] guns on the level system and not let the kids start running the show”. Oliver² agreed wholeheartedly. He also believed that when there were “too many qualifiers” placed on a person’s level then everyone was “not on the same page anymore”. Zac² believed that all staff needed to be specific with adolescents with anorexia when setting targets. They needed to let them know that there would be consequences when targets were not met.

...basically the doctors get lenient with some and not others and they change it [the rules] according to the patient (Donna²).

...sometimes it is unfair, that yeah someone is not doing well and they get rewarded. If it works on the reward program, they should be penalised as well as rewarded (Donna²).

It’s the part where you let the team they are under know [they are misbehaving] and they leave them on the same level and nothing is done about it. So why should we keep punishing these children when um nothing is going to be done about it from a level or medical point of view? (Veronica²).

...occasionally people arbitrally stray from it [the level system]. Um without explanation…When you start straying too much from the program you just open yourself up for disaster (Oliver²).

I find it very difficult with the doctors who will come and change things… (Mandy²).
Gabrielle² and Paige² mentioned that there was “disharmony” between the doctors and patients and that patients perhaps felt intimidated when doctors delivered the news following a meeting. The two main doctors being male and the majority of patients being female would increase the uncomfortable nature of the situation when doctors “look at their feet or their backs to see if they have been exercising and things like that”. Even though females are present while the medical assessment is performed, Gabrielle² felt that it was wrong for people with a body-image problem to be in a position where “they are more on show”. Sometimes other patients may be in the room and “they will hear every word. So if they haven’t happened to tell them why they are in hospital, they will know now…So it really is a breach [of privacy]”. Gabrielle² and Paige² both suggested strongly for a nurse or family member to be there as a support and advocate for the patient while the doctors delivered the ‘news’ to patients.

…often pull the curtains around them, which is fine, then a few of them just go in there and stand at the end of their beds. There doesn’t seem to be really any conversation back and forwards…I guess that the doctors are the ones that have admitted them, so there is a lot of disharmony between the patient and the doctor (Gabrielle²).

…the patients…I will say appear to have no real rapport with the doctors. The doctors are the ones who largely make the decisions um of course there is nursing input…But I think the doctors largely have a big say in that and they will come along and spill their news to them whether it be good, whether it be bad…There is no privacy taken into account…They might draw the curtains but everyone else in the room can hear. Um quite often there’s a few doctors so…they are intimidated. They don’t get to ask questions or um even argue the decision or those little things…Yeah I find that frustrating and I don’t think that’s right (Paige²).

PROGRAM

Most nurses were satisfied with ‘The Level System’ program. They saw it as a “stepping stone” or as a “ladder” for the adolescents with anorexia. The nurses felt that the levels were fairly “self-explanatory” and easy to follow and the program kept the adolescents occupied so that they did not have too much time “to think and stress out”.

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Zac² described it as giving them:

…and something to aim for…They see, Ok we are up to Level Two, let’s try and get to Level Three. What do I need to do to get there?…It’s just like a stepping stone for them, like a ladder to get out of here. They can see where they are going, where they have come from. So it sort of helps them put things into perspective…And also for us we can see how they are going as well with ‘The Level System’…We know that if they’ve done a few things wrong, they’re likely to take a step back or if they are doing really well we can see that they should be moving up and towards out of here (Zac²).

They saw the program’s benefits in that most of the adolescents “let go of that whole power struggle” perhaps because those factors contributing to their need to control were mitigated by this program. This was why nurses felt that being consistent with the program was so crucial otherwise they “get…more leverage on the staff” and they retain their control through manipulation tactics.

…when they come from home where there is all…these dynamics that require them to exhibit, consciously or subconsciously, exhibit…controlling behaviours, like…refusing to eat or whatever it might be. Then when they come into a place like this and they know that their parents…or the people in their lives who might be contributing to this are only visiting two hours a day, three hours on weekends…um maybe they let go of that whole power struggle (Oliver²).

Thomas² liked that the Levels were clear and concise and the limitations for each of the levels were clear. His only dislike was that the adolescents were no longer on phone restrictions (two in and two out) and many now carried mobile phones on the ward. Donna² and Gabrielle² thought that these Levels could be fine-tuned further. They wanted stricter and clearer guidelines made as to what authority nurses had to keep a patient safe. Donna² felt that there was confusion among staff regarding whether a nurse can put someone on twenty-four hour ‘bed rest’ or not. Donna² felt as their carers, nurses should be able to do, within reason whatever needed to be done to keep a patient safe, especially on weekends or when doctors from the team were unavailable. Each of the levels could be defined further for the staff, parents and the adolescents in regards to what authority nurses had within the confines of the program. Oliver² felt that the rules within the program needed to be concrete with “no room for ambiguity”. 

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...nothing is clearly outlined, like what we as nurses have the authority to do. We are the carers. We care for them 24 hours a day. It's not the doctors so, yeah it needs to be outlined that...we have the authority to do, whatever we need to do, to make sure that the patient is safe (Donna²).

...having a consensus on the program and then sticking by that program and being able to enforce that program so therefore being able to say that if the nurse does find you in this situation she will do this. So yes we [then] have got more autonomy but it is also set autonomy, I guess you can say (Gabrielle²).

While Riley² felt introducing more levels may help the current system. He also insisted there needed to be a place for additional minor modifications to each of the Levels to suit the individual patient. These needed to be clearly documented in the patient’s notes because he believed very strongly that not all patients are the same and thus should not have exactly the same rules imposed. In accordance with Riley², Veronica² and Gabrielle² agreed that the current program did not cater to “individuality and personalities”. They suggested “more levels” so that the adolescents took “little steps rather than big steps” with more choices and privileges bestowed if they are progressing well. If they lost weight they needed to drop down a level rather than stay on the same level and this they felt would be a greater incentive in that “there is something to gain, if they do gain weight”.

...we do need a program, but maybe some flexibility...if they realise the consequences of maybe them choosing this path in the program compared to this, means you are here longer...But at least that is their choice... (Gabrielle²).

The nurses felt that they should be informed of the therapy that an individual was receiving or at least told the reasons behind the history of the illness and some aspects of the family dynamics. If the information cannot be written in the notes for confidentiality reasons, a meeting or case presentation should be organised to discuss these issues with nursing staff. As Donna² remarked, “she might get upset...and I am blubbering on about the wrong thing and she is upset about another thing. Well it makes it frustrating that way”. Better communication among all members of the health care team was highlighted as needing further improvement. Nurses felt that their position in the program was seen by others as making sure the adolescents followed through and complied with the program guidelines. They believed that other members of the team did not think that they needed to know anything else apart from this. This left nurses under the impression that the
hospital program provided very little psychological help for the adolescents and thus did not “really get to the core” of their issues.

...we don’t really get to the core um but having said that I don’t know what they do in outpatients either...and maybe that's where they get their psychological therapy from...But I really do think it is going through the motions a lot of it. Come in, get fed, do the best we can while you’re here and send them back home (Paige²).

...the people who get the information just don’t think we need to know it. We have got our program and we stick to that and we don’t need to know it and I think um also for patient privacy, confidentiality. But I don’t really agree with that because you know we are part of the team and we need to know... (Paige²).

Nurses believed that they were kept out of the loop and not made privy to a lot of pertinent information. Having greater involvement and understanding would increase their empathy for these adolescents. Paige² remarked, “I think sometimes if we knew that [sort of information it]...would help care for them. You know getting to know them and supporting them if we knew a bit more about where they are coming from”. Gabrielle² suggested that the enrolled nurses or junior staff needed to start going to the case conferences if they were to continue being the main caregivers on the ward. Oliver² explained earlier that for a time nurses tried to become more involved in the family meetings however after a while he remarked, “we either were not invited to the meetings [or] they were held without our knowledge”. He felt that a nurse could only better understand a family situation by being present in a family meeting and visually seeing the interactions that take place. These interactions cannot be communicated on paper. Riley² agreed and stated that once a nurse found out the background information “sometimes it actually changes the way you feel about that patient and it can actually promote a better relationship”.

Basically we care for them 24/7 but we are not involved in family meetings or therapy sessions which I think nursing staff should be (Mandy²).

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6 As referred to in Chapter One, concomitant therapies were available to adolescents with anorexia and their families while an inpatient or following discharge. However both nurses and patients, in this study, were ill-equipped to speak adeptly about these services. Many patients were confused about what other treatment they were receiving and many believed they did not receive any further therapy apart from being on ‘The Level System’. Nurses were similarly unaware of the extent and the variety of concomitant therapies being provided to adolescents with anorexia.
Many nurses, as alluded to earlier, also agreed with the adolescents that there was a lack of psychological support for the adolescents as an inpatient. They believed that ideally the program aimed to be holistic but did not know if that was always achieved. Linda advised that the family dynamics needed to change with 99.9% of the cases otherwise “these girls are just going to be continually revolving doors”. The program was seen by most nurses and adolescents as a “feed you up, get you healthier physically and not mentally and...send you home”.

*I think there needs to be more psychological...input...involve the family much more. I think we focus very much on the girls and that's appropriate in the fact that some of them make themselves really ill with the amount of weight they lose but I think we need to look at the broader picture and say, Well why have they gone to these extremes? and then look at the family dynamics...and look at the relationships between each of the family members as well as the family on a whole (Linda²).

*I don’t think there’s enough to do with their mind, I don’t see that as being addressed here, I think it’s really to get them medically safe to be at home (Paige²).

Gabrielle agreed wholeheartedly that the program was aimed specifically at weight gain and the program did not address the psychological side of the illness as much as it should. As nurses carrying out the program she felt that the adolescents would be wary of confiding and trusting a nurse with their psychological issues or problems. Gabrielle suggested that someone needed to spend at least an hour a day Monday to Friday “touching base” with each of them.

*I think also with anorexia it is such a psychological illness as well. That doesn’t get addressed for them. We just seem to expect them to get better on their own if we feed them and totally forget the whole family dynamics. And they’ve got no one really they can rely on. Because, yes we are meant to be an advocate for them, but we are the ones that still carry out the nasty things I think like putting down a NG tube, making them be on ‘bed rest’. We carry that out. They have no outlet...So I find that really hard to cope with...I can’t see how we are helping them properly if we are not addressing their psychological needs as well... (Gabrielle³).

The ward environment was perhaps not seen as the best place for the care and treatment of adolescents with anorexia because of the acuity of other patients impinging on the time available for adolescents with anorexia. For Zac the “long term aspect of being on the ward” made some adolescents feel very comfortable in this environment and made some
nurses feel like they were “going in on their turf”. Sometimes this led to patients not doing things that they have been asked to do by nurses as they had taken over “ownership of the ward”.

...they should have a separate setting sort of, ah where time can be...spent with them getting to know them better because here they are seen as a very easy task patient. Like...if you have a very busy day, you just forget about them (Mandy²).

It’s a hospital environment and that’s going to make it much more difficult to interact with people anyway...I don’t know whether something more like, working with them from a half-way house or something with a much more homely environment would work...(Linda²).

The hospital environment was, in the main, seen by nurses as less conducive to therapeutic relationships than say a “community day care centre or safe house”. Zac² saw the downside of the acute care setting in the long-term “because you have long term kids mixed in with newly diagnosed kids, so the long termers, if they are quite strong, they will take on that mentor role and will teach the new kids bad habits and how to get away with things...sometimes breeds bad habits”. Paige² and Oliver² agreed, having newly diagnosed patients with readmitted patients meant “they can also learn from each other so there is a bad side from that too”. Again, the perils of confinement in this environment, like in a prison, and the learning of bad habits from one another, were mentioned by the nurses.

...there would be this whole kind of maelstrom of deceit and learning the tricks (Oliver²).

As mentioned earlier, nurses did feel that sometimes the adolescents developed a “fear [of] going back into real society” and the hospital became for them a “little safe house of its own”. For Zac² though, this environment did have its benefits in the short-term, as a “respite” in terms of getting away from the stressors in their life and achieves medical stability. Oliver² agreed with Zac² and in the quote below described how for some adolescents being on this program gave them the space to think without added pressures.

...maybe it just gives them time to think without being talked over and just you know clear their mind as part of the process. I am not saying that’s the whole process... (Oliver²).
Overall though, most nurses believed treatment in the community or as an outpatient would be the best solution unless the person was medically compromised. In these other environments they can get “more attention” and feel a sense of “normalisation” in being able to go out and eat socially. Thomas² pointed out, “it would also take the unpleasantness of being in hospital full time for the patients off them”. For Veronica² they needed to be in a homely environment with no other distractions or critically ill patients and “where people can actually sit down and talk to them and build a rapport with them a lot easier”. She felt that they should come to hospital for therapy but that it should be managed if possible primarily as an outpatient. Parents needed to be given greater support and education to manage the illness at home. The nurses felt that there was always going to be a “push for hospital beds” within the acute care setting.

…I think it is much better for their mental health to be at home. You don’t want to be institutionalised you know at 15, 16 (Linda²).

Donna², on the other hand, felt that the adolescents with anorexia should be cared for in a specialised unit rather than a mixed adolescent ward. She saw disadvantages to the current setting with some patients with eating disorders comparing themselves with cystic fibrosis sufferers and saying things like, “Oh she is not on a meal plan and she is skinnier than me”. Vice versa she has seen some adolescent girls with other conditions showing greater concern about their own weight. She has also witnessed adolescents with anorexia giving other patients money to acquire prohibited items such as chewing gum or prunes or prune juice for them. Thereby other patients become in some ways an ‘accomplice’ in their unhealthy deeds. This behaviour is also not uncommon within prisons, where there are those inmates who smuggle contraband items, such as messages, money, tobacco or drugs between prisoners.

…food wise as well I have know for eating disorder patients…to give money to some other patient to go get chewing gum for them or prunes or prune juice (Donna²).
Riley agreed with Donna and had seen “fragile” adolescent patients with other conditions “pick up bad traits” from the patients with an eating disorder. But then he felt that being in a specialised unit also had its disadvantages in that the adolescents would constantly “pick each others brains and then they pick up each others bad habits, and go, Oh yeah that sounds like a good idea. I’ll do it that way”.

Oliver, on the other hand, saw the advantages to a mixed ward in that patients with anorexia were socialising with other sick peers. Nurses too were able to take a different patient load if they were exhausted from caring for adolescents with anorexia. Thereby he and Paige saw it as the place to be if they were medically ill because of the availability of numerous health professionals but perhaps not as secure as a specialised unit.

In terms of the current program, Zac suggested that the adolescents needed “more leniency in social interaction outside the hospital”. He felt that for many it was daunting to go back into society and keeping them in contact with their friends was important at this stage of their development. Some adolescents he believed required the respite but for others it was important that they remained linked with life outside the hospital. Going out with friends to see a movie or friends visiting was seen as a way for the adolescents to keep in contact with peers (see Appendix N69). Zac believed this “leniency” should be encouraged on the program rather than “them [being] locked away in here and going out whenever they have done things right”. Gabrielle agreed with Zac, in that socialisation with peers was an important part of their adolescent development.

...but I think for adolescence it’s such an image time that it’s peer relations and that is who they get their identity from...I think that whole idea of doing some kind of social things for them while they are in, no matter what level they are on...if they’re not kept in contact with their friends well what have they got to look forward to. They are going to be on the outer when they get out. So having their friends in or doing social things and encouraging that may make them want to get out...and think, Okay well I have still got my friends and they are encouraging me to get out so I do really want to get out. It may actually even wake up their friends to say, Oh look anorexia is not this cool thing. It’s not this trendy thing that just people in Hollywood get anymore. I guess real life. This is the situation. It is not nice (Gabrielle).

Many nurses believed that ‘gate-passes’ prepared the adolescent for discharge. The recently started overnight ‘gate-passes’ were considered a great idea. It allowed the adolescent an opportunity to see how well they would cope at home again. It was a way to
ready them for going home and give them the desire to want to go home, see their friends again and sleep in their own beds (see Appendix N70 & N71).

Paige² agreed with most of the adolescents in that she felt that the group sessions should not be compulsory and the adolescents should “have a bit more choice in terms of whether they go to group” because there might be groups on that they are not interested in or find childish. They may want to “stay back and listen to their music”. So she felt the introduction of “an ‘out’ card” that they could use once a fortnight might be received positively by the adolescents as a privilege and may be seen as an element of ‘control’ for them. Paige² also felt that the adolescents should be encouraged to “keep diaries” as a form of therapy for themselves especially “if they can’t tell somebody else” how they feel.

Parents were also seen as an important part of the program and it was best if they were on side with the program rather than against the program. A working partnership with parents was seen as essential for better relationships with the adolescents. It was also suggested that a buddy system could be organised where discharged patients who were doing well and coping after treatment could return to the ward as a ‘special guest’ to talk about their life. The adolescents can then see and listen to the stories of others who have been in the same situation and hopefully see the benefits to not being hospitalised and “see how other people have dealt with it”. Paige² thought that this sort of “peer support group” might help them on their road to recovery because sometimes nurses “were not viewed as the good person”. Similarly, in Walsh’s (2006, p. 126) study of prisoner rehabilitation in Queensland, young ex-prisoner respondents voiced, that “peer support and mentoring by persons with an understanding of their struggles would go some way towards assisting them to ‘stay out of trouble’”.

I’d like to see the girls like helping each other. At the moment they almost feed off each other in a negative way in terms of no one wants to finish first and everyone wants to be the slowest and cut the apple the smallest. It would be really good if there was some sort of peer support group whether that meant bringing over older or even maybe some recovered eating disorders, bringing them in, so that they feel a bit of a kinship type thing (Paige²).
Nurses similarly felt that prolonged nasogastric feeding was unnecessary and detrimental to recovery. Gabrielle\(^2\) believed it was “force-feeding”. Initially though they saw its advantages in increasing weight for the severely undernourished adolescent but felt that it was an “unpleasant” procedure and “if the option [wa]s there for a child to have their feed a different way and they [we]re prepared to do that then [they] would rather see that [happen]”. If the adolescent was refusing to eat then the nurses saw that it made sense to feed them overnight with a nasogastric tube and it made sense to have a ‘bolus-exchange’ system. The ‘bolus-exchange’ system ensured the adolescents had their full complement of nutrition if they were struggling with their meals. The system had an added benefit by dissuading from food refusal those patients presently without a nasogastric tube. But in the long term nurses believed nasogastric refeeding “defeats the purpose” and boluses were considered “a cop out” because they “don’t have to face [their] demons”.

*I think it is really good because…the…kids don’t always have the ability to eat that much food and they can find some relief in the NG feeds so it helps them out as well. It also takes control off them at times which is sometimes what they like to have. They’re not eating it, someone else is making them have it. So that can help them in their mind set as well. But…prolonged NG feeds I don’t see as all that good because…you can’t live off NG feeds for your whole life (Zac\(^2\)).*

*In some cases when they are first admitted and they are medically unstable I am strongly with it, I do agree with it um but I don’t agree with having it in permanently as a replacement of a meal. I would encourage the kids to eat their normal food instead of giving them boluses and giving them the nasogastric feeding overnight and get them to maybe increase their meal plan instead… (Donna\(^2\)).*

*…they’re good to stabilise a patient (Riley\(^2\)).*

*I think they need to be given a chance first. Again they have lost all their power, we don’t trust them, they are probably feeling very isolated, and we throw a tube down their throats. If we give them a chance to first prove and we say that, Ok great you prove to us, if you cannot manage it, then yes you are going to need a bit of help to supplement. But I have a problem with so quickly putting down a nasogastric tube (Gabrielle\(^2\)).*

Donna\(^2\) also suggested that they should be allowed an optional glass of water with dinner because at present this meal did not have a drink. She felt that the meal choices were good and giving the adolescents too many food choices on the menu would add to greater
confusion and stress. So she felt that the current three options for each main meal were sufficient for the adolescents with anorexia. Thomas\textsuperscript{2} even suggested sometimes allowing the adolescents to “go out to the cafeteria and get something there and be like a ‘normal’ person”.

In terms of the number of adolescents with anorexia on the ward, Veronica\textsuperscript{2} recommended that there should be a maximum number of four at any one time. She felt that when there was greater than four on the ward, nursing staff had “less tolerance and less want to build a relationship because there are so many of them…”. Paige\textsuperscript{2} agreed and remarked when “you have anymore than say four it can be very, very difficult to give equally good care to all of them”. Veronica\textsuperscript{2} added that the adolescent ward should not be the only ward in the hospital to care for the adolescents with anorexia and that other wards within the hospital should also care for them.

*...because the more you put together the more they learn from each other (Gabrielle\textsuperscript{2}).*

In terms of the visiting restrictions, Donna\textsuperscript{2} and Gabrielle\textsuperscript{2} felt that these should be individualised to the family dynamics. For those parents or family members that were non-compliant with supporting the program, they believed the restrictions should be in place to remove adolescents from the “highly stressed” environment of home. But for others who are supportive of the program, she felt the restrictions could be relaxed to take into account things like the distance they travel (e.g. those outside of Sydney) and thereby increase the time they can visit. For those who live quite a distance from the hospital exceptions can be made to include their grandparents or other relatives as a replacement when parents cannot drive in.

*...also the family relations can be strained so having their family told they can only come in for a couple of hours each day, can be a relief for some of them. Especially not having them there at the meal table...I mean quite often that’s where the fights at home would happen. Um I think while there is initial resistance, over time they probably...can see it as quite helpful (Paige\textsuperscript{2}).*
RECOVERY

To assist in the adolescents’ recovery, nurses needed to be consistent, clear and firm because their judgment is clouded and they “need someone to step in and break the cycle”. Mandy² felt, “it’s not only that person with anorexia you are treating you have to treat the whole family” for recovery to occur. Veronica² and Paige² saw the friendships they made with other patients while in hospital as being positive for most adolescents and assisted with recovery and bolstered their self-esteem. Gabrielle² felt that the relationship adolescents had with ward nurses was “very clinical based” because of their role as an authority figure within the program. She felt they needed someone not caring for them on the ward that they can develop a relationship with, who could be a confidante and advocate for them because more often than not they would not feel comfortable in confiding in ward nurses. As a nurse working within the program, her theory was “if they don’t like you, then you are doing your job”.

I think it’s good to have um a few of these patients in together, where they are eating together and sharing the same experiences. To get that support from each other… (Paige²).

Gabrielle² pointed out that “the way they get rid of them is really poor”. She felt that in a way “we set them up a bit for failure”. She felt there needed to be some kind of progressive plan for discharge. If aiming for discharge in two to four weeks then she felt they should resume their normal school and come back to the hospital after school so the support can continue or allow them full weekend ‘gate-passes’ to ready them for final discharge.

...as I said it is easy while they are in here to eat because someone is watching you. But as soon as you get home…I think we set them up a bit for failure (Gabrielle²).

Like the adolescents, the nurses too felt that educating parents prior to discharge was essential for a smooth transition back into the home environment. Zac² remarked, “you can see it in a parent’s face…the fear of, What am I supposed to do with them when I get home? And you hear stories about parents being quite strict…they have to eat all of that exactly as it is…as if they were still an inpatient and not allowing any leeway. Whereas other parents don’t care and just let them eat what they feel like when they feel like it…”.

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Dieticians need to really sit down and kind of enforce the parents to comply with the menus and make them aware of how much each portion is and yeah what they need to have (Donna²).

...parents should have much, much more involvement in their care...in terms of the amount, of how their foods are presented and um what food they need to have and the volume and the quantity and all that sort of stuff (Linda²).

Most nurses felt, as the adolescents did, that Level Five of the program needed to be re-introduced prior to discharge, “because it would almost be like a testing stage for a week or so to see if they can cope”. This stage of the program allowed the adolescent to take responsibility for their eating and during this stage they were able to eat in different places without being under the supervision of a nurse.

...so Level Five was basically like they eat themselves. We don’t have to supervise. It’s just like they are practicing to go home and I think that was a very good thing...[that] they were allowed to do that... (Mandy²).

I think Level Five is more beneficial for them, where they get to choose whatever they want to eat and they get to choose where they eat it but we still keep a little eye on their weights and their obs and stuff... (Gabrielle²).

Nurses thought the idea of parents partaking in a meal or two with their child on the ward, with the support of a nurse, might be useful during the transition phase as the adolescent nears discharge (while on Level Five). This may alleviate the parent’s stress as well as the child’s about going home. Nurses can also assess how well parents are going to cope and whether they need additional advice on how to negotiate issues or tackle problems at home. For recovery though it was also important to have someone that the adolescent could feel comfortable to talk openly with and who they felt valued their opinion and did not judge them. The adolescents needed a supportive family but most of all they needed time to recover.

...there needs to be an adult around that they can trust and talk to (Linda²).

For those who kept returning as a “regular admission”, Gabrielle² suggested that as a team they needed to seriously rethink their approach and find out “what fails them when they get home [and] how are we failing them in here that is not equipping them for when they get home”. She felt strongly that it was more to do with the lack of psychological help.
given during their stay in hospital and after discharge than to do with “the actual amount they can hold in their stomach”. She also suggested linking the adolescents up with a “community liaison” who has “some kind of contact that is long-term”.

Finally nurses, like Mandy² felt that it would be nice to hear back about those patients they have cared for on the ward. They would like a follow-up report themselves to find out how these adolescents are going at home and in the community. Mandy² suggested the doctors meeting with nursing staff and providing this update. Finding out that adolescents are doing well or coping post-discharge would be a rewarding incentive for nurses and would increase nurse satisfaction (see Appendix N72). It would then acknowledge and validate that the hard work and effort put in by nurses each day is, as Gabrielle² earlier remarked, “worth all the fight that you possibly can do”.

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Chapter Six

DISCUSSION

“...ruled by her body, imprisoned in it and condemned to struggle against it”

ENTERING THE SYSTEM

As the results of this study demonstrate, there are clear parallels between ‘life on the ward for an adolescent with anorexia’ and ‘prison life’: these similarities prompt some useful questions and suggest some interesting lines of inquiry. In many ways both cohorts enter their respective institutions, because as Roach-Anleu (1997) argues, powerful stakeholders within society determine that behaviours they display are ‘deviant’. Thus these stakeholders impose formal and informal sanctions in order to maintain the ‘status quo’ and modify or reduce these unruly behaviours (Roach-Anleu, 1997). For the adolescent with anorexia, psychiatry legitimises the use of programs such as ‘The Level System’, based on behaviour-modification principles, as being rehabilitative and as facilitating positive change in all aspects of a person’s health and well-being. The analogy with the penal system is self evident in that the legal system similarly legitimises imprisonment for criminal deviance, as being “to contain but also to correct or rehabilitate” the prison inmate and their ‘deviant’ behaviour (Cameron, 2001; Tupper & Wortley, 1990a, p. 2, current author’s emphasis; Walsh, 2006).

Metaphorically, ‘The Level System’ program with its ‘rewards and punishments’ brought forth stark resemblances to a prison system’s associated regimes. However, it should be noted that the metaphor presented is based on ‘stereotypical’ representations in the popular media and may not correspond to the reality of the prison system of today. Nevertheless, the presentation of these images arises from the experience and ‘stories’ of study participants who would be unlikely to have an ‘evidence based understanding’ of the prison system, but are more likely to reflect the stereotypical images presented in the popular media to which they are more likely exposed. In particular the language and terminology seemingly instinctively adopted by the adolescents with anorexia in this study further illuminated these relationships. In the case of the ward functioning allegorically as a prison, adolescents with anorexia became its ‘inmates’ and in effect, the doctors and nurses became their ‘wardens’, in loco parentis and in loco medicis (Shoebridge, 2002, p. 6).

The opening quote to the results chapter: “everyone … must follow the rules” was chosen from Ken Kesey’s (1988, p. 25) novel entitled ‘One Flew Over The Cuckoo’s Nest’. A central character within this novel, Nurse Ratched, employed within a mental institution,
believes in the enforcement of rules and regulations as a means of maintaining order within society. Riley², a nurse within this study, mentioned her name during his interview which then made me revisit this childhood novel to discover an interesting insight. Nurse Ratched made the following declaration in Kesey’s (1988) novel:

‘Please understand: We do not impose certain rules and restrictions on you without a great deal of thought about their therapeutic value. A good many of you are in here because you could not adjust to the rules of society in the Outside World, because you refused to face up to them, because you tried to circumvent them and avoid them. At some time – perhaps in your childhood – you may have been allowed to get away with flouting the rules of society. When you broke a rule you knew it. You wanted to be dealt with, needed it, but the punishment did not come. That foolish lenience on the part of your parents may have been the germ that grew into your present illness. I tell you this hoping you will understand that it is entirely for your own good that we enforce discipline and order’ (p. 153-154).

Riley², and many of the other nurses, did not want to be like Nurse Ratched and hoped that they did not espouse her ideals but, in reality, they were enforcing the rules and regulations of ‘The Level System’ protocol because many believed in its therapeutic value in achieving medical stability. As nurses, they believed they had an obligation and a duty to provide this care. As Oliver² pointed out, nurses within this program had a responsibility “to be on high alert for deviation from the program”. Interestingly Oliver² also saw the program as “very much about getting the family well, as well, so that the adolescent doesn’t lapse back into these behaviours”. Oliver², suggesting perhaps, as Nurse Ratched has, that the family may share some responsibility for their child’s present condition and consequently requires adequate education and support in order for the child to get better.

According to the nurses, the program’s restrictions were in place because these adolescents were “physically” and “mentally” unwell on arrival. Consequently health care professionals would be displaying gross negligence on their part if they did not follow through with the set guidelines. In retrospect, the adolescents did agree that nurses performed their role within this program “…for [patients’] own good”, even though many vehemently disliked the restrictions while they were on the program. In one particular
case, that of Josephine’s¹, ‘The Level System’ program was seen as “emotionally detrimental”.

Trust for some adolescents, like Megan¹, may have initially been violated by their parents or concerned others who brought them into hospital under ostensibly false pretences. Thus this violation of trust then adversely affected the adolescents’ trust in health care professionals on the ward and, as Linda² suggested, adults in general who were trying to help them get better. Various strong emotions were expressed by many, if not all, of the adolescents including confusion, anger, fear and depression when they eventually came to the realisation that they were to be hospitalised and were ‘to enter the system’ for treatment. For many this was a distressing and terrifying experience as this had been their very first hospitalisation.

It was extremely difficult and perplexing for most adolescents to understand the rationales behind the rules and regulations of the program, especially when the adolescent felt well. Perhaps one of the reasons for this difficulty was that, adolescents with anorexia (and additionally the nurses who care for them) have not been educated on the key principles and strategies of behaviour-modification and behaviour therapy. An understanding of the assumptions, strategies and rationales underpinning ‘The Level System’ could help to allay anxieties, as an understanding could be attained that this model is not a ‘punishment model’ but one that is based on shaping desirable behaviours.

Subsequent admissions were easier for some adolescents who were by then more familiar with the program’s rules, the nurses and the ward environment. While for some, subsequent admissions were more difficult as they felt a need to rebel against the restrictions for greater independence. Commonalities can be seen within a prison system, with some inmates settling in to their environment easily (“doing it easy”) while others continue to struggle to fit in (“doing it hard”) (Tupper & Wortley, 1990b, p. 2). This depiction was confirmed in Easteal’s (2001, p. 95) study of female inmates in Australia, which described how “the ‘easy time’ prisoner learns quickly to respond in an appropriately deferential tone when spoken to”.

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Overall, ‘The Level System’ program was perceived in a positive light by the nurses, who described its intentions as “honourable”, in attempting to modify the adolescents’ ‘deviant’ behaviours such as their refusal of food and their engagement in unhealthy weight loss practices. The program endeavoured to achieve two main goals: medical stability and psychological improvement so that the adolescent’s behaviours returned to ‘socially acceptable’ standards. Hence according to the nurses, these adolescents then avoided further ostracism from society and their peers.

Also, in similarity with the penal system, each individual level within ‘The Level System’ had set rules and restrictions imposed with limitations placed on personal liberties, such as toilet and shower use. According to Poole (1997, p. 175) similar limitations may be experienced by an inmate including “be[ing] searched, undressed, bathed, disinfected, fingerprinted, forced to wear a uniform, and given a number rather than their name”. In common with the adolescents’ perceptions of confinement, Donna², a nurse, had described entering the system and being placed on Level One as comparable to “being locked up in jail...isolated from everyone else”. Since these adolescents were not free to discharge themselves, they effectively were ‘locked up’ until they had gained weight and achieved medical stability. Adolescents themselves instinctively described that being on ‘The Level System’ program engendered feelings of being “quite cooped up...like you’re in jail in a way”. Additionally, the adolescents expressed feelings of a loss of “freedom” and a sense of “normality”.

Normal activities, such as going to the bathroom or leaving the ward, became privileges for the adolescents on this program. Compliance with the program’s rules allowed the adolescent to move up the Levels and receive greater rewards. Again the similarities were evident in the descriptions related by participants in this study, to the privileges that may be bestowed on a prison inmate for their good behaviour and their compliance with prison rules while ‘doing time’ in a prison system (“Department of Corrective Services” [DCS], 2002; Easteal, 2001; McIlveen, 2006; Wilson, 2003).

Once over the initial shock and formally integrated into ‘The Level System’, the adolescents with anorexia had to quickly ‘learn the ropes’ from fellow inpatients. They had to learn to accept the rules which now regulated their lives. The daily routine for an adolescent with anorexia very much resembled the ‘institutionalised’ daily schedule for a
prison inmate. Morgan (1981, p. 263) confirmed that “prison inmates have little choice but to accept the rules which regulate their lives. They eat, rest, and work on orders from guards, whose enormous power represents society’s grasp over the prisoners”. Not unlike the prison inmate, the adolescents’ timetable assigned times for waking, showering, eating, sleeping, school, group, physiotherapy and visitors and these were to be strictly adhered to with little variation. However, the adolescents had some small concessions in terms of being able to wear their own clothes and decorate their bed and bed spaces making their experience less oppressive. This can be seen as akin to the prison inmate who may be permitted to decorate or keep approved personal possessions in his cell (DCS, 2002; “Just Oz”, 2004).

The new prison inmate too needs to ‘learn the ropes’ in order to ensure his survival and adaptation into his new surroundings (Easteal, 2001; Tupper & Wortley, 1990a). Likewise, the adolescents with anorexia displayed a socialisation process which Zac² described as being a “pack mentality”. He commented that these adolescents, whilst in the system, tended to ‘stick together’, protecting and supporting each other, like a pack of wolves¹. Thus, raising connotations of ‘predatory’ and ‘group survival’ common to wolves. Interestingly, both the nurses and adolescents in this study, symbolically portrayed part of the nurse’s role in the program as being like “hawks”, which are also noted for their fierce predatory behaviour². Symbolically the combination ‘predator versus predator’ is an ominous sign as it encapsulates the difficulty in establishing therapeutic relationships between nurses and adolescents with anorexia within ‘The Level System’ program.

Despite the above observations, the solidarity and support expressed among the adolescents was generally positive and reassuring. This solidarity and support is also not uncommon in the prison environment (Tupper & Wortley, 1990a; Wilson, 2003). However, Zoe¹ acknowledged that the close knit nature of the relationship among the adolescents could also be unproductive and damaging. As Zoe¹’s mother had explained to her, entering this system was like entering a prison system and opportunities would present themselves for learning little tricks or ways to ‘rort’ the system from others who had been there and done this all before. Learning ways to manipulate the system was ultimately detrimental to the adolescents’ progress and prolonged their stay in hospital. The insights

¹ Wolves are predatory mammals that hunt and live in packs. Wolves protect each other and provide each other with the strength to ensure their survival and continued existence in the wild (Broadley, 1982).

² According to Brown (1982) hawks are also fierce predatory birds.

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expressed correspond to Tupper and Wortley’s (1990a, p. 7) descriptions of prison life in early Australia: “It has been said many times that prison is a university of crime and that the young prisoner learns skills and techniques and makes associations that mean they may perform their anti-social craft more efficiently when leaving prison”. Consistently, Roberts and Hough (2005, p. 297) recently reported that worldwide public opinion remains largely unchanged today with many people describing “prisons as schools for crime”.

**LIFE WITHIN THE SYSTEM**

As part of ‘The Level System’, nurses were faced with a frustrating ethical conundrum. As primary caregivers for the adolescents on the ward, nurses were technically “the face of the program”. One of their primary roles was to implement and enforce the rules and regulations of the program while doctors remained the main decision-makers. Nurses had an obligation to enforce rules and regulations that the adolescents generally were not particularly receptive to; at times, they believed them to be punitive, annoying and unnecessary. The adolescents themselves described nurses as competent in “lay[ing] down the law”. Undertaking the ‘law enforcement’ work - abiding by the structures of the program and applying the rules and sanctions - meant that nurses were not simply enforcing the system as ‘law’ but, in the eyes of the adolescents, had become the very embodiment of the system.

Consequently, nurses described the conflicting role they played within the behaviour-modification program as ultimately inhibiting therapeutic relationships with these patients. As part of the program nurses had to take on “observational” roles as the “disciplinarian” or the “policeman” in catching the adolescents misbehaving. Yet they were also expected to spend time establishing a rapport and developing trust so as to build a therapeutic relationship with their adolescent patients. However, these competing, and perhaps self-inhibiting goals raise serious questions. For example, how were nurses to be patient advocates and to provide this emotional support to patients, something which nurses believed was critical for their therapeutic management and eventual recovery, if they were, at the same time, the very enforcers of the program? Although most nurses acknowledged the importance of a therapeutic relationship and some professed that they attempted to provide this support, these relationships did not develop effortlessly on the ward. As Zac² revealed, he did not actively “pursue these kids to talk to them”. Many
nurses admitted that they principally attended to the physical care tasks that needed to be done on a shift. This perhaps was a way of avoiding the other dimension which reflected the more emotionally challenging and frustrating nature of their care.

This study has revealed that the most time consuming task, though not necessarily the most important, was the supervision of meals. This task according to Paige² required “the most attention” as adolescents with anorexia would generally manipulate staff at this time. Forms of manipulation included concealing, discarding or not using the correct portions of food, eating inappropriately and splitting staff. ‘Keeping a watchful eye’ at mealtimes was another role which nurses did not particularly enjoy especially since they were telling “four young people who don’t want to eat: Come on. It’s time to go off and do something you hate”. Some nurses felt they were being “pathetic” at times when they “knit picked” about the amount of butter that needed to be used. But all the nurses, with the exception of Veronica², felt that, because of their disorder, they could not be “100% sure” the meal had been completed unless they watched the adolescents eat their meal. They justified this position in terms of their responsibility to ensure that the adolescents in their care did not get any sicker than they currently were.

Most nurses believed that sitting and watching them eat was beneficial in that they could provide the adolescents with encouragement and guidance through a most stressful time. Veronica², on the other hand, felt that their weight should be an indicator of whether they were eating or not. Veronica² insisted that monitoring meals was a drawback to forming a therapeutic relationship as the adolescents would have difficulty establishing trust with an authority figure and nurses in this position were taking on an “authoritarian” role.

Notwithstanding Veronica’s² comments, the meal table seemed an ideal opportunity for conversation to take place and for a relationship to be developed. Yet, according to the nurses, interactions at the table depended on the patients’ or nurses’ personality. At times it would be difficult for nurses to engage in conversation when particular patients were still struggling with their eating and displayed “really combatant” behaviour. Riley² labelled these patients “hardcore”, not unlike the label of “hard man” given to the rebellious, strong-willed dominate inmate within a prison system, who does not comply with the system’s rules and regulations (Tupper & Wortley, 1990b, p. 1). It was in these instances that nurses had to wield their power and authority to maintain order and control of the
situation. Oliver\(^2\) instead believed that conversation and interactions at the table depended on the nursing staff member’s style. He believed some nurses were able to balance being in control with chatting and socialising, while some did not engage and were quite rude. A further group, were too flexible and lenient allowing the adolescents to get away with too much.

Oliver\(^2\) felt consistency and a balance were crucial, yet noted that, this was not always apparent, leaving staff members frustrated and emotionally drained by the enormity of the task. Eight out of ten nurses admitted to being inconsistent in their following of the program rules at mealtimes and on other occasions, while two nurses followed the rules unwaveringly. A similar type of inconsistency among different prison officers and the rules was reported by inmates in Easteal’s (2001, p. 100) study, with interviewees commenting: “One will tell you one thing; another will tell you the opposite”. Inconsistency caused great confusion not only for patients but for staff as well and was often the basis for feuds on the ward. Nurses felt that once again they were placed in a precarious situation of attempting to form a solid therapeutic relationship through conversing with their adolescent patients, but at the same time needed to be the disciplinarian or law enforcement officer handing out “warnings” of a bolus if the adolescents were misbehaving or “cutting it fine” in terms of finishing their meal on time.

The adolescents with anorexia described the role nurses played on the ward in a similar vein with Danielle\(^1\) innocently reporting: “they [nurses] make sure we’re not getting into any trouble outside of meal times”. The adolescents felt that nurses were a fairly good support to them in hospital as they helped them to “adapt to normal eating again” through their encouragement. Additionally they verified that the nurses had a very difficult job in that it was extremely difficult to trust adolescents with anorexia around food. The adolescents found mealtimes to be an “uncomfortable” experience and acknowledged that those nurses that engaged in conversation or brought down a magazine to read, made the process less daunting and less stressful. The majority of nurses were described as “nice” by the adolescents. Some, however, were considered “mean”, “unfriendly” and “unnecessarily strict” specifically because they stared, interrogated, spoke curtly or initiated little to no conversation at meal times. Obviously the adolescents with anorexia would be resistant to forming a relationship with these latter nurses.
Nursing education tends to emphasise the importance of professional communication, which entails negligible self-disclosure and avoidance of superficial conversations (Crisp & Taylor, 2005). Yet it is interesting to note that light, social conversation, especially at mealtimes, was generally viewed as therapeutic, as a mode of distraction, for the adolescents in this study. The nurses who brought their own food and ate with the adolescents allayed the adolescents’ anxieties and fears and decreased stress levels. In fact, Deering (2007) proposes, “[b]reaking bread together at a table has an incredibly levelling effect on all parties” (p. 3). It may be that formal recognition of this potential and its incorporation as a strategy within the program could improve therapeutic outcomes.

As part of their role within the program, nurses were expected to monitor all aspects of the adolescents’ behaviour whilst on the program and this surveillance by nurses was not surprisingly expected by the adolescents with anorexia. ‘Bed rest’ after meals was supervised and some nurses it appeared did not tolerate misbehaviour. Amber¹ recalled one nurse making the adolescents endure another half an hour ‘bed rest’ for leaving the bed rest area (Moroccan Area) five minutes early. Attendance at school and group activities was monitored. Zac² called this the “in between times”. Nurses also had an obligation to monitor visiting that is, who visited and for how long but most found this a difficult area to “police” and reported their inconsistency in following this rule. Showers were monitored and they needed to be a maximum of ten minutes once per day and time spent in the bathroom for toilet use needed to be kept to an absolute minimum while on the program.

If the adolescents were taking too long in the bathroom, nurses described how they would “listen at the door” then check their pulse and respiratory rate on exiting. Excessive bathroom use necessitated toilet restrictions. If the adolescent was discovered exercising in the bathroom after a warning had been given, then nurses described how they had the power to place the adolescent on “twenty four hour bed rest”. ‘Specialling’ of adolescents occurred in extreme circumstances when patients continued to ignore the rules of the program, absconded from the ward, used manipulation tactics or when patients were engaging in self-harming behaviours. In some ways this can be considered comparable to the use of seclusion or separate confinement in prisons for a ‘troublesome’, ‘non-compliant’ or suicidal inmate (“Department of Corrective Services”, 2003; Easteal, 2001; Walsh, 2006). The adolescent was usually confined to a single room with a nurse
watching over them 24 hours a day. Currently ‘specialling’ seldom occurs on this ward and is not a routine part of the program. Most importantly, the monitoring also included the medical monitoring of stability and safety that is, assessing temperature, heart rate, blood pressure and respiratory rate.

Most of the adolescents lost their privacy as soon as they entered the system. Nurses again felt that it was not something they wanted to do “willingly or voluntarily” but because of the adolescents present condition they were not behaving in a “logical kind of way” and consequently nurses needed to take measures to prevent them from harming themselves. For instance, when an adolescent was in the bathroom for a prolonged period or nurses could see feet moving under the door, they insisted that they always provided the adolescent with “due warning” before invading their privacy. Most nurses maintained they knocked first or warned them that if they did not come out soon then someone would be coming in. In some instances, locker searches of patients' belongings were undertaken to check for any prohibited items, such as syringes, sugar free gum or diet drinks, bottles of water and laxatives. The commonalities are clearly evident, between these locker and room searches, to the cell search or personal/strip search that may be conducted in a prison system (Easteal, 2001; “Just Oz”, 2004; Walsh, 2006), when prison officers are suspicious that contraband, such as cash or drugs, may be being concealed within an inmate’s clothing or in their cell.

Nurses felt that these invasions of privacy were “the parts [of their job they] hated most” and it made patients angry and their day with them a lot harder. The adolescents agreed being on the program meant they lost their privacy and in retrospect it was not the nurses’ fault because “a lot of it was on the program for them to do”. Some patients realised that it was needed for those who would continue with dangerous weight loss practices if situations were not handled appropriately by staff. In contrast to the nurses’ assertions of always providing “due warning”, the adolescents provided examples when nurses had not given a visible warning prior to opening curtains around their bed or opening the toilet door.

The insertion of a nasogastric tube was considered an “unpleasant”, “pretty awful”, “uncomfortable” and “distressing” procedure for nurses to undertake and could be seen as a ‘bodily invasion of privacy’ by the adolescent. Yet again nurses justified their actions as
for the patient’s own good. At times nurses described having to sedate a patient or forcibly hold a patient down while inserting the tube. This was distressing not only for the patient but for the nurses involved as well. Mandy recalled an instance where she questioned whether what she was doing was ‘unethical’ and felt that nurses should not be “hold[ing] them down” because “they are not criminals”. Retrospectively though, she decided that as nurses caring for adolescents with anorexia it was something “you have to do”. Linda summed up the feelings of the majority of nurses by saying: “it is just part of the job and there are parts of any job that people don’t like to do, but you’ve got to do it whether you like it or not…I see that as something that has to be done”.

The adolescents, as well as the nurses, acknowledged the humiliation and embarrassment felt by patients on weigh day. Not unlike a prison inmate who may be forced to wear a uniform with a number emblazoned across it, the adolescent wore a gown usually with their backs exposed and were expected to carry a bedpan of urine out to the nurse for testing on weigh days. Many of the adolescents were appreciative that other patients on the ward were not awake to see them. Weigh days were significant in deciding whether ‘rewards’ or ‘punishments’ would be bestowed. ‘Punishments’ included withdrawal of physiotherapy, no ‘gate-passes’, moving down a level, or being placed on Level One-‘bed rest’. The nurses added that the hospital admission and threat of a nasogastric tube were also considered ‘punishments’. The greatest reward for the adolescents was a ‘gate-pass’ which for them meant “freedom” and time away from the “controlled environment”, again, not unlike time in the ‘exercise yard’ for the prison inmate who can get some fresh air and exercise. However, unlike inmates who may still be under the constant glare of prison officers, this actually afforded adolescents some relief from the constant watch of nurses, though parents would in some respects take on this responsibility.

As the prison officer, nurses described their frustrations with caring for adolescents with anorexia. It appeared that they became ‘protocol driven’ in their care of these inpatients. Many nurses described the nature of their care as being “routine”, “automatic” and “monotonous”. They could set themselves to “auto-pilot”. Many described how they would “go in, do [their] job and go out”. Thus in effect many admitted they attended to the physical care tasks without developing any sort of therapeutic relationship. As a result of the role nurses played within the program many believed “it [was] such a challenge…to
interact with them or get them to interact with you and build a rapport”. Many nurses went into this “policeman mode” of nursing as a “self-defence mechanism”. The work for nurses was “a lot more demanding” and “frustrating” because the improvements happened a lot more slowly and were more indiscernible than with other patients. Some reached their target weight for discharge but would return a few weeks later sometimes in a much worse state. This made nurses feel they were “banging [their] head against a wall”.

Most nurses described how adolescents with anorexia did not see themselves as sick or as needing the help that nurses offered them and consequently, by following the program rules, nurses were “doing things to them against their will”. Most nurses, though, said that they enjoyed caring for adolescents with anorexia “but in small doses”. It was always going to be exhausting and draining to take on the role of “Food Nazi” and to discipline adolescents when they pushed the limits around the prescribed rules. Some nurses, on the other hand, did not feel that what they were doing truly constituted ‘nursing’ and had to remind themselves that these patients were sick and had a mental illness. Some nurses admitted they did not enjoy caring for adolescents with anorexia and some did not display compassion towards their situation. Mandy² believed they have “a choice”. Others “tolerate[d] them”. Veronica² explained that it was “hard to build…relationships up with them” and that was why staff became ‘protocol driven’ and their “emotional support” suffered. The nurses explained that they were not fully informed about a patient’s family and social situation or the triggers to the onset of the disorder. Nurses felt that if they had this understanding this would aid their attempts at forming relationships with adolescents with anorexia without worrying about saying the wrong thing. Overall, it is evident that frustration tended to encourage a view of anorexia as not really a ‘genuine illness’ or, at least, to allow these nurses to forget this fact.

The adolescents described most nurses as “nice”, caring and flexible and as “doing…what they’ve been told to do”. So the majority of adolescents felt the actions of nurses implementing a demanding and restrictive program should not be seen to reflect on them personally. Nevertheless, the adolescents tended to focus on the negative experiences or interactions that occurred on the program. A reason for this may be that these experiences were remembered more clearly because they had a greater impact in making their time more arduous than it should have been and the adolescents were particularly sensitive to these experiences. It is also not unusual that adolescents with anorexia, when
provided the opportunity to reflect on their experiences as an inpatient, often against their wishes, would focus exclusively on the negative aspects of the program and their care. As the nurses assumed, entering ‘The Level System’ as an ‘inmate’ made the adolescent feel abnormal. Some of the adolescents described feeling inferior to the other patients on the ward and that some of the adolescents with cystic fibrosis made them feel this way too. They felt, or were made to feel, that they were not as sick as the other inpatients with other diagnoses. Amber¹ also added that nurses giving bolus feeds down her nasogastric tube made her feel inferior to everyone else. Cameron¹ initially felt “demoted” and “embarrassed” by his nasogastric tube but then considered that anorexia was “an illness” and equated the nasogastric tube to “having one of those IV’s in your arm”.

The adolescents described numerous negative experiences with nurses while on the program. The nurses that were considered “really strict” with the program or acted like “the boss” were the ones adolescents “hated”. Some explained that “it was a bit of overkill” in that these nurses classed every little thing such as, “swinging on…tables”, “shaking…legs” to juggling as forms of exercise. The adolescents felt that on the program they were not treated as individuals and these particular nurses performed their job without “putting feelings into the equation”. Some nurses, they claimed, forgot they were human beings.

Female inmates in Easteal’s (2001, p. 99) study also felt that there was a “general attitude displayed toward them that seemed to say that they were somehow less than human”. This occurred unintentionally but the adolescents were acutely sensitive to “labels” such as “anorexics” or “ED’s”. Amber¹ felt that the manner in which a nice nurse said: “Okay, I’m going to feed the ED girls”, made them feel like “zoo animals”. Inmates, again in Easteal’s (2001, p. 93) study, expressed similar sentiments of feeling demeaned and having a ‘childlike dependence’ on prison officers. They too (grown women) were labelled as the “girls” (Easteal, 2001, p. 93). With eerie similarity to Amber¹, a Victorian inmate in Easteal’s (2001, p. 93) study said, “You don’t get treated like anything…like an animal, like you’re in the zoo”. Another adolescent described a nurse who commented about a new patient with anorexia by saying: “Yes, she is one of your lot!” The adolescents were highly sensitive to the tone of voice and the manner in which nurses spoke to them or about them.

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The adolescents knew that some nurses did not enjoy caring for them and these nurses had minimal contact and engaged in little conversation at the dinner table. Adolescents said they made them feel like “a waste of space” or “like crap” and they exuded sentiments which made patients feel that they should not be here. Unfortunately, these nurses often did “the bare minimum” and forgot mealtimes which the adolescents equated with a lack of care for them. The adolescents explained that the nurses who did not like them often thought of them as not being “sick” or as “doing it for attention” and that, when they had to care for them, they had drawn “the short straw”. Some nurses, particularly casuals, tried to force “God on you” which they felt was unhelpful. Personal comments clearly hurt the feelings of adolescents with anorexia. On the other hand, some of the adolescents felt that it was this “easy” nature of the work and “low maintenance” of patients that appealed to some nurses who did not mind caring for them.

Negative experiences with nurses and doctors while on the program obviously affected the establishment of a therapeutic relationship. The worst experiences were related by Josephine¹ who retold how, during one of her early admissions, some nurses were “really sarcastic” and “hurtful”. One particularly poignant example she related was that nurses would request the song “Eat It” by “Weird Al Yancovic” and then tease the adolescents as the song played. Adolescents with anorexia are acutely affronted by personal comments about their condition and nurses being insensitive, as the above suggests, would not foster trust or any level of comfort within which to initiate the building of a therapeutic relationship, as these comments would be difficult to expunge (if it all) from an adolescent’s memory. Cameron¹ explained that adolescents with anorexia were also “judged” more than other patients and the nurses verified that they did tend to “look out for their behaviour” more.

The feeling of being “trapped” on the program was expressed by two adolescents. Josephine¹ reported a time when she had been placed on Level One orders by the doctors and was regularly sedated with valium by the nurses (as per doctor’s orders) after she hit a doctor with a mathematics book. Her worst experience though was the time she spent in the Intensive Care unit³. Of the events she could remember, she reported being

³ The adolescent in this instance was recalling an admission to the PICU (Paediatric Intensive Care Unit) that took place in 2002. This decision was made after numerous admissions to the inpatient ward setting, the adolescent’s complete refusal to eat and drink and non-compliance with the program resulted in persistent chronic weight loss. This patient had been scheduled under the Mental Health Act and with her family’s consent and support was sedated and fed continuously via a
“drugged” and fed through a nasogastric tube. She remembered feeling “tired”, “distressed” and “dribble[d]” because “[she] couldn’t control anything”. Amber¹, alternatively, felt “trapped” when she received “bad news” from the doctors. She felt she was “never going to get out”. She was trapped here against her will.

Overall though, as stated earlier, most adolescents felt the majority of nurses were nice. They made them feel normal, encouraged them, were talkative, supportive, friendly, caring and a few (not many) even felt comfortable enough to approach certain nurses with their problems. Zac² explained this situation clearly by saying: “I think it is more the action you take rather than the person you are that they don’t agree with”. Nevertheless, there was an apparent ‘us versus them’ mentality on the ward or, as earlier pointed out, a symbolic ‘predator versus predator’ standoff because there was a clash of goals between what nurses were trying to do and what patients wanted to do. The manipulation of nurses and of the system by patients was rife on the ward: it was a means of rebelling against the controlling conditions, the program and its expectations. Manipulation by inmates may also be seen within prisons. In Easteal’s (2001, p. 97) study, prison officers likewise saw the women inmates as “devious” and “manipulative” especially in regards to drug trafficking.

Doctors, as part of the program, were described by patients and nurses alike as the main decision makers. Adolescents explained that doctors were in a powerful position as they ultimately controlled their lives, took away their freedom and gave the orders. Nurses unfortunately were not far behind as they carried out the doctors’ orders. However, some adolescents acknowledged that this was ‘not the nurses’ fault’ and that often they became the “scape goat” with adolescents displaying anger towards them for decisions that were ultimately made by the doctors. The adolescents reported the numerous tactics they used, or have seen others use, to manipulate the program and the nurses caring for them. It was reported that some adolescents informed on others who were misbehaving, for example, by informing a nurse that all food requirements have not been consumed by a particular patient or informing doctors that someone had been exercising at night. Such behaviours can be seen to have a clear parallel with the not uncommonly known role of the ‘informant’ within the prison system. Initially the adolescents explained that their

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¹ Amber
² Zac

(nasogastric tube in the Intensive Care Unit. This is a rare occurrence within the institution under study and the PICU setting has not been used since for the treatment of an adolescent with anorexia nervosa.)

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reasons for the manipulation were that it was “hard to break a habit” but had a “drive to do it”. Nurses and doctors were making them do things that ‘the anorexia’ (i.e. the disease itself) did not want, and through manipulation they felt less guilty because they were able to appease the anorexia.

The way nurses approached a patient in response to their inappropriate behaviour would impact greatly on whether a relationship of sorts formed between a nurse and patient. The nice nurses displayed greater respect for the adolescents and would “knock on the door”, hand out a warning for a ‘first offence’, thus allowing them the opportunity to maintain a “clean slate”. They also continued to provide the adolescent with constant encouragement to do better. Other nurses, however, were not as discrete and would say things like, “Get out now! You’ve been in there too long”, or, “Show me your pockets”. Nevertheless, patients eventually realised that they could not ‘buck the system’ forever. In order to “get out” they needed to comply with program rules. According to Morgan (1981), the term ‘programming’ within the prison system, is reminiscent of the above and is used to denote the inmate “who adheres to the rules and does his assigned duties so he can get as favourable a break on his parole record as possible [by] following his program” (p. 265).

There was a difference of opinion between nurses and adolescents in interviews, in that adolescents believed that most patients did follow the program while nurses felt they definitely did not, especially those that had been admitted more than once. Nurses insisted there were many instances when adolescents appeared to be following the program but they were losing weight and so clearly something else was happening. Nurses felt that staff were definitely manipulated by patients on this program and they saw a ‘befriending relationship’ breaching that nurse-patient boundary. Nursing staff reported seeing other colleagues being “played” by adolescents who were “clever” at building up a friendship with a member of staff who was not as tough on the rules and this then allowed them to receive special favours or get away with certain behaviours that they may not have with a different member of staff. This befriending was also explained by an adolescent who described trying to be friendly with the dietician in the hope of receiving better treatment. Flattery was also used by adolescents to compare one nurse’s abilities to another in the hope of getting on a nurse’s good side. Not surprisingly, within prisons this behaviour also occurs with inmates, according to Morgan (1981, p. 264), “strok[ing]…the power brokers by playing up to them in hopes of receiving favors, now or
in the future”. The ability of adolescents to “play staff” and cause conflict among staff was a consequence of the inconsistent approach taken by staff members in following the rules of the program.

Most nurses, though, were aware of manipulation and had seen many instances. The nurses who had been working with adolescents with anorexia for many years expected manipulation and paradoxically reported being concerned when they did not see it. Most were aware that at times they would need to undertake unpleasant tasks such as inserting a nasogastric tube, looking for contraband items by undertaking “locker checks”, or needed to check pulses if they felt an adolescent had been exercising or needed to tape nasogastric tubes if they suspected manipulation of feeds. This was their job. They understood that these adolescents were ill and would ‘buck the system’ in order to “progress in the program without having to gain weight” thus achieving a “victory” in their minds. However, the “spotting of [this] weakness” in the program that they could “exploit” to “get out” only led to a vicious circle as they usually returned. The nurses did consider the rebellion to be a part of adolescence but they all predominantly felt, that in the case of adolescents with anorexia, it was also a component of the illness. Nurses believed they denied any illness and felt that they do not need any help. They “don’t want [the eating disorder] fixed right now”. Nurses explained that each nurse had a different way of managing manipulation. Most nurses would inform each other of their suspicions so everyone can “keep a closer eye on it” and then the information was passed on at meetings. Some handed out automatic punishments such as 24 hour ‘bed rest’ but the ‘better’ nurses would hand out a warning, sit down and talk about the behaviour and then instigate 24 hour ‘bed rest’ if the behaviour continued.

Building relationships with adolescents within ‘The Level System’ program was particularly onerous for nursing staff. Obstacles were a direct consequence of the behaviour-modification program and the varied roles nurses played within this controlled environment in terms of being vigilant and wary. As Zoe¹ explained, nurses “walk a fine balance between being caring and connecting with you and doing their job”. The relationship reached a point but could not advance further past this point into something more substantial and potentially healing.
The adolescents described their difficulties in trusting and forming a connection and a positive relationship with someone who was enforcing the rules of the program (that is, “doing [the physical tasks] of their job”). The adolescents “hated” what nurses did because ‘their anorexia’ rejected it. The most concerning aspect was that the adolescents felt that they could not confide in a nurse because in effect “they [were] an extension of the doctors” and had an obligation to report to them. The adolescents were thus wary of what nurses told doctors and what they wrote in their nursing notes. Such sentiments are not unfamiliar in a prison system, in which inmates are reluctant for a disciplinary report known as a “ticket” appearing in their prison file (Morgan, 1981, p. 266-267). The adolescents described nurses as spies for the doctors who interrogated them for information. Some reported feeling that any conversation was a guise to obtain further information. Nurses corroborated the view that they were the “eyes and ears” for doctors and were always judging behaviours to ensure they adhered with the program. Decisions at meetings were influenced by these observations.

The nurses’ personality and gender affected relationships on the ward. The female adolescents feeling greater comfort and compassion from female nurses while the sole male adolescent felt more comfortable with male nurses. Overly strict nurses were viewed as having had no compassion or understanding of their situation. Nurses still remained the “enemy” in the eyes of the adolescents. Nurses were always going to be overly suspicious and mistrustful of adolescents with anorexia and this feeling was shared by all the adolescents.

The adolescents described they were content with nurses efforts but my influence as researcher and nurse for this study may have affected their comments. The relationships being formed on the ward were clearly not ‘textbook’ therapeutic relationships as discussed in Chapter Three and it was evident that some nurses were better at the ‘balancing act’ than others. These nurses according to adolescents were “fair” but “flexible” and knew “what to push and what not to push”. Some of the ‘nice’ nurses who were also perceived as being strict were indeed the adolescents’ ‘favourites’. In this way adolescents were quite sophisticated and mature in their views, describing some nurses as both ‘nice’ and ‘strict’. In this respect the two labels were not perceived as being mutually exclusive with the key apparently being that these nurses were perceived as not
“overly” strict and their personality enabled them to compensate for the level of strictness they employed.

The adolescents believed their illness would never allow them to completely trust nurses within this system. The treatment revolved around food and the adolescents could not trust people when it came to food. The adolescents described being “intimidated” by nurses who were “following a procedure”. They felt most were ‘robotically’ fulfilling a job and did not “really care” about them. The role nurses played within the program once again diminished the trust in the relationship. For some of the adolescents, nurses pouring out overnight feeds into bags without allowing the adolescent to watch diminished their trust in them. Zoe¹ commented: “an anorexic person will never trust you if you don’t show them”.

Additional negative experiences demonstrating what the adolescents conceptualised as the nurses’ suspicious nature within the program, included nurses ripping open the curtains around their beds, opening the toilet door without warning, rechecking their food containers after they had shown the nurse that the container was empty, re-weighing patients, checking pockets for food, placing ears to the toilet door or asking others such things as: “How long have they been in there for?”. The adolescents believed that even the ‘nice’ nurses were suspicious of them. These negative experiences upset the adolescents and many times they felt they were falsely accused. The false accusations made the adolescents unwilling to trust these nurses or inclined towards forming a trusting relationship with them. The adolescents reported that the ‘false accusations’ were difficult to disprove and the adolescents felt wounded by them because the nurses did not believe them when they denied these accusations. Melinda¹ reported it makes you “not like” or “want to talk to” certain nurses and for Cameron¹ the constant accusations almost made him want to engage in these practices. The adolescents suggested that it would help relationships on the ward if nurses gave them ‘the benefit of the doubt’ the first time something appeared suspicious rather than jumping to conclusions. Similarly, Zoe¹ argued strongly that adolescents with anorexia should be considered “innocent until proven guilty”.

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The adolescents described overhearing nurses talking with doctors or other nurses at the nurses’ station desk about another eating disorder patient. The adolescents felt they could not trust that nurse and if they had a relationship with the nurse it broke down once conversations were overheard at the desk. Thomas², a nurse, corroborated this account and said that he had heard nurses discussing patients at the desk. Again for many adolescents the main issue was that they could not trust nurses on this program because nurses colluded with the doctors, enforced their orders and reported to them.

Nevertheless, retrospectively all the adolescents admitted that nurses’ fulfilling their role within this program was essential otherwise adolescents with anorexia would not eat or would misbehave if no-one was watching. They understood and believed that part of the nurses’ role and job was to be suspicious. Despite this Megan¹ explained that there would only ever be a “level of trust” between nurses and patients with anorexia nervosa and this took a long time to develop. They trusted very few nurses. These nurses were nice, competent, aware of the program rules, fair to all patients, engaged in conversation, provided support and listened to their concerns. Adolescents needed to feel a sense of security and comfort in the relationship which was extremely difficult to achieve within this program and with nurses and doctors controlling everything. Zoe¹ insisted that even though adolescents with anorexia mistrusted nurses, that this did not reflect poorly on their efforts to engage with them in a relationship, with many nurses putting in an enormous effort and, as Cameron¹ revealed, were “trying to their potential”.

The nurses agreed they were not working within a treatment environment (or context) conducive to the development of therapeutic relationships. Nurses “call[ed] a lot of the shots” and were the “baddies” of the program. The adolescents were obviously placed under a lot more restrictions than other patients and had minimal choices with consequences for the choices they did make. The nurses were aware that establishing rapport and trust with an adolescent with anorexia would be exceptionally difficult with these barriers in place until they reached the recovery period. As with the adolescents, nurses confirmed that they needed to be suspicious of the adolescents with anorexia. It was “the nature of the work”. They had seen it all before: the watering of feeds, the aspirating of tubes and the exercising making them constantly mindful of the need to be alert to this manipulation. This is why they needed to check overnight feeds regularly, taped or marked bags and their connections and watched like hawks at the meal table or...
listened at doors for exercising. The desperation of the adolescents was such that there were too many who would “swear blue in the face that they [were] not doing something when it is quite obvious that they [were]”. The nurses felt that the adolescents’ negativity to the program was enhanced because they did not consider themselves ill or needing help and were entrenched in their behaviours. The negativity from patients had the effect of increasing nurses’ stress and frustrations, as well as inhibiting appropriate relationship formation. Nurses, as with the adolescents, stated that personalities clashed on the ward and gender and age was also found to affect the quality of and capacity to form positive relationships.

Additional obstacles for therapeutic relationships included the ward environment and staffing levels. With the current high acuity of other patients and busyness of the ward this meant the enrolled nurses, junior staff or even casual nurses were often allocated the adolescents with anorexia. Nurses and patients both agreed that the adolescents with anorexia were accorded a “really low priority on people’s lists”, with the care considered being straightforward. However, many of these nurses were being ‘burnt out’ and frustrated by the emotionally draining assignment and this led to inconsistency of care, as well as enabling the splitting and manipulation of staff. The emotionally challenging nature of their care often left these nurses exhausted. They would reach a breaking point where they reverted to task-oriented nursing rather than holistic nursing just to “get [their] job done”. Inconsistency of care among all staff members led to increased manipulation by patients and, for patients, less trust in nurses. Thus the therapeutic relationship suffered as time and effort would not be devoted to this aspect of their care. The numbers of patients being admitted at one time also affected the quality of relationships especially when a “confrontational” leader of the group influences the others to “test [the nurses’] authority”. Interestingly the majority of nurses believed that they did remain honest and faithful in their encounters with adolescents with anorexia. However, some also acknowledged that, on occasions they did make promises that they could not keep and this was detrimental to obtaining trust in the relationship. Similar behaviours within prisons are reported by Easteal (2001), where promises may also be made but not kept.

Unfortunately, though, the “power struggle” between nurses and adolescents with anorexia cannot be avoided on a program such as this and in effect, impacts negatively on the establishment of therapeutic relationships. The mutual mistrust that each had for

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one another was considered a "safety net". For Linda and she did not mind being the enemy and stated, “I am paid to do a job, so I do it effectively”. Doctors and nurses were in control and this was considered essential by the nurses as “their [patients'] disordered eating” was “out of control”. Despite this, nurses felt that control should gradually be reinstated yet were forced to recognise that the program provided little “room for movement”. The adolescents were given minimal choices on the program and there would always be parameters around these. Not having the background information about the onset of the disorder, a patient’s family and social situation also made the task of forming a therapeutic relationship difficult and more frustrating for nurses. With nurses like Veronica being less “compassionate” towards their situation. Additionally hostile parents were regarded as obstacles to therapeutic relationships, with nurses having to not only battle against the eating disorder but hostile parents who found it difficult to understand and follow the rules and were essentially supporting destructive behaviours.

The nurses understood that therapeutic relationships and positive interactions with adolescents with anorexia were critical for the adolescent “to embrace that recovery process”, yet these relationships were incompatible with the behaviour-modification program and the nurses’ role within the program. With the multitude of obstacles in their way nurses still believed they never stopped trying to form this connection with their adolescent patients. This effort was also acknowledged by the adolescent patients in the study. The nurses were able to provide excellent advice for others on how one should approach caring for adolescents with anorexia, yet understood that for them it was a challenging feat in terms of the program they worked within. My observations as researcher for this study validate as accurate the stories and descriptions provided by patients and nurses throughout this study.

The inherent conflict between the opposing logics of treatment based on behaviour-modification, on the one hand, and the need for the formation of therapeutic relationships, on the other, was the main complexity for nurses in forming therapeutic relationships with their adolescent patients (Shoebridge, 2002, p. 3). With the intense demands on nurses’ time within an acute care setting, nurses appeared to revert to ‘task-oriented nursing’ becoming ‘protocol driven’ in their care of adolescents with anorexia and thus losing the centrality of caring. The key attributes nominated in Chapter Three for a successful therapeutic relationship conflict strongly with the logic of a behaviour-modification
program. How can there be trust in the relationship when nurses are always suspicious of their patients or are reporting to doctors? How can there be unconditional positive regard and a non-judgmental attitude when nurses are obliged, within this ‘Level System’, to constantly judge their adolescent patients’ behaviour in order to either punish or reward them? (Shoebridge, 2002, p. 3). How can there be empathy when nurses feel they lack understanding of individual patient’s condition and personal circumstances? How can there be limit setting and boundary setting when nurses and doctors are inconsistent in their adherence to the program and some nurses are crossing the nurse-patient boundary?

In agreement with the literature (Deering, 1987; Garrett, 1991; George, 1997; King & Turner, 2000; Ramjan, 2002, 2004), it is challenging to form therapeutic relationships with adolescents with anorexia but this is made even more challenging within the context of a behaviour-modification program like ‘The Level System’. Manipulation allows the adolescent to maintain a stronger hold on their eating disorder while rebelling against the program’s authority figures. The conundrum nurses faced was that following the program meant that they were doing something ethically valid, that is, saving a life, whilst this effectively led to the downfall of trust and essentially, the capacity to form therapeutic relationships with their adolescent patients. The power imbalance led to an ‘us versus them’, ‘hawks versus wolves’, or ‘predator versus predator’ situation. That is, a ‘no-win situation’. The nurses were enforcing the program, negotiation was minimal and adolescents were denied basic rights. As Oliver² explained nurses were “expected to do two things that [we]re pretty much diametrically opposed”. They were supposed to engage with adolescents on a “personal supportive level” but then as part of their job they were “taking them down [for meals] and leaning on them to cooperate and do what they know is right”. In essence nurses were symbolically the “evil clinician” or “Nurse Ratched”. They were the “people that carr[ied] out…the you do’s, you don’ts” and thus became “the bad guy and the good guy all in one”. The nurses tried to their individual potential to form therapeutic relationships against all odds, but trust (or a ‘level of trust’) became trust in the nurses’ competence to care for them in a physical sense, as care became ‘protocol driven’, rather than trust in a person to confide in, as in ‘holistic caring’.

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ON PAROLE OR RELEASE

Discharge from the hospital program for the adolescent with anorexia can be seen as being similar to ‘release’ from prison for the prison inmate who has shown that he has been ‘rehabilitated’ or has served his ‘sentence’. The inmate may be someone that has remained on their best behaviour while in the prison system; not being involved in fights or disruptions. They would more than likely have an early parole hearing because of their overtly ‘clean slate’ while in prison.

Once an adolescent had been discharged and was believed to be on track towards a healthier lifestyle they were expected to come in for weekly “check-ups” with the doctors in the Adolescent Medicine Unit (AMU). The check-ups were designed to monitor whether the adolescent was coping out in society, whether they were maintaining their weight and maintaining a healthy social life. Again, this can be considered comparable to the recently ‘paroled’ inmate, who may have to attend regular visits to the authorities, such as the police or parole officers, who monitor their progress. Walsh (2006, p. 114) reported that “prisoners may be monitored in a number of ways while they progress to liberty; however, best practice suggests that they should be personally supervised by a community corrections officer, who also provides them with emotional and practical support” similar to that provided to adolescents attending the AMU. Parole violations may necessitate re-entry to prison while for the adolescent with anorexia, an inability to maintain weight and progress on the ‘outside’ may necessitate re-admission.

The phrase ‘doing time’ means “serving a sentence” and this phrase according to Tupper and Wortley (1990b, p. 3) encapsulates “the sense of futility and waste that is a prison sentence”. For a few of the adolescents with anorexia, the multiple, lengthy admissions to hospital were eventually seen in this same light. The impetus for recovery for these adolescents was a realisation that they did not want to spend the rest of their life in hospital. For many their turning points were a realisation that they did not want to do this anymore and that they had other goals and aspirations in their sights. Some kept reassuring themselves that things were better when they did put on weight as they did not want to be sedated or to spend their whole life in hospital. Zoe exclaimed, using prison terminology again, that it was “better being out than in”. This is similar to the feelings of inmates in Wilson’s (2003) study who described how “prison was not a good place, but a
‘pause’ in their lives that stopped them achieving what it was that they had wanted to achieve” (p. 422).

Recovery took a long time for most adolescents. Some adolescents decided that they would never completely recover and would always be a ‘recovering anorexic’ who could “get in a spiral again”. For some recovery was being ‘normal’ again and was a realisation that “who you are isn’t [dependant on] how much you weigh”. Nurses agreed and felt that recovery was a change in mindset, with the adolescents having plans for their future and returning to a ‘normal’ life. Nurses, too, felt that for some adolescents, the anorexia would always stay with them. Akin to the institutionalisation process seen in prisons, some adolescents feared going home and felt inadequately prepared for the ‘outside world’. Thus the ‘revolving door syndrome’ was apparent. Nonetheless those adolescents that were on the road to recovery described their relationship with healthcare professionals as somewhat helpful, but they found the support they required for a genuine therapeutic relationship elsewhere, in family, friends, Church, school and other patients with an eating disorder. Similarly, in Wilson’s (2003, p. 419) study of young black men in prison, he described how “these young black men would look to each other as sources of comfort and support at times of crisis and conflict”. Like the people in the study by Garrett (1998), recovery for these adolescents with anorexia took place within a therapeutic relationship where a ‘new identity’ could emerge and they could feel a sense of normality.

There were clear parallels between ‘life on the ward’ and ‘prison life’. Nurses had become “jailers who made them eat, administered punishment for not eating, and in other ways disrupted their sense of control” (Beumont, 1992, cited in Irwin, 1993, p. 349). Adolescents, not unlike prison inmates, were confined and dependent on others when in the system. Their outlet was to rebel against the power-brokers so as to recapture something of their independence, their space, and their rights. ‘Reforming the system’ will take time but may decrease the level of frustration for nurses and patients, may enhance therapeutic relationship formation and may even reduce the ‘revolving door syndrome’. Adolescents may then be ‘eating to recover’ rather than ‘eating to get out’. The final chapter (Chapter Seven) sets out the recommendations from this study for ‘reforming the system’ as well as areas for further investigation.
Chapter Seven

CONCLUSION

“...the prison is a silent world still shrouded in mystery”

Blom-Cooper, 1978, p. 72
This thesis set out to investigate whether the formation and maintenance of therapeutic relationships were possible between nurses and adolescents with anorexia within an inpatient behaviour-modification program. This study is in agreement with the plethora of literature within the nursing field, particularly mental health nursing, that asserts that the formation of a therapeutic relationship is fundamental for the successful treatment, care and recovery of a person with anorexia (Deering, 1987; Garner, Vitousek & Pike, 1997; George, 1997; Halek, 1997; Lilly & Sanders, 1987; McNamara, 1982; Muscari, 1998; Sloan, 1999; Wolfe & Gimby, 2003), and agrees that the establishment of such a relationship with an adolescent with anorexia is an extremely challenging task for nurses (Deering, 1987; Garrett, 1991; George, 1997; King & Turner, 2000; Ramjan, 2002, 2004). Yet the challenge in forming this positive relationship appeared ever so more pronounced within a behaviour-modification treatment program such as ‘The Level System’, where metaphorically the hospital became a ‘prison’, adolescents with anorexia became its inmates and nurses and doctors took on the role of prison officers. Thus, this study revealed a strong problem-laden or oppressive metaphor driving the ward which clearly needs to be reflected upon, revised and replaced. Bonner and Greenwood (2005, p. 70-71) have described that “[m]etaphors are pervasive in everyday thought, language and action. In particular, they are literary devices which assist in understanding difficult concepts”. Metaphors can be subtly shaping and constraining for practice if they are not consciously surfaced, considered and revised. In this chapter a number of recommendations for action are offered to achieve this.

This chapter focuses on providing an account of the recommendations for change that the participants have advocated, assessed in terms of their consistency with theoretical understandings within the literature as well as their usefulness, practicality and potential to be implemented. Before discussing these recommendations, it is important to recognise future areas for investigation and the limitations of this study. Firstly, many other multidisciplinary team members are involved in the care of adolescents with anorexia on this program. I have not included their particular viewpoints of the program and their relationships with patients with an eating disorder. The viewpoints and opinions of these groups and their various experiences should be a subject for another study. Furthermore, as I was unable to provide a comparison of different hospital programs and nurses’ abilities to form therapeutic relationships with patients with anorexia, this should also be a future area for investigation. A further consequence of this study is the evident need for
critique of ‘The Level System’ program itself, including how well the goals, assumptions, strategies, system of rewards and consequences are made explicit and accessible to those implementing it. Similarly, as this study did not dwell on the ethical implications of the care being given in programs like ‘The Level System’, these are other pertinent areas for further investigation.

As explained in Chapter Four, the naturalistic approach was deemed the most appropriate approach for this study in order to elicit ‘context’ and ‘time’ specific constructions of the daily experiences of ward life, for adolescents with anorexia and their nurses. Thus these recommendations and findings will have most relevance for the ward under study. The ‘time’ and ‘context’ bound nature of this study; the use of one adolescent ward as well as the small sample size limits the generalisation of findings. Nevertheless, this study still provides insights and understandings which may be more broadly applicable.

As the foregoing analysis demonstrates, ‘The Level System’ program, based on behaviour-modification principles, was at odds with the elements of a therapeutic relationship. Many nurses within this program became ‘protocol driven’ and reverted to ‘task-oriented’ nursing rather than ‘holistic nursing’, thus often neglecting the psychosocial aspects of the adolescent's care. Nursing ideology professes a holistic model of care which was framed in direct contrast to and critical of the biomedical model (which the behaviour-modification program exemplifies), emphasising task-oriented care (Short, Sharman & Speedy, 1998). ‘Task-oriented’ nursing was thus easier to achieve within this highly medically oriented program. Beumont and Vandereycken (1998, p. 6) pointed out: “[nurses often] face the conflict between forming a trusting relationship with the anorectic patient while simultaneously showing distrust in respect to her (sic) behaviour by supervising meals and daily activities”. This was the case within the program studied. In many ways, nursing care for the adolescent with anorexia reverted to a type of custodial care of being “a passive watcher and guardian…” (McEwan, 1961, p. 13), with nurses’ attempts to establish a therapeutic relationship being limited by the role they played as enforcers of this paternalistic program.

Hannah-Moffat (2001, p. 18) in her book, Punishment in disguise: Penal governance and federal imprisonment of women in Canada, claimed, “the relations among the ‘keepers’ and the ‘kept’ are shaped by the institutional dynamics of imprisonment”. Similarly, within

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this study, nurses’ relationships with adolescents with anorexia were influenced, or ‘shaped’ by the role assigned to nurses, their fundamental mistrust of their charges and the rigid rules and protocols of ‘The Level System’ program (i.e. environment). Whilst Hannah-Moffat (2001, p. 199) claimed “[prisons] are not the solution”, so did some nurses within this study similarly feel that the ‘institutionalisation’ of adolescents with anorexia nervosa in an acute care setting was inappropriate. The multiple readmissions and ‘revolving door syndrome’, characteristic of this program, left nurses disheartened with their efforts. Some nurses believed that a more homely environment (if a patient was medically stable) such as a “half-way house”, “community day care centre” or “safe house” was an environment more conducive to the development of therapeutic relationships. In these environments, it was perceived that the appropriate attention and support could then be provided.

A critical question raised by this study is what environment is best suited to the treatment of adolescents with anorexia. It would appear that the acute care paediatric setting is not the most conducive environment for such patients, as the results support a conclusion that these nurses, whose primary role is acute care nursing, were inadequately educated and trained in mental health issues. Adolescents with anorexia do require nurses who have specialised mental health training and experience in forming therapeutic relationships. Nurses with specialised training in mental health nursing are more likely to have acquired knowledge and skills to assist them in caring for people with this challenging condition. The establishment of therapeutic relationships are a critical component for healing and recovery but overwhelmingly there is also a need for the successful treatment of adolescents with anorexia to create an optimal therapeutic milieu structure.

Arguably such a therapeutic milieu could be accommodated in the present hospital if the hospital system is responsive to this urgent need. In this respect, a specific purpose designed ward, limited to adolescents (i.e developmentally age appropriate) with specialist nurses could be formulated within the current paediatric hospital setting. Education for these specialist nurses would need to include an understanding of the elements, stages and turning points in recovery from anorexia nervosa and not only of its manifestations and aetiology. Additionally if behaviour-modification therapy approaches are used, then staff (and patients) need training in the principles and strategies of behaviour modification and behavioural theory. That is, they need to understand that the focus of treatment is on

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promoting positive behaviours, essentially shaping and rewarding positive behaviours, rather than being preoccupied with eradicating negative behaviours, such as ‘food refusal’ or ‘deviance’. As this study has demonstrated, this is not currently the case.

Roberts and Hough (2005) reporting on the British prison system, showed that there is public scepticism regarding the ‘rehabilitative’ nature of prison systems and so, too, there was scepticism among these nurses (as there were with nurses in my previous study) regarding recovery or healing for adolescents with anorexia being a realistic goal within such a program as that studied. Similar to the institutionalisation process and recidivism rates seen in prison, the hospital became a “safe house” for some adolescents, who were frequently readmitted due to what appeared to be inadequate support systems and follow-up on the ‘outside’. Goffman (1961) claimed, that a side-effect of hospitalisation is that some patients do not want to leave. Due to the stigma of having a mental illness and being hospitalised for a considerable period of time, in-patients fear the ‘outside’ world. They are comfortable within the dynamics of their ‘new’ environment.

A recommendation proposed for reforming the current system includes the employment of a dedicated specialist nurse (who does not regularly care for the adolescents), to touch base with them each day, to spend time talking with them, educating them about their illness, overseeing cooking classes, befriending them and developing that much needed therapeutic relationship. This nurse, if successful in developing a therapeutic relationship, would be perfectly suited to continue to follow-up and meet regularly with patients at home to assess their progress (Ramjan, 2004) and thus provide the additional support that appears, at present, to be lacking. The existing follow-up appointments with the Adolescent Medicine Department (AMU) were seen as positive but may not be sufficient and certainly do not provide a continuous and coordinated service of the kind recommended above. This more continuous and coordinated service would mean that the specialist nurse could then provide ward staff with a follow-up report on an adolescent’s progress in the community, thus increasing ward nurses’ satisfaction, self-esteem and morale levels by validating the hard work and effort that they are employing each day as worthwhile.

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There were numerous further recommendations for reforming the system identified by both the adolescents and nurses in this study. The nurses and adolescents reported that ‘The Level System’ itself was generally positive and they were satisfied with it in terms of encouraging adolescents to increase their weight so that they were physically better to go home, but believed that it focused on this exclusively to the detriment of addressing psychological needs. This was the biggest area they felt needed ‘reform’. Participants questioned the adequacy of the current psychological therapies being provided to patients once they were discharged. A further recommendation from this study is the need for more one-on-one psychological therapy while an inpatient to assist with the transition from hospital to home. Some adolescents explained that when they were discharged they still felt ill-equipped with the coping skills required to feel comfortable with eating on their own. There is consequently a need for greater psychological therapy to be offered as an inpatient and then better services ‘outside’ hospital; that is, more frequent and continuous psychological therapy as an outpatient. Both nurses and adolescents also need to be made more aware of the current concomitant therapies available to patients, as an inpatient and outpatient, and be aware of how to access these services if they are not already receiving this additional support.

Another drawback of the system was that adolescents never reached the top level of the program and were often discharged on earlier levels. Many adolescents felt that this was demoralising and set them up for failure. For many, reaching the highest level was important to them and indicated that they had reached a milestone. The re-introduction of Level Five is a practicable recommendation. Reaching Level Five prior to discharge may help adolescents feel they have accomplished a goal and thus may increase their self-esteem. They may then not feel as though they are ‘failing’ in the program. Level Five was a “testing stage” to see how well the adolescent could cope with being in charge and in control of their own eating without the excessive scrutiny from nurses. Some nurses had explained that Level Five was removed due to cost-cutting and the need for beds in the hospital, thus patients were discharged earlier and this level disappeared altogether from the program. This reinforces the need for continuity of care for adolescents with anorexia post-discharge, especially if they are to exit the program early.
Additionally, the formulation of a ‘user-friendly’ pocket ‘survival guide’ of sorts, outlining the program rules and its rationales may reduce an adolescent’s worries and anxieties on arrival to the ward. A contract on arrival outlining both the nurses’ and patients’ obligations on the program may also increase feelings of control for the adolescent. The ability to be able to negotiate their rights and treatment options in terms of a contract may enhance their feeling of control while on the program. Healthcare professionals do need to see their adolescent patients as an integral part of the treatment team. A set of ‘confidentiality rules’ could be included within this contract, so that adolescents are aware of when and what they may talk to nurses about, without fear that this information will be passed on to the doctors or documented in the medical notes. Many adolescents suggested that their parents should have unlimited visiting rights initially whilst a patient was on Level One. It would not be unreasonable to also allow the person on Level One to spend a half an hour each day in the courtyard, supervised if necessary by a nurse or parent, to get some sun and fresh air. The visiting restrictions could generally be relaxed too and made dependent on family dynamics and travel requirements. A greater selection of activities for those on Level One could also definitely be organised as well as trialling the introduction of unlimited visiting for those on this Level as well.

If a nasogastric tube needs to be inserted, the adolescents felt that a thorough explanation was necessary and an acknowledgement that it might be uncomfortable and sore for a while. They believed that another patient with a nasogastric tube may be able to provide moral support for the adolescent while the tube is being inserted. This can be accommodated if another patient is willing to act as this ‘emotional support person’ and is something which could be trialled in the unit.

For nurses to be able to establish a therapeutic relationship within ‘The Level System’ program, treatment needs to be firm but fair. Staff need to be consistent in following the rules. There should not be too much flexibility but appropriate flexibility in such cases as a patient truly disliking the meal, the incorrect meal being sent or an alternative being available on the ward. The ‘no swapping’ rule needs to be retained because the adolescents realised that they would always attempt to swap for less. Nurses can trial sitting next to a different patient at each meal to make it fair for everyone at the table and nurses can trial eating with patients while engaging in ‘normal’ conversation. This conversation needs to be therapeutic in the sense that adolescents are distracted from

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thinking about what they are doing. Thus it is best if it focused on personal interests, home, school life and avoided discussion of diets, food or the program. This is consistent with Anderson’s (1996, p. 932) insistence of the need to “[a]void extensive discussion about food at meal times by encouraging conversation about other topics of interest”.

A further recommendation arising from this study is for nurses to re-think the value and potential of joint meal experiences between nurses and patients with anorexia. Nurses meeting and developing a consensus for how to handle these ‘therapeutic meal times’ would elevate the experience from ‘boredom’ to an important nursing intervention. Further discussion would also allow nurses to clarify their own roles within the program, reduce their anxiety about boundary blurring and develop a protocol for handling this emotionally difficult situation. It may be that formal recognition of this potential and its incorporation as a strategy within the program could improve therapeutic outcomes.

The half an hour time limit should start once everyone is seated and nurses should refrain from staring during meals, perhaps by eating with the adolescents or reading a magazine. Food and containers need to be checked inconspicuously during or at the end of the meal. Opportunities to sit and eat outside the ward should be made possible and encouraged. Some adolescents felt that other patients being in the kitchen/playroom (eating or playing) while they ate made the environment a more ‘normal’ environment. In fact, allowing other patients, like those with cystic fibrosis, to sit at the table with them was viewed in a positive light. Looking at the meals these patients ate, the adolescents realised that their meals were not as “scary”. By allowing other patients to sit at the table this may make the adolescents feel less ‘on show’ and more ‘normal’. Additionally, if a patient requires a ‘bolus’ or overnight feeds, to increase trust, nurses could also allow the adolescent to watch them pour out their feeds until they feel comfortable enough or have greater trust in the nurse’s competence.

Nurses caring for adolescents with anorexia need to be encouraging and supportive at the table. Away from the meal table they need to be someone who listens empathetically to them, comforts them, gives advice, is honest with them and does not judge or label them. The nurse needs to be a friendly person who greets them, smiles and acknowledges them each day regardless of whether they are eating or not. Nurses need to treat the adolescent as a normal, respected and valued person and to be fully aware of the

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potential impact which not doing so has on these adolescents. Trust and a therapeutic relationship with an adolescent with anorexia, within a program like ‘The Level System’, takes a long, long time to achieve and can only ever reach a certain point, but adolescents were aware of and appreciated the efforts of those nurses who continually attempted to form this type of relationship with them. McAllister and Walsh (2003, p. 41) described the above as engagement and as “building a trusting partnership through listening, empathizing, conveying hope and concern, motivating the person to do the work necessary to achieve self-understanding and facilitating a sense of meaning and manageability in the illness or recovery experience”.

Nurses should spend more time talking and getting to know their adolescent patients. The half an hour ‘bed rest’ time could be used as a time where nurses played a game of pool or played a board game with patients and thus got to know them better. In effect, most adolescents felt that the ‘bed rest’ time was unnecessary and that as long as patients were away from their bathrooms then they did not see any harm in patient’s watching television, playing pool or participating in other ‘sit down’ pastimes in the playroom.

The staff caring for adolescents with anorexia should be regular nursing staff who feel competent, familiar and up to date with the program’s rules. These staff members need to learn ways to approach patients and handle situations in a non-confronting and supportive manner. Nurses needed to follow the rules but need to think: “Well how can I do what I have to do in the least destructive way?”. These nurses need to be nice as well as able to provide the adolescent with “a clean slate” each day. They need to be able to provide the adolescent with ‘the benefit of the doubt’ the first time misbehaviour occurs and if the misbehaviour continues then this nurse should approach them away from the other patients, have a talk with them and explain the consequences of the behaviour, including documentation in the notes.

Nurses caring for adolescents with anorexia should never communicate or have feelings suggesting that the adolescents are “doing it for attention”. Insensitive personal comments were not conducive to therapeutic relationship formation and maintenance. Nurses can tactfully ask about a particular patient’s situation but should not assume they know why someone has anorexia. Interpreting another person’s worldview is unhelpful and a barrier to effective communication (Burnard, 2005). Nurses need to understand that the
adolescents are not happy and indeed, at times are frustrated with themselves. Adolescents felt strongly that no nurse truly understood their situation, indicating a need for greater education and training for nurses in this area (Garrett, 1991; King & Turner; Ramjan, 2002, 2004). Interestingly, one adolescent and one nurse in this study felt that those nurses who disliked caring for the adolescents with eating disorders should care for them more often as a way of helping them overcome their negative attitudes and become more tolerant if not empathetic. The adolescent also believed that other patients on the ward who disliked them should also be nursed in the same room so that negative feelings and issues can be rectified. As this study demonstrates, the care of adolescents with anorexia is a complex task which requires specialist training, time and experience to develop the range of skills, knowledge and attitudes. This is contrary to the general perception on the ward that the care of adolescents with anorexia is generally easy work and in most instances the allocation of these patients is an afterthought.

More negotiation should occur between the adolescents and the doctors without compromising their physical care. Prior to each meeting doctors should have a quick chat with the adolescents so that the adolescents can voice concerns and make requests before final decisions are made at the meeting. Doctors should also meet with them after the meeting to provide a personal update even if no changes are taking place. Though the updates should not take place in the four-bedded room as privacy is not maintained and there should only be one to two doctors present, otherwise it becomes intimidating for patients who are unable to voice their concerns. A nurse or, if possible, a family member should be present when doctors deliver the decisions from meetings to patients. Once a week, the doctors should also provide the family with a phone call or personal update on the adolescent’s progress.

The decision making power for adolescents should be increased and needs to be dependent on their age, maturity, thinking processes and medical stability. In this case the adolescents’ voices will be heard. By and large currently, nurses and doctors hold all the power and control. Nurses and doctors thus need to be aware of the potential power and control they hold within a program like ‘The Level System’. The adolescents described a strong need for empowerment. Prilleltensky, Nelson and Pierson (2001) described this as enhancing mental health and wellbeing. They described empowerment as: “the aim toward which we strive, a state of affairs in which people have enough power to satisfy
their needs and work in concert with others to advance collective goals. Unrestrained use of power by any one individual can most certainly interfere with the self-determination of others and their ability to participate in decisions affecting their well-being” (Prilleltensky, Nelson & Pierson, 2001, p. 145). It is important for nurses and doctors to work together collaboratively with adolescents to achieve the best health outcomes for the patient (Arnold & Boggs, 2007). Even though adolescents with anorexia may have a reduced capacity for power, control and decision-making, within ‘The Level System’ program, it is still an appropriate goal.

Female patients felt that it was sometimes difficult to experience true empathy and support from male doctors. Thus there is a need for a qualified female doctor to be available to talk with them. It was also important and respectful for them to have doctors obtaining consent from them and not just their parents before going through their belongings. Communication was another important factor. Doctor’s notes should be clear without any ambiguity, especially regarding ‘gate-passes’, so that there will be no difficulties or misunderstandings on the weekends, regarding the amount of time allowed out or the type of ‘gate-pass’ (internal or external) which are sanctioned.

External ‘gate-passes’ were something that all adolescents thoroughly looked forward to and were considered an excellent reward. They represented their “freedom” from this ‘prison’. However, some felt internal ‘gate-passes’ were a waste of time. There may be a need to re-think the benefits of internal gate-passes for adolescents with anorexia. If the adolescents are still unwell and unable to be responsible for their own eating, then perhaps the internal ‘gate-passes’ could be changed to a walk with a nurse off the ward for a prescribed period of time. In this instance, mealtimes would still be supported and supervised on the ward.

Group sessions within this program also need to be re-assessed. There is a tremendous need for group sessions to be therapeutic for the adolescents with anorexia. Group sessions specifically tailored to the needs of adolescents with anorexia need to be organised with at least an hour session per week. These groups should be viewed as a haven, a place to attain support from staff and peers, and an opportunity to be heard and empowered without condemnation. Within these sessions therapeutic relationships should be allowed to flourish and adolescents should be provided with education regarding their

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illness (from nurses and dieticians) and the treatment approaches being implemented. Journal writing may be a therapeutic component of the sessions as a form of catharsis. A buddy system or peer support group could be organised during the sessions, where the adolescents act as motivational supports for each other while on the program and on the outside. During these sessions, as an adolescent moves higher up the levels, they could be challenged to take part in food challenges, such as eating chocolate together or making your lunch classes without cheating. In fact, discharged patients who have successfully transitioned could be invited back to the ward as ‘motivational speakers’ to talk to current inpatients during these sessions. Topics could include life ‘outside’, coping strategies they have employed on the ‘outside’, the obstacles they have faced and the strategies they have found helpful to overcome these obstacles and the benefits of not being hospitalised.

Weigh days could be reduced to once a week and the adolescent should be allowed to choose whether they see their weight or not as the adolescents commented that this was an extremely stressful event. In maintaining fairness, the rewards bestowed by doctors should be reflective of how well they have each done for the week. In terms of visiting, all the adolescents recommended the inclusion of friends (1 or 2) to visit once a week as this made it easier for them and less of a shock for peers when they returned to school. Similarly, nurses felt that adolescence was an important time for peer relations and felt that the program should allow for this social interaction by allowing them to, for example, go to the movies with their friends. Peer relations, during adolescence, are extremely important and so it is strongly recommended that the program include the introduction of friends being able to visit. This support from peers may be significant in assisting patient healing and recovery in the long term.

In terms of the program, nasogastric feeding was seen positively by both nurses and adolescents, as an excellent way to boost weight initially. However, it should be avoided at all costs if the adolescent is able and willing to eat and drink normally. The adolescents should ‘face their demons’ by consuming the food rather than resorting to ‘boluses’. The adolescents themselves agreed that the ‘bolus-exchange’ feeds can be easily manipulated by some patients who work out the ‘bolus’ is fewer calories than the actual food and take the easy way out by refusing the food item and having the ‘bolus’. Thus, the least intrusive interventions need to be implemented first, so rather than resorting to
nasogastric feeding in the first instance, an adolescent should be given the opportunity to eat and drink normally first.

Other suggestions for changing the program included greater contact with the dieticians throughout the admission. This increased involvement and contact could be achieved with dieticians visiting the ward during therapeutic group sessions as suggested above. Adolescents also suggested the introduction of optional water and salt into meal plans (with limits on amounts per day). Indeed, since the commencement of this study an optional glass of water has recently been introduced to the meal plan.

Both nurses and the adolescents agreed that, for those almost ready for discharge, the overnight ‘gate-passes’ assisted in making a smooth transition from hospital to home and enabled the adolescents to test their improved eating habits. The impetus for recovery for many adolescents was a realisation that the eating disorder was precluding them from attaining broader life goals and aspirations. Some used ‘self-talk’ to convince themselves that life was better out of hospital than in hospital. When at home they wanted others to realise that they were still struggling but managing their symptoms and they felt strongly that their parents, family and friends needed to understand this. For a smooth transition from hospital to home there needs to be a progressive plan for discharge. The overnight ‘gate-passes’ were a good starting point along with the suggestion that the adolescents resume school and return after school for continued support with meals. For discharge to be successful, parents require education and skills on how to handle the eating disorder symptoms at home. A dietician or specialist nurse needs to explain the parent’s role on discharge, how they can support their child at home, where they can get additional assistance, how they can set ‘ground rules’ for meals and even be given a meal plan to follow initially with an explanation of appropriate serving sizes and types of meals. As eating, becomes less stressful for the adolescent, the meal plan can be abandoned. Prior to discharge parents partaking in a few meals, with an experienced nurse (ideally the nurse specialist) and their child, may help parents to learn strategies or techniques to handle difficult situations when at home.

Consistency was an area that needed the most improvement. Multidisciplinary healthcare team members need to keep nursing staff fully informed and up to date with changes by increasing the number of multidisciplinary meetings and opportunities for communication.
All staff need to be firm but fair and consistent in their application of rules. In particular, all nurses need to consistently follow the rules and doctors need to follow through and be consistent with decisions made by nurses rather than overriding them. Rules are only to be broken in exceptional circumstances. This would prevent the manipulation and deliberate ‘splitting’ among staff and would assist in reducing nurses’ stress and burnout. Rotating care among staff and sharing the load is also a means of reducing frustration and burnout and ensuring that everyone on the ward is aware and up to date with the program’s rules.

Confrontation, in regards to misbehaviour, should be avoided and discussion should be initiated instead. Increasing an adolescent’s autonomy in decision making (whether good or bad) would provide the adolescents with an element of control. Finding a common interest and establishing a rapport between nurses and adolescents was essential and could only be accomplished through nurses spending time and communicating with the adolescents. These opportunities for nurses to spend time and establish a rapport and to increase an adolescent’s autonomy could be achieved during the therapeutic group sessions, outlined above. Nurses realised that for positive relationships to form they needed to be upfront, honest, approachable and respectful towards the adolescents and the way they communicated and approached tasks would affect the relationship. Most nurses also felt that it was important to realise that anorexia nervosa was a ‘genuine illness’ and nurses need to be sensitive, empathetic and professional towards patients with this illness. Nurses who show an aptitude for this work and an empathetic understanding of this challenging condition would be more likely to form therapeutic relationships with patients.

Some nurses suggested, as the adolescents did, that the program could be a little more relaxed especially on weekends. They felt that it might be good to trial taking patients to eat meals off the ward or allowing them to have a meal from home or the cafeteria occasionally. They too felt that the half an hour ‘bed rest’ time could be better utilised for a nurse-patient activity.

Another important insight was that nurses felt that they needed education in counselling methods (Burnard, 2005) and perhaps nurses reluctance in initiating conversations with the adolescents was a fear of saying the wrong thing (Stickley & Freshwater, 2002).
Nurses in this program do require adequate training in counselling methods to increase their confidence in ‘knowing what to say’ to fragile adolescents. Nurses require the interpersonal skills necessary to form a therapeutic relationship. Thus another recommendation is that nurses receive training in learning informal counselling skills (not to a full professional level), but enough to be able to listen, talk to and support these vulnerable adolescents through their personal issues. Having these skills on board may enable adolescents to feel more comfortable in opening up to staff especially during the therapeutic group sessions. Nurses need to understand the components of a therapeutic relationship, how important it is for recovery and how to build one while still maintaining that firmness and consistency. Welch (2005) also advocated the need for nurses to have appropriate training and practice in this skill. Having appropriate empathetic listening and communication skills facilitates therapeutic relationships (May & Alligood, 2000; Reynolds, Scott & Austin, 2000).

With the program as it currently stands nurses believed that they were often ‘left out of the loop’ by doctors and other multidisciplinary team members. They felt that often they were not privy to information regarding a patient’s background, family dynamics, social situation or the care being provided by other team members. In order for a program to work effectively, nurses need to be intimately involved and aware of these issues if they are to attempt to form positive relationships with their adolescent patients. Better communication was clearly seen as essential by the nurses in this study. If personal information cannot be recorded in the medical notes, doctors then need to update staff through a case presentation or a staff meeting. This would then increase empathy among nurses for adolescents with anorexia. If enrolled nurses continue to provide the majority of care on the ward, then they should also be attending the family meetings.

Nurses felt that the support given by consultants was excellent but contended that, at times, they lacked that same level of support from their resident medical officers and registrars. They wanted their nursing notes and input to be acknowledged by all doctors so that any misbehaviour noted could be considered during the meetings. Nurses were with the patients twenty-four hours of the day and felt that their opinions should be respected. Some nurses did feel that the program could be fine-tuned further and that certain guidelines could be made a lot clearer and less ambiguous, such as what authority nurses have to keep a patient safe. That is, do they have the authority to place a patient

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on 24 hour ‘bed rest’? Some felt that the number of levels could be increased so that patients took incremental, baby steps. With greater levels, patients would have more choices and privileges during their stay. With the recommendations set out in this chapter, there is a need to re-visit the program guidelines and fine-tune aspects of the levels.

Nurses also thought that restricting numbers of patients on the ward to four at one time would increase their ability to form relationships as they usually felt a diminished tolerance and emotional exhaustion when there were more than four on the ward. With the increasing numbers of admissions to the ward this may not be possible to achieve thus reinforcing the desirability of and need for a dedicated nurse specialist for adolescents with anorexia nervosa. This nurse specialist could be a valuable resource for supporting staff with acknowledging their own personal feelings about patients and the behaviours they display. Recognising these feelings through peer debriefing sessions and self-awareness will prevent a nurse from acting on these feelings in practice.

One of the respondents in the recovery study by Garrett (1998) commented on how annoying it was to hear health professionals blaming people with anorexia for not getting better instead of looking at their own therapeutic programs and why they may be failing. Similarly, in the present study, a nurse suggested that if an adolescent kept returning, then as a team they needed to reassess ‘why they’re failing’. Communication and negotiation among health professionals is imperative to reform the current system so as to be more therapeutic and beneficial to the adolescents it cares for.

Many of the main changes for ‘reform’ suggested by both the nurses and adolescents do at times converge. It would be reasonable to implement or at least trial some of their suggestions on the ward to see if these assist with improving the quality of the nurse-patient relationship and ultimately the potential for patient recovery. A desirable ‘reform’ would be the need for alternative settings (such as ‘community day-care centres’ or ‘safe-houses’ or ‘purpose-designed and homely’ adolescent facilities) for the care of adolescents with anorexia. These particular settings, with appropriately trained mental health staff, would be more appropriate than the acute care ward with its increased patient acuity and the limitations on nurses’ time. There is no condemnation of the current system as it stands, as it achieves the necessary weight gain to ensure medical stability however,
there is a realisation that ‘The Level System’ program, by itself, does not assist with the formation of therapeutic relationships. Thus modifications are necessary.

If treatment continues within the acute care setting then modifications are needed, in terms of nurses reverting to ‘holistic nursing’ and embracing the importance of the therapeutic relationship for recovery. As stated earlier, this would mean that nurses receive extensive education and training to assist them with caring for people with anorexia. Nurses will also require adequate training in counselling methods to increase their confidence in ‘knowing what to say’ to fragile adolescents (Burnard, 2005). Nurses do require the interpersonal skills necessary to form a therapeutic relationship. Nurses who show aptitude for work with adolescents with anorexia and show an understanding that anorexia is a ‘genuine illness’, would be better able to form therapeutic relationships (Wright, 2001). These nurses need to possess the qualities of being encouraging, supportive, caring, and able to empathetically listen to the adolescents. They need to be able to give the adolescents ‘a clean slate’ each day. These nurses need to avoid confrontation and blaming tactics so power struggles do not occur, but must attempt to negotiate treatment options within boundaries. These nurses require the communication skills to be able to approach adolescents sensitively so that they feel they are a respected and valued person. Adolescents want to feel respected and treated as individuals, not to be labelled, judged, identified or equated with the disorder. With the appropriate training and education in hand, nurses may be better equipped to motivate and empower adolescents to embark on the slow, journey to recovery.

Different strategies need to be implemented or at least trialled such as those espoused to by the participants above. In order to increase trust, we need to, within limits, increase the adolescent’s ability to negotiate within the treatment program. Although an adolescent with anorexia will have a reduced capacity to share power and control within a program, such as ‘The Level System’, this should still be an appropriate goal. Adolescents should be provided with the opportunity to negotiate treatment decisions and ‘voice’ concerns with their doctors prior to their meetings. The adolescent should be considered a part of the treatment team. As stated earlier, this meeting should take place in a private room, with one to two doctors present, and if the adolescent wishes, a nurse or parent could be present as an advocate. The capacity for adolescents to ‘voice’ concerns would be increased with the implementation of the therapeutic group sessions.
All members of the multidisciplinary team need to show greater consistency with following the rules and guidelines of the set program. Doctors in particular need to learn to respect and support the decisions made by nurses and not override them. All care-givers demonstrating consistency means manipulation on the ward will reduce (Anderson, 1996; DeLaune, 1991; Marks, 2000, 2002; Nield-Anderson et al., 1999). The treatment being provided by nurses needs to be firm (appropriate limits set) but fair with appropriate flexibility for trust to improve between nurses and adolescents with anorexia.

Communication among all healthcare workers could also be improved along with their support for the staff caring for these adolescents on a regular basis. Nurses need to also be aware of concomitant treatments being provided so that they do not feel ‘left in the dark’. Nurses, who are intimately involved in the care of adolescents with anorexia, need to be aware and informed of each individual patient’s family and social situation, along with the background to the illness, if they are to form therapeutic relationships with these patients. A case presentation should be organised fortnightly to discuss individual patient issues. Within the current program, primary nursing as suggested in the literature (Cleary et al., 1999; Forchuk et al., 1998, 2000; Garrett, 1991; Morse, 1991; Williams & Irurita, 1998) is not possible. What should happen though is that the number of people caring for adolescents with anorexia should be limited and these nurses should ‘share the load’ to obtain the necessary consistency and to prevent emotional exhaustion and ‘burnout’ (Morse, 1991). Additionally, if enrolled nurses continue to provide the majority of care for adolescents on acute wards then these nurses should be invited to and should be attending meetings (such as the family meetings or eating disorder meetings). This factor (enrolled nurses providing the majority of care) reinforces the need for a specialist nurse position and the potential for this position to provide education and training to the non-specialist nursing staff, who have openly acknowledged their deficits in skills, training and understanding. This could be a more cost effective strategy, as opposed to the (perhaps optimal) suggestion of a specialised non clinical setting, once weight and physical health are restored.

Examples of additional rewards that can be trialled within the program include, half an hour in the fresh air for those on Level One, the introduction of walks with a nurse, the introduction of food challenges and ‘extras’ lists of food to choose from the higher a person moves up the levels. Dieticians also need to meet regularly, so if not at present,
this needs to be rectified. The addition of salt to the meal plan, within limits, could also be trialled and if not abused could become a permanent fixture. The program could be a little more relaxed on weekends, with the introduction of meals from home, cafeteria or a meal off the ward on these days. If resources were available the introduction of an outing to the movies or shops to have lunch may assist the adolescent’s with resuming eating socially in public places; however at the moment this would not be possible due to financial constraints and staffing levels.

As Cashin (2006, p. 100), explains, “[i]ncarceration along with depriving inmates of their liberty deprives them also of their voice”. This study has attempted to shed some light on the ‘silent world’ of life within a behaviour-modification program for adolescents with anorexia and has given ‘voice’ to those within the system. The illumination of parallels between the prison system and the behaviour-modification program provides insights and ways of conceptualising and understanding the experience of those within this program and highlights some parallel implications and challenges which offer the potential to learn from this very different area of enquiry.

It is clear that therapeutic relationships between nurses and adolescents with anorexia were inhibited predominantly by ‘The Level System’ program, in which nurses had competing and perhaps, self-inhibiting goals, to take on “observational” roles as the “disciplinarian” or the “policeman” in catching the adolescents misbehaving. It is also clear that both the nurses and adolescents in this study recognised the value of and had an expectation that nurses would spend time establishing a rapport and developing trust so as to build a therapeutic relationship with their adolescent patients. The primary conclusion of this study is the validation that, regardless of their custodial role as enforcers of this program, nurses should never abandon the goal of forming therapeutic relationships with patients and providing ‘holistic’ nursing care. The challenge is to find ways, without losing the benefits which the behaviour-modification program provides, to trial (and evaluate) modifications, such as those suggested by participants in this study. This is consistent with Garrett’s (1998) assertion of the need to reassess why the program may be failing some patients, as evidenced by the reported ‘revolving door syndrome’, thus constantly seeking its improvement.
Most participants, both nurses and patients, admitted a therapeutic relationship with someone was a major impetus for an adolescent’s recovery and healing. The adolescents also acknowledged that they did appreciate the efforts of nurses to form these relationships with them. They explained nurses were ‘trying to their potential’. The formation of a therapeutic relationship is an essential element in recovery and ‘The Level System’ does make it much more difficult for such relationships to form between nurses and adolescents with anorexia but attempts should never be abandoned. The inherent conflict between the opposing logics of treatment based on behaviour-modification, on the one hand, and the need for the formation of therapeutic relationships, on the other, was the main complexity for nurses in forming therapeutic relationships with their adolescent patients (Shoebridge, 2002, p. 3).

In agreement with Welch (2005) the formation of a therapeutic relationship is challenging but due to its importance requires the appropriate validation within mental health settings as well as acute care settings. This relationship rightly deserves much extensive validation and support than it currently is being afforded given its minimal prominence within ‘The Level System’ policy document. Thus changes are necessary for the further development of the program to acknowledge and place a greater emphasis on the importance of this relationship in the healing and recovery process of adolescents with anorexia. If some or all of the above changes can be trialled or implemented, nurses may be better equipped with the appropriate interpersonal and counselling skills, to help motivate the adolescents with anorexia to ‘break free’ and ‘eat to recover’ rather than ‘eat to get out’.
REFERENCES


References


References

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References 340


References


References


References


APPENDIX A

Floor Map
APPENDIX B
Photographs

Photograph 1

Photograph 2
APPENDIX C
The Levels

LEVEL ONE
- Complete bed rest – use of toilet and the shower will be based on medical condition and decided in consultation by the nurses and doctors.
- Menu/Meals – meal plan will be decided on and written by the dietician, patient will not receive a menu, meals to be eaten while patient is sitting on their bed
- Physiotherapy (stretches on bed) may begin if patient remains on level 1 greater than 1 week
- Individual activities will be arranged by the group work team, dependent on patients condition
- Weight Tuesday & Friday
- Visitors – 2 hour on weekdays, 3 hours on weekends. Immediate family only

LEVEL TWO
- 30 minutes bed rest after main meals
- To remain on ward
- Menu/Meals – meal plan to be decided and written by dietician, the patient may self select from the menu depending on their condition, meals to be eaten in dining room supervised by nurse
- To attend school and group (wheelchair may need to be used for group as indicated by staff)
- Physiotherapy to begin/continue
- Weight Tuesday & Friday
- Visitors – 2 hours weekdays, 3 hours weekends, immediate family only

LEVEL THREE
- 30 minutes bed rest after main meals
- Is able to leave the ward with parents, staff or responsible adult for up to 20 minutes per day after informing the nurse
- Menu/Meals – Selects from menu according to meal plan, menu selections to be monitored by dietician. Meals to be eaten in the dining room supervised by a nurse
- To attend school, group.
- Physiotherapy to continue (increase from stretching to strengthening)
- Weight Tuesday & Friday
- Gate pass – 1 or 2 half or full days dependent on weight gain and general compliance
- Visitors – 2 hours weekdays, 3 hours weekends, immediate family plus one other relative

LEVEL FOUR
- 30 minutes bed rest after main meals
- Is able to leave the ward with parents, staff or responsible adult for one 40 minute periods.
- Menu/Meals – Selects from menu according to meal plan, menu selections to be monitored by dietician. Meals to be eaten in the dining room supervised by a nurse
- To attend school, group and social eating group
- Physiotherapy to continue
- Weight Tuesday & Friday
- Gate pass – 1 – 2 half or full day gate passes, dependent on weight gain
- Visitors – 2 hours weekdays, 3 hours weekends, unrestricted but must not interfere with the program
APPENDIX D
Ward Timetable

EATING DISORDER PROGRAM
WARD TIMETABLE

<table>
<thead>
<tr>
<th>TIME</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.00-8.00</td>
<td>GET UP, have a SHOWER, and get DRESSED</td>
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<tr>
<td>8.20-9.00</td>
<td>BREAKFAST</td>
<td></td>
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<tr>
<td>9.00-10.30</td>
<td>SCHOOL</td>
<td></td>
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<tr>
<td>10.30-11.00</td>
<td>MORNING TEA (20 minutes)</td>
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</tr>
<tr>
<td>11.00-12.00</td>
<td>PHYSIO School School School School School</td>
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<td>12.00-12.30</td>
<td>School School School School School</td>
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<tr>
<td>12.30-1.00</td>
<td>LUNCH</td>
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<tr>
<td>1.00-1.30</td>
<td>½ hour bed rest</td>
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<tr>
<td>1.30-2.00</td>
<td>Free time</td>
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<tr>
<td>2.00-2.45</td>
<td>Group Group Youth Arts Youth Arts Group</td>
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<tr>
<td>2.45-3.30</td>
<td>Group Physio Group Group Physio</td>
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<tr>
<td>3.30-4.00</td>
<td>AFTERNOON TEA (20 minutes)</td>
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<tr>
<td>4.00-6.00</td>
<td>Free Time</td>
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<tr>
<td>6.00-6.30</td>
<td>DINNER</td>
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<tr>
<td>6.30-7.00</td>
<td>½ hour bed rest</td>
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<tr>
<td>7.00-8.30</td>
<td>Free Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.30-9.00</td>
<td>SUPPER</td>
<td></td>
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<tr>
<td>9.00-9.30</td>
<td>Free Time</td>
<td></td>
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<tr>
<td></td>
<td>BED TIME</td>
<td></td>
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<td></td>
<td></td>
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</tbody>
</table>

REVIEWS

Medical: Monday 1pm, Tuesday 2pm, Friday 1pm
Families seen: Friday 3-5pm
Dietician: usually everyday
APPENDIX E
Meal Plans

Patient’s Name

Date:

Nutrition Management Plan

Breakfast: 2 bread or equivalent + topping OR cereal & milk
1 fruit juice (220ml) OR 1 fruit
1 glass milk (150ml) OR 1 tub yoghurt OR 2 slices cheese

Am Tea: 1 fruit juice (220ml)
1 fruit

Lunch: 1 sandwich with egg/ meat/ fish/ cheese/ peanut butter
1 fruit juice (220ml) OR 1 fruit
1 tub yoghurt OR 1 glass milk (150ml) OR 2 slices cheese

Pm Tea: 1 bread or equivalent + topping
1 fruit juice (220ml)

Dinner: 1 serve meat/ fish/ chicken/ vegetarian meal
2 serve potato/ rice/ pasta/ chips/ 4 slices bread
2 serves vegetables OR salad

Supper: 1 bread or equivalent + topping
1 milk drink (150ml) OR 1 tub yoghurt OR 2 slices cheese

Toppings for bread or crispbread include butter, margarine, peanut butter, mayonnaise or cheese. The appropriate serve size for these toppings is half a teaspoon margarine (1/4 pcp), 1 teaspoon of peanut butter/mayonnaise or 1 slice of cheese on each slice of bread, crumpet or cracker equivalent.

Bread equivalents - 1 slice of bread/1 crumpet/3 Vita-weats or Jatz crackers/3 pikelets/ ½ serve of Sara Lee cake (no topping required)/2 sweet biscuits (no topping required)

Vegetarian Meal - once a week only
APPENDIX F
Meal Plans

Patient’s Name

Date:

Nutrition Management Plan

Total Volume of Ensure Plus (Ensure 1.5 Conc): 1600mls/day

<table>
<thead>
<tr>
<th>Time</th>
<th>Meal</th>
<th>Total Volume</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Breakfast</td>
<td>(130ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>2 bread or equivalent + topping</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>OR cereal &amp; milk</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 fruit juice (220ml) OR 1 fruit</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 glass milk (150ml) OR 1 tub yoghurt OR 2 slices cheese</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>Am Tea</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 breads or equivalent + topping</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 fruit juice (220ml)</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 glass milk (150ml) OR 1 tub yoghurt OR 2 slices cheese</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>Lunch</td>
<td>(195ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 sandwich with egg/ meat/ fish/ cheese/ peanut butter</td>
<td>(65ml Ensure)</td>
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<tr>
<td></td>
<td>1 fruit juice (220ml)</td>
<td>(65ml Ensure)</td>
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<tr>
<td></td>
<td>1 tub yoghurt OR 1 glass milk (150ml) OR 2 slices cheese</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 fruit</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>Pm Tea</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 bread or equivalent + topping</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 fruit juice</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>Dinner</td>
<td>(100ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 serve meat/ fish/ chicken/ vegetarian meal</td>
<td>(260ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>2 serve potato/ rice/ pasta/ chips/ 4 slices bread</td>
<td>(70ml Ensure)</td>
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<tr>
<td></td>
<td>2 serves vegetables OR salad</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 fruit juice (220ml) OR 1 fruit</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>Supper</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 bread or equivalent + topping</td>
<td>(65ml Ensure)</td>
</tr>
<tr>
<td></td>
<td>1 milk drink (150ml) OR 1 tub yoghurt OR 2 slices cheese</td>
<td>(65ml Ensure)</td>
</tr>
</tbody>
</table>

Bolus Exchange Plan
- At the end of meal, add up total volume of Ensure Plus equivalent next to foods which are not eaten. For example if all foods are consumed at lunch then no Ensure needs to be given, sandwich only is consumed then 195ml Ensure Plus must be given.
- Give feeds as a bolus at the end of the meal.
- Entire food portions must be consumed including toppings.
- There are no changes to volume of feeds given overnight if on overnight feeds.

Please see separate information sheets regarding meal time behaviour, menu ordering, appropriate toppings and alternative foods available to order.

Appendixes 356
All components required

A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).

B. Intense fear of gaining weight or becoming fat, even though underweight.

C. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.

D. In postmenarcheal females, amenorrhea, i.e., the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g., estrogen, administration).

Specify type:

RESTRICTING TYPE: during the current episode of Anorexia Nervosa, the person has not regularly engaged in binge-eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

BINGE-EATING/PURGING TYPE: during the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)
APPENDIX H
ICD-10

All components required

(a) Body weight is maintained at least 15% below that expected (either lost or never achieved), or Quetelet’s body-mass index is 17.5 or less. Prepubertal patients may show failure to make the expected weight gain during the period of growth.

(b) The weight loss is self-induced by avoidance of “fattening foods”. One or more of the following may also be present: self-induced vomiting; self-induced purging; excessive exercising; use of appetite suppressants and/or diuretics.

(c) There is a body-image distortion in the form of a specific psychopathology whereby a dread of fatness persists as an intrusive, overvalued idea and the patient imposes a low weight threshold on himself or herself.

(d) A widespread endocrine disorder involving the hypothalamic-pituitary-gonadal axis is manifest in women as amenorrhoea and in men as a loss of sexual interest and potency. There may also be elevated levels of growth hormone, raised levels of cortisol, changes in the peripheral metabolism of the thyroid hormone, and abnormalities of insulin secretion.

(e) If onset is prepubertal, the sequence of pubertal events is delayed or even arrested (growth ceases; in girls the breasts do not develop and there is a primary amenorrhoea; in boys the genitals remain juvenile). With recovery, puberty is often completed normally, but the menarche is late.

DIFFERENTIAL DIAGNOSIS: There may be associated depressive or obsessional symptoms, as well as features of a personality disorder, which may make differentiation difficult and/or require the use of more than one diagnostic code. Somatic causes of weight loss in young patients that must be distinguished include chronic debilitating diseases, brain tumors, and intestinal disorders such as Crohn’s disease or a malabsorption syndrome.

(Adapted WHO, 1992, p. 177)
APPENDIX I
Interview Schedule

Topics to be discussed with nurses:

1. Discussion of the elements of the treatment program and what nurses think of these elements in respect to both their efficacy and impact on nurse-patient relationships
   - Nasogastric feeding
   - Bed rest
   - General nursing care/Nursing support
   - Mealtimes
   - Medication administration
   - Weight measurements
   - Visitors and Family
   - Activities e.g physiotherapy, school, group and gate-passes
   - Team meetings
   - Therapy e.g family, CBT (cognitive-behaviour therapy)

2. Advantages or barriers to the success of treatment programs for nurses
   - General discussion regarding 'how the program is going?' ‘Is it working?’ ‘In what ways?’ ‘What do you think of the program?’ ‘What is its value?’ etc

3. Therapeutic relationships
   - Are nurses successful in establishing therapeutic relationships within the boundaries of the program? Why/Why not?
   - How could this be improved?
   - What do you feel patients think of nurses’ efforts to establish therapeutic relationships?
   - How important is it to successful outcomes?
   - Examples of how nurses attempt to form such relationships (tell stories)

4. Feelings
   - Perceptions of adolescents with anorexia
   - Caring for adolescents with anorexia on a general ward
   - Available support and Coping with stress
5. Recovery

- What will improve the quality of patient’s lives in the present/short and medium term future?

6. Recommendations For Change/Improvements To Nursing Practice

**Topics to be discussed with patients:**

1. Treatment programs and nursing practice

- General discussion about their particular treatment program. What is involved? How they feel about it? How they feel about staff? etc.

2. Advantages or barriers to the success of treatment programs for patients

- General discussion regarding ‘how the program is going?’ ‘Is it working for them?’ ‘In what ways?’ ‘What do you think of the program?’ ‘What is its value?’

3. Therapeutic relationships

- Are nurses successful in establishing a relationship with you? Why/Why not?
- How could this be improved?
- What do you think of nurses’ efforts to establish therapeutic relationships?
- Have there been any particular nurses whom you have felt particularly ‘connected’ with/helped you? What was it about these particular nurses/their behaviours and approaches that you found particularly helpful?

4. Feelings

- Perceptions of nursing staff/allied health staff
- Being cared for on a general ward
- Available support and coping with stress

5. Recovery

- What will improve the quality of your life in the present/short and medium term future?

6. Recommendations For Change/Improvements To Nursing Care
NURSING STAFF PARTICIPANT INFORMATION SHEET

Nursing practice and an inpatient program for adolescents with anorexia nervosa: A comparison and critical analysis from the nurses’ and patients’ perspective.

Investigator: Ms L Ramjan [hospital name, ward and phone number concealed for anonymity]

Supervisors: Dr. B Gill [university contact details]
Dr. E Watson [university contact details]
Ms C Irving (NUM) [hospital name, ward and phone number concealed for anonymity]

We would like you to consider participating in a research study that will be conducted in the adolescent ward/department at [hospital name].

What is the study about?

We are conducting a study to gain an in-depth understanding of clinical nursing practice and the establishment of therapeutic relationships, within the context of a particular treatment modality for adolescents with anorexia, from the perspective of both nurses and patients. The study ultimately intends to compare and contrast nurses’ and patients’ feelings and perceptions of nursing practice and the therapeutic relationship within the therapeutic milieu. A secondary aim is to extract the knowledge gained by experience and clinical ‘expertise’ of experienced nurses and the ‘expertise’ of eating disorder inpatients about the essential nursing practice requirements, that will improve the quality of patients’ lives in the present, short and medium term future.

Who can participate in the study?

Registered Nurses or Enrolled Nurses working on the adolescent ward at [hospital name] with more than one year’s experience working with adolescents with anorexia will be invited to participate in this study. Excluded from the study will be pool, casual and agency nurses, as they may not have sufficient experience to contribute to the aims of the research.

What will the study involve?

We would like you to consider participating in an interview. The interview will take approximately sixty to ninety minutes to complete. Interviews will be recorded on audiotape for transcription and analysis.
Are there any benefits for nurses participating in the study?

There are no known benefits for nurses participating in this study. We hope that the results from this study will lead to the development and improvement of current treatment programs and an enhanced nurse-patient relationship.

Are there any side-effects and risk associated with this study?

There are no known side-effects or risks associated with the participation in this study. However, if for any reason information in this study should cause distress to you (the interviewee), you may choose not to answer specific questions. Distressed participants will be offered the opportunity to speak with a social worker or counsellor. The interview may be stopped temporarily or permanently at the participant’s discretion.

Other information

All information will be anonymous and confidential. Codes or pseudonyms will be used for all transcripts and interview data. No individual’s complete interview will be available to anybody except the typist, investigator and academic supervisor.

All data collected, that is computer disks, files and transcripts will be stored in a locked, secure storage cabinet at [hospital name] for five years after which the information will be erased, deleted and shredded respectively.

Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time this will not affect your employment at the hospital.

If you have any concerns about the conduct of this study, please do not hesitate to discuss them with my supervisor Dr. B Gill (phone number) or myself (phone number) or with Anne O’Neill (phone number), the Secretary of the Ethics Committee at [hospital name], which has approved this project.

This Information Sheet is for you to keep. We will also give you a copy of the signed consent form.
APPENDIX K

Participant Information Sheets

PATIENT PARTICIPANT INFORMATION SHEET

Nursing practice and an inpatient program for adolescents with anorexia nervosa: A comparison and critical analysis from the nurses’ and patients’ perspective.

Investigator: Ms L Ramjan [hospital name, ward and phone number concealed for anonymity]

Supervisors: Dr. B Gill [university contact details]
Dr. E Watson [university contact details]
Ms C Irving (NUM) [hospital name, ward and phone number concealed for anonymity]

We would like you to consider participating in a research study that will be conducted in the adolescent ward/department at [hospital name].

What is the study about?

We are conducting a study to gain an in-depth understanding of the nursing care for adolescents with anorexia nervosa and the establishment of nurse-patient relationships, within an inpatient treatment program. The study ultimately intends to compare and contrast nurses’ and patients’ feelings and perceptions of nursing practice and the nurse-patient relationship within the treatment setting. A secondary aim is to extract your ‘expert’ knowledge and that of nurses, regarding the essential nursing practice requirements, that may improve the quality of your lives in the present, short and medium term future.

Who can participate in the study?

Adolescents with anorexia nervosa currently being treated on the adolescent ward at [hospital name] will be invited to participate in the study. Excluded from the study will be medically unstable patients as determined by their treating physician.

What will the study involve?

We would like you to consider participating in an interview. The interview will take approximately sixty to ninety minutes to complete. Interviews will be recorded on audiotape for transcription and analysis.
Are there any benefits for patients participating in the study?

There are no known benefits for patients participating in this study. We hope that the results from this study will lead to the development and improvement of current treatment programs and an enhanced nurse-patient relationship.

Are there any side-effects and risk associated with this study?

There are no known side-effects or risks associated with the participation in this study. However, if for any reason information in this study should cause distress to you (the interviewee), you may choose not to answer specific questions. You are also free to withdraw from the study at any point in time. Participants will be provided with the opportunity to have a parent present during the interview. Distressed participants will be offered the opportunity to speak with a nurse or counsellor involved in their care. The interview may be stopped temporarily or permanently at the participant’s discretion.

Other information

All information will be anonymous and confidential. Codes or pseudonyms will be used for all transcripts and interview data. No individual’s complete interview will be available to anybody except the typist, investigator and academic supervisor. Staff from the institution will not have access to any information provided.

All data collected, that is computer disks, files and transcripts will be stored in a locked, secure storage cabinet at [hospital name] for five years after which the information will be erased, deleted and shredded respectively.

Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time this will not in any way affect the care you receive or your ongoing relationship with hospital staff.

If you have any concerns about the conduct of this study, please do not hesitate to discuss them with my supervisor Dr. B Gill (phone number) or myself (phone number) or with Anne O’Neill (phone number), the Secretary of the Ethics Committee at [hospital name], which has approved this project.

This Information Sheet is for you to keep. We will also give you a copy of the signed consent form.
APPENDIX L
Parent Information Sheet

PARENT INFORMATION SHEET

Nursing practice and an inpatient program for adolescents with anorexia nervosa: A comparison and critical analysis from the nurses’ and patients’ perspective.

Investigator: Ms L Ramjan [hospital name, ward and phone number concealed for anonymity]

Supervisors: Dr. B Gill [university contact details]
Dr. E Watson [university contact details]
Ms C Irving (NUM) [hospital name, ward and phone number concealed for anonymity]

We would like you to consider allowing your child to participate in a research study that will be conducted in the adolescent ward/department at [hospital name].

What is the study about?

We are conducting a study to gain an in-depth understanding of the nursing care for adolescents with anorexia nervosa and the establishment of nurse-patient relationships, within an inpatient treatment program. The study ultimately intends to compare and contrast nurses’ and patients’ feelings and perceptions of nursing practice and the nurse-patient relationship within the treatment setting. A secondary aim is to extract the ‘expert’ knowledge of patients and that of nurses, regarding the essential nursing practice requirements, that may improve the quality of patients’ lives in the present, short and medium term future.

Who can participate in the study?

Adolescents with anorexia nervosa currently being treated on the adolescent ward at [hospital name] will be invited to participate in the study. Excluded from the study will be medically unstable patients as determined by their treating physician.

What will the study involve?

We would like you to consider allowing your child to participate in an interview. The interview will take approximately sixty to ninety minutes to complete. Interviews will be recorded on audiotape for transcription and analysis.

Appendixes 365
Are there any benefits for my child participating in the study?

There are no known benefits for your child participating in this study. We hope that the results from this study will lead to the development and improvement of current treatment programs and an enhanced nurse-patient relationship.

Are there any side-effects and risk associated with this study?

There are no known side-effects or risks associated with the participation in this study. However, if for any reason information in this study should cause distress to your child, they may choose not to answer specific questions. They are also free to withdraw from the study at any point in time. Participants will be provided with the opportunity to have a parent present during the interview. Distressed participants will be offered the opportunity to speak with a nurse or counsellor involved in their care. The interview may be stopped temporarily or permanently at the participant’s discretion.

Other information

All information will be anonymous and confidential. Codes or pseudonyms will be used for all transcripts and interview data. No individual’s complete interview will be available to anybody except the typist, investigator and academic supervisor.

All data collected, that is computer disks, files and transcripts will be stored in a locked, secure storage cabinet at [hospital name] for five years after which the information will be erased, deleted and shredded respectively.

Participation in this project is voluntary and if you decide your child should withdraw at any time from the study or not take part this will not in any way affect the care your child receives or your ongoing relationship with hospital staff.

If you have any concerns about the conduct of this study, please do not hesitate to discuss them with my supervisor Dr. B Gill (phone number) or myself (phone number) or with Anne O’Neill (phone number), the Secretary of the Ethics Committee at [hospital name], which has approved this project.

This Information Sheet is for you to keep. We will also give you a copy of the signed consent form.
APPENDIX M
Informed Consent

NURSING STAFF CONSENT FORM

**Name of study:** Nursing practice and an inpatient program for adolescents with anorexia nervosa: A comparison and critical analysis from the nurses’ and patients’ perspective.

**Name of Investigator:** Lucie Ramjan [contact details]

**Name of Supervisors:**
Dr. Betty Gill [contact details]
Dr. Elizabeth Watson [contact details]
Ms Clare Irving [contact details]

I have read and understand the Participant Information Sheet and consent to participate in this research study, which has been explained to me by

............................................................................................................................................................................

I understand that I am free to withdraw from the study at any time and this decision will not affect my employment at the Hospital.

Name of Participant.........................................................................................................................(Please Print)

Signature............................................................................................................................................

Date..................................................................................................................................................

Name of Witness.................................................................................................................................(Please Print)

Signature............................................................................................................................................

Date..................................................................................................................................................
PATIENT/PARENT CONSENT FORM

Name of study: Nursing practice and an inpatient program for adolescents with anorexia nervosa: A comparison and critical analysis from the nurses’ and patients’ perspective.

Name of Investigator: Lucie Ramjan [contact details]

Name of Supervisors:
Dr. Betty Gill [contact details]
Dr. Elizabeth Watson [contact details]
Ms Clare Irving [contact details]

I have read and understand the Participant Information Sheet and give my consent for

..............................................................................................................................................................................................................................................................
to participate in this research study, which has been explained to me by

..............................................................................................................................................................................................................................................................

I understand that I am free to withdraw from the study at any time and this decision will not affect my child’s treatment at the Hospital.

Name of Participant.................................................................(Please Print)

Signature........................................................................................................

Date...................................................................................................................

Name of Parent..............................................................................................(Please Print)

Signature........................................................................................................

Date...................................................................................................................

Name of Witness............................................................................................(Please Print)

Signature........................................................................................................

Date...................................................................................................................
APPENDIX N
Supplementary Data

‘LEARNING THE ROPES’

1. I get up in the morning. I usually take a shower then have breakfast. Then if it’s not school holidays, go to school, then come back at 10.30, have morning tea, then go back to school at 11.00, then come back at 12.30 for lunch. Then after lunch, we have half an hour bed rest. Then we usually go to Group at 2.00 to 3.30 and at 3.30 is afternoon tea. Then my mum usually comes and visits and 6.00 is dinner and then we have half an hour bed rest after that. Then I usually read….Then supper is at 8.30 and then I get ready for bed (Melinda¹).

2. …they do all hang out together (Paige²).

3. …they generally talk to each other-they build up a relationship or friendship with each other, which is a good thing that they have some peers going through the same thing and they’re able to talk about it (Veronica²).

4. …you’re not allowed to swap and…you can’t leave half way through your meal. You have to wait until everyone else is finished (Cameron¹).

5. You are not allowed to keep getting up and out of your seat and doing something but if you want to toast your toast, you are allowed to do that (Chloe¹).

6. …they usually have Ensure 1.5 concentration [for boluses]…For example for apple juice, they have to have 65 mls…and it is all documented on their meal plan. So basically…they can’t have half. They have to have the whole amount of apple juice…otherwise they have to have the bolus. They can’t just say ‘Oh I have had half of the apple juice or half of the sandwich’…they have to finish their meal otherwise they have to have boluses (Mandy²).

7. …we are kind of giving them the timetable and saying you have to conform to this… (Paige²).

‘Keeping A Watchful Eye’

8. It’s like the policeman making sure everything is going…according to plan…it can be quite uncomfortable (Thomas²).

9. …I mean it’s got to be done. Otherwise all of a sudden, if you let them do their own thing…I mean, it’s easy enough to sort of flush a sandwich or something down the toilet. So, um it’s a means to an end I guess you could say… (Riley²).
10. I know there are some kids who always eat their meals and one mealtime they don’t get whatever they want…I’ll make that leeway. But for other kids that always require boluses, I make sure they stick with what they get. So it depends on the patient (Mandy²).

11. …most of the ones we get are pretty nice…they talk to us at meals and stuff and they’ll sit down and have something with us…and talk to us…in our room and stuff like that but the mean ones they just come in…”Okay. I’ve got you tonight, girls’ and then come in for meals…and they sit at the table and stare at us and don’t talk to us or anything and it’s a bit uncomfortable (Amber¹).

‘The Surveillance Continues…”

12. …I guess because of the nature of the illness…These patients are mentally ill. They don’t think they are thin and so they are going to do whatever they can…to make sure they get thin and…a lot of the time that means hurting themselves whether it be exercising too much or purging…I think part of our role, to get them better, is also to prevent them from continuing with these behaviours…Quite often they are very secretive. It requires us to be extra, you know, on the ball. So yeah, it does feel like a surveillance thing all day, it really does. Even when um you are not doing anything that I would call obviously therapeutic, I mean if you are just in the background, you are still watching and wondering… (Paige²).

13. The monitoring and the observations are very important to make sure that they are medically stable. Um the observations such as their temperature, pulse, and blood pressure indicates their medical stability…If their temperature is below say 35.5º um it indicates that they’re…not getting adequate nutrition and therefore can’t maintain their own temperature and…therefore…we put an overhead heater on them. And their heart rate is quite important. If it goes below a certain level then we do need to look at their nutrition…as well, because it does cause bradycardia (Veronica²).

‘No More Privacy’

14. I like my own privacy so I hate taking it away from people (Linda³).

15. I feel a bit uncomfortable…they are crying…But ah then I think ‘Okay I am doing this for the benefit of them’…They need to have the rehydration…Just need to give them reassurance…It’s not a painful procedure but it is very uncomfortable (Mandy²).

‘Life As The Prison Officer and Life As The Inmate’

16. …I think that we know that these girls are on a program and they must eat at these times and they must have these observations done. You must make sure they are on ‘bed rest’ after main meals and so that’s what you do. It’s kind of like a surveillance thing almost…Your whole day is very routine (Paige²).
17. …I could take them home with me and do the same thing (laughs) (Donna²).

18. …the…repetitiveness of having to tell them the same thing day in, day out. They know the rules, they know what they’ve got to do but yet they continually push the limits…want to know how far they can go. So just having to repeat yourself day in, day out is just…It’s too draining and…that is what I dislike (Zac²).

19. …ultimately I can only do…what’s expected of me. Namely make sure you eat, try and make sure you don’t exercise…to maintain your weight…It’s no use going crazy…if they dip their weight. Ultimately they’re the ones that suffer, not us (Riley²).

20. On the whole no….I thought they often thought…we shouldn’t be here and that it’s like a waste of space and that type of thing (Zoe¹).

21. They would be like ‘Hurry up! You are taking so long! This is so boring!’ and stuff like that and then try to do anything but doing what they had to do (Megan¹).

22. …they’re like ‘Oh hurry up or I’ll give you a bolus’ [brash tone of voice] and stuff like that and the nice nurses are like ‘Okay, hurry up girls, you need to be a bit quicker’ [gentler tone of voice] (Amber¹).

23. But some nurses…said the wrong things…Like some nurses commented on how much we had to eat and would say ‘Oh how can you eat all this?’ and that type of stuff and that’s not very helpful. Because you always feel like you are eating heaps anyway (laughs) (Zoe¹).

24. …you just kind of feel like trapped when they tell you bad news, because it feels like…‘Oh you’re never going to get out’. ‘You can’t do anything’…(Amber¹).

25. But some are really caring like you know they really want to help and…you know they feel that you’re a good cause…and that makes you feel better about having to eat because…someone…doesn’t just think…yeah ‘if you eat, you eat but if you don’t want to, that doesn’t matter’. It makes you think that you mean more, sort of thing. When people…[say] ‘Oh come on, you can do it, you can eat, you can eat it’ [soft, encouraging tone of voice] and…at the time you sort of think ‘Oh well maybe I should, you know maybe it’s okay’…So when someone is really caring and…chats with you and helps you and everything it makes you feel so much better than if someone is like ‘Oh just eat it okay! You know you have to eat it or you won’t go home!’ [stern tone of voice] (Zoe¹).

‘BUCKING THE SYSTEM’

26. …throw away stuff, half drank things um and they used to always pick things that they thought were like the lowest in calories…Even if it was disgusting…they made themselves eat it every week… (Megan¹).
27. I don’t think they catch people tampering with feeds as much as people do tamper with feeds (Zoe¹).

28. …It’s very individual um some of them adhere to the program that they’re put on very stringently, um but others can be very manipulative of the program and of the staff members and ‘The Level System’ itself as well (Veronica²).

29. …if a patient’s been in like more than once, they sort of know what goes on and …they can manipulate the system a bit better, I guess you could say (Riley²).

30. …they will find staff I think that they can manipulate or that are a bit more lenient with things and they will request them, they will play up to them… (Gabrielle²).

31. …there is no consistency you know. People will do different stuff. Some [nurses]…have a very soft spot for them and they let them do whatever they want to do… (Mandy²).

32. …we have to be very careful with them like sometimes they will be very manipulative and be very sneaky and so that’s why we sometimes have to do locker check ups (Mandy²).

33. …they are perfectionists so…I guess with that, they actually need to be successful in what they are doing. I think it would be very hard for them to actually know that they are not achieving, or failing is maybe…what they might see themselves as doing, in some way. By manipulating people they can get what they want…and achieve their goal of getting out of here or whatever it is…Their way of manipulating people is their way of actually being seen to fulfil their contract or program without actually really having to do it (Gabrielle²).

34. The manipulative behaviour is part of the illness. The obsessive compulsive behaviours usually go with eating disorders. They are um obsessive compulsive about exercising, about the calories that they are having and…when you have got a disease like obsessive compulsive disorder combined with an eating disorder, it’s…totally understandable why they would do that (Veronica³).

‘WALKING A FINE BALANCE: BUILDING RELATIONSHIPS’

35. …you hate what they are doing so therefore you just hate them…If you met them…as any other patient you’d probably think they were really lovely people. But then as an eating disorder patient you sort of don’t like what they are doing. So you don’t trust them. You don’t want to be around them that sort of thing (Zoe¹).

36. …they are trying to give you food and you don’t want to eat it and so it is kind of like ‘Why are you trying to make me eat it?’. So that is definitely a big one… (Megan¹).
37. …you just want to be sure that, that’s the right amount that you’re supposed to have. In whatever circumstance you just want to have fair treatment to all the other girls. You don’t want to be getting any more than them because sometimes you might feel…like it’s double standards for one person (Danielle¹).

38. I think they should always…show you your bottle or if you are having 1.5, they should show you the can and say ‘Okay you are having this’… (Zoe¹).

39. Some nurses, who don’t have us very often, they don’t really know and people get away with things, like not eating certain things and you don’t feel as though you can trust them as much because they don’t really know what you’re meant to do (Melinda¹).

40. …putting the pump on a pole that they can’t take to the bathroom with them. Saying it is ok for them to go to the toilet…let us know…buzz. We will disconnect you… (Gabrielle²).

41. …Um (laughs) some kids do try and tip some of the feeds out and replace it with water so they are not getting the full strength and some disconnect the actual connection between the NG tube and the tube lining so sometimes that needs to be taped up so that, that cannot be disconnected and the actual opening to the bag can be taped down as well (Veronica²).

42. …It probably depends a lot on what their experiences have been. There are some who are distrustful of all adults in general…I won’t even pretend to know what the reasons are (Oliver²).

43. …we should have four at one time but sometimes we have six. But sometimes if they have more anorexic kids waiting to come in, they have to discharge them even though they are on Level 2 or Level 3. They will discharge them. So it’s just about like getting beds, not enough beds. So it’s all about upstairs [administration], bed numbers. And sometimes they are here on false pretences, like you know, they will have a different diagnosis. But they are anorexic kids but they are having failure to thrive or something like that (laughs) (Mandy²).

‘The Balancing Act’

44. …I guess building a relationship like anyone else. Talking to them and make sure that they know that they can talk to you about anything and um let them know a bit about yourself as well so they can build trust in you…You build a relationship that way. Through talking and communication (Donna²).

45. It’s my job. I think that the kids need continuity (Veronica²).

46. …it’s part of my job and sometimes it’s a pleasant part of my job, sometimes it’s not so pleasant (Thomas²).
‘DISCHARGE, RELAPSE AND RECOVERY’

47. … say on our program having people who are going through the same thing maybe at the same rate is really good. So you come in at the same time and you kind of go together and you are much more stronger and more friends with them as opposed to people who come in later because…it is easy for you to slip back down to what they’re at because they are going to be asking questions that maybe you were asking weeks ago. So that is always hard. But yeah, having people going through what you are going through and having…someone to talk to. It is good (Megan¹).

‘FINAL ADVICE FROM INMATES’

48. …not to…take it out on us even if they are taking it out on everyone…Just try not to because you are in…fragile enough emotions at the moment anyway…You don’t want to be eating and they are making you eat and if they are in a bad mood you are just going to snap…do something stupid…(Megan¹).

49. …be quite lenient and…instead of…straight away getting nasty at them…be a lot more yeah easy going and explain to them and maybe talk to them a lot more…(Cameron¹).

50. …well I guess…the main doctors…it’s just a job for them, I guess…(Chloe¹).

51. It’s what they want goes. And that’s basically it…And most of the time they don’t really care what you say. It’s like ‘I’m the boss here and you do what I say’ (Melinda¹).

52. …if we could have our own little kind of meeting…with the doctors…It would be good…So um we could…talk for ourselves kind of thing, without the doctors talking for us. If you know what I mean…(Isabel¹).

53. I don’t like how they all come round in a circle round your bed and stuff (Chloe¹).

54. …It was quite fair [‘The Level System’]…when I think back now. When you’re in it, you think it’s really unfair (laughs) but if you think back now it is quite fair and everything is…set at a good standard (Cameron¹).

55. I think it’s good because as you put on weight, you get more privileges, so it’s kind of like, if you’re losing weight they should probably take away some of the privileges because otherwise you wouldn’t get anywhere. I mean, people wouldn’t really care about putting on weight and they’d just not eat (Sara¹).

56. Like they don’t really do much with us apart from feeding you up…But I am not sure that they can…Like they sort of try and get you to eat and keep you eating but then sometimes as soon as you go home and you are allowed to do whatever you want then…[voice softens and carries away] (Zoe¹).
57. …we had to make um short bread biscuits and um she wanted us to mix all the stuff together with our hands and I do a lot of cooking at home and usually I would use electric beaters to mix it… I didn’t want to touch it because I didn’t want to get my hands dirty or anything and she was saying, ‘Oh [Amber¹] this is ridiculous! You are making a spectacle! You can’t absorb calories through your skin from butter!’ and I didn’t say anything along the lines of that and I wasn’t even thinking that and she just said it randomly and it was so…demeaning. She like classified me as thinking that just because of why I’m here (Amber¹).

58. Like Monday groups are a bit dodgy because you don’t want to have to talk about feelings and stuff when you’re feeling crap….That might sound contradictory…Like when you’re feeling bad, you don’t want to talk about it. But often…just give me a craft thing that will be fun (Zoe¹).

59. …it would be good if we could have a choice um though…whether…we can go or not because sometimes you so don’t feel like it but um yeah on other days it is good because it takes your mind off things… (Isabel¹).

60. Group’s good. But on Tuesdays and Fridays, which is the days we have the meetings and we find out the news like just before group, we are always like a bit depressed and we don’t want to go to group… If we don’t go, we get into trouble and I don’t think it should be compulsory on those days (Amber¹).

61. …because people would usually get really nervous the night before or people may water load the night before like put on fake weight. Maybe if they were just randomly [weighed]…they would get your true weight and you wouldn’t be freaked out because they could just happen whenever. So just be woken up ‘Ok let’s go now’ kind of thing. I think that would be better (Megan¹).

62. …there were two things: it was good to gain weight but then there is also that side of you that is kind of like ‘Ha ha I didn’t gain as much as you’ especially if they don’t gain as much and…they get a better reward then it is kind of like, ‘Whoa! hang on! I am going to try and lose, not put on as much and still get the rewards’ that is when the competition starts. And then losing weight, it is really bad to lose weight but then also they kind of feel a bit happy because they have [lost weight], until the doctors come around and then they are kind of like sad again (Megan¹).

63. …the dietician has never come to see me… I have only seen her twice since I have been here um which was like just a couple of days ago….So I think they could be a bit more involved and yeah should come…Apparently one of the patient’s told me they were supposed to come on like your first or second day and talk to you and stuff, which never happened to me but it would have been good if they had… (Isabel¹).

64. I haven’t spoken to the dietician (Amber¹).
65. I’ve been here for like six weeks and I’ve had three different dieticians. The first one knew what she was doing, the second one didn’t and the third one didn’t. And then every single dietician has different rules, in a way, like some of them say you do have to have spreads, some say you don’t, and they keep changing their mind and I think they should all stick by the same rules (Melinda¹).

66. …like they have just done it at other places, but if you are not ready to do it then it is their choice they really don’t have to do it but if they get to a certain level, kind of make it, this is the kind of thing to do and you find that they talk about it a lot. Everyone talks about it and they really encourage themselves to do it (Megan¹).

‘FINAL ADVICE FROM PRISON OFFICERS’

67. …go off the ward for a meal together even if you take your trays, go sit somewhere different…The time that we do have perhaps needs to be utilized better um perhaps that bed rest time could even become a nurse-patient interaction time for some kind of therapy or activity or something that’s done with the nurse (Paige²).

68. I think it is very dangerous sometimes what we can ask. Um I was taught that if you were afraid of the answer, don’t ask…and that is not only even with our eating disorders. I think it is across the board in a lot of things…I think…well what do you say to someone if they turn around and say, ‘Well no I don’t care. I want to die’…So yeah…I think [learning] how to build a proper therapeutic relationship and not just thinking we know what it is…Also recognising the influence that our behaviour has on them and the good nurse, bad nurse and everything else like that…Getting together and really learning those skills would really benefit us as well as them and all the other kids (Gabrielle²).

69. I would like to see maybe the option of having a bit more leniency in social interaction outside the hospital. Just because for some kids it is such a daunting thing to go back into society. And that was never a problem for them in the first place. So just having that option there rather than having them locked away in here and going out whenever they have done things right (Zac²).

70. It gets them ready for discharge (Thomas²).

71. …overnight ‘passes’ which have only just started now need to have been done a long time ago and be done as a build up to going home. It is no good just saying suddenly ‘See you later. There’s the door. Go home, try and cope’ when they really haven’t had to cope the whole time they have been in hospital. Which could be 10 plus weeks…So they…learn to eat again with their families (Gabrielle²).

72. …we should have a…meeting, with the doctors who see the kids as outpatients…to know what is going on. So it can also be rewarding for us. That we are doing something for the better (Mandy²).