Disrupted Mothering:
A drama in four acts

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3rd December 2012
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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.

Tamara Power

3rd December, 2012
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OUTCOMES OF THIS THESIS TO DATE

(Please note my surname changed from Vallido to Power during this candidature)

Publications


Presentations


ABSTRACT

The majority of women in the world will experience motherhood, and for most of them it is a profound and life-changing undertaking. In Western society contemporary motherhood is beset by social constructions of ‘good’ mothering. The social construct of the ‘good’ mother has consequences for how women enact and experience mothering, often culminating in feelings of intense responsibility, guilt and shame. These feelings are magnified when women are disrupted in their mothering by illness. Although some literature has explored mothering in the context of specific illnesses, the concept of disrupted mothering in itself has not been elucidated previously in the literature. This study aimed to explore women’s experiences of mothering disrupted by illness.

This research used a qualitative methodology drawing upon principles of feminism, social constructionism and storytelling. Data were collected during face-to-face and online interviews, and via the telephone. The twenty-seven women who participated were from either Australia or the United States of America, had between one and six children, and identified themselves as having been disrupted in their mothering by illness or injury. Once collected, data were analysed thematically and overlaid with a theatre metaphor. The theatre metaphor was extended to the entire thesis to give the work cohesion. In addition to the themes, theatrical scripts were created, distilling the women’s experiences into a single narrative and offering alternative renditions of the play.

Four dominant themes, each consisting of three sub-themes (referred to in the thesis as Acts and Scenes), were revealed in the women’s stories. ‘Act I - Playing the Part’ revealed how illness impacted upon the women’s maternal lives, mothering activities
and treatment decisions. ‘Act II - The Health Care Subplot’ encompasses their experiences with health professionals, as well as the way being hospitalised affected their interactions with their children during the period of hospital confinement. ‘Act III - The Supporting Cast’ makes explicit women’s main sources of support, namely their partners, female friends and relatives and others who indirectly helped the women with maintenance of maternal responsibility by supporting their children. ‘Act IV - Reviewing the Performance’ details how the women evaluated the quality of their mothering.

The findings of this study have provided greater insight into: the way illness can threaten women’s views of themselves as mothers; the impact illness can have on mother-child relationships; and the sources of support available to women in illness. The storytelling methodology and theatre metaphor revealed the way women justified their performances, re-wrote the motherhood script and re-cast themselves into the role of the ‘good’ mother despite facing the adversity of illness.

Findings from this study suggest that health professionals have a major role to play in reducing women’s distress over how they perform as mothers during illness. Health professionals are in a position to empower women and facilitate their mothering of their children, help them identify sources of support and contribute to deconstructing the myth of the perfect mother.
THESIS OVERVIEW

Synopsis begins by synthesising the extant scholarship on mothering. Mothering is defined and contemporary ideas about mothering are explored. Included in this discussion are the Western cultural ideologies of mothering and the significance they hold for the way that women enact the mothering role. The roles that define my own life and my own experiences of both mothering and being mothered are also discussed in order to position myself in the research and make explicit the perspective from which I research and write.

Exposition explores the existing scholarship on mothering disrupted by illness through a review of the present literature. The search strategy produced papers that referenced mothering, illness and disruption. The review reveals that mothering disrupted by illness is both a source of despair and inspiration for women. Despite illness women still strive to mother their children to the same standards they had before becoming ill. Health professionals are perceived as unhelpful in facilitating mothering and sources of support are ill defined. The review concludes with how the current study will address deficiencies identified in the scholarship on disrupted mothering.

Direction and Cues represents the method and methodology section of this thesis. This study was conducted within a framework formed by three intersecting, theoretical positions: social constructionism, feminism and storytelling. This section discusses the selection of these theories, ethical issues, the enhancement of rigour and thematic narrative analysis.

Prompted by the idea of mothering as a public performance, and the naming of one of the sub-themes ‘the understudy’, a theatre metaphor was applied to this thesis. Although the use of metaphor will be explored more fully at the beginning of the findings section
‘Disrupted Mothering in Illness: A Drama in Four Acts’, the concept is introduced here to explain the seemingly eclectic section titles. The initial application of a theatre metaphor to the findings made those sections incongruent with the rest of the thesis, so theatrical terminology and concepts were extended to the entire thesis to make it a cohesive theoretical whole.

Disrupted Mothering: A Drama in Four Acts presents the findings of this study. In line with the theatre metaphor, themes and sub-themes are referred to as Acts and Scenes. Act I - Playing the Part begins with a discussion of the presentation of the findings. The application of the theatre metaphor is explained and language choices used in the narrative are justified. The women who participated in this study are then introduced. Following these explanations and introductions, the difficulties the women had mothering while ill and the way they attempted to reconcile their mothering responsibilities with the demands of their illnesses are revealed. Act II - The Health Care Subplot uncovers women’s experiences of hospitalisation and encounters with health professionals. Act III - The Supporting Cast delves into the sources of social support the women included in their stories. Act IV - Reviewing the Performance explores the consequences maternal illness had for the women’s relationships with their children and their experience of maternal guilt and blame. However, this Act also details how the women renegotiated their identity as mothers through their stories.

Exegesis contains a discussion of the findings contrasted with the existing literature. Exegesis highlights the challenges of disrupted mothering and the moral conflict experienced by the women and contemplates the way the women experienced and responded to the disruption. Epilogue summarises the study, reveals its limitations, and offers direction for further research and the implications for nursing practice.
Please note sections of this thesis have been previously published (Power et al. 2011; Vallido et al. 2010). Furthermore, early in the candidature published autobiographies were briefly considered as a data source which resulted in a third publication (Power et al. 2012).
SYNOPSIS

We know more about the air we breathe, the seas we travel, than about the nature and meaning of motherhood

(Rich 1986 p. 11)

INTRODUCTION

This thesis is about mothers, mothering and motherhood. It is about trying to be a ‘good’ mother despite devastating illness. Facing major disruption to their life course, women focus upon their children. The subject of this thesis ‘disrupted mothering’ was first identified by Jackson (2000). Jackson’s (2000) thesis explored women’s writings to gain insight into the realities of the lives and concerns of Australian women. Although Jackson (2000) predominantly discussed disrupted mothering in the context of child relinquishment or maternal abandonment, she also documented the grief and trauma that women can experience when they are separated from their children even briefly as a consequence of maternal illness or poverty. This thesis further reveals the experiences of women whose mothering has been disrupted by illness either temporarily or completely, and the consequences this held for their relationships with their children and views of themselves as mothers.

MOTHERHOOD

Motherhood changes women. Becoming a mother is an irrevocable act with far-reaching consequences that cannot be fully appreciated until experienced firsthand (Green 2009; Meyers 2001). Discussing birth, Maushart (1997 p. 15) wrote, “... it is the initiation rite par excellence: the portal through which, once having passed, one can never return.” Although much research has examined mothering and paid employment,
and mothering in the early post-partum period, rarely does the literature address how central mothering is to many women. Yet, during research interviews, women invariably raise issues related to motherhood, even when the research topic is unrelated to mothering (Wilson 2007).

Motherhood has been increasingly theorised over the past few decades, often from a feminist perspective (Baraitser & Spigel 2009; Goodwin & Huppatz 2010b; Jackson & Mannix 2004; Porter 2010). This burgeoning interest in mothering has, not surprisingly, coincided with the influx of women into science and other scholarly pursuits (Maushart 1997). Within this discourse motherhood has been viewed in various ways. Motherhood has been seen as problematic for women. They may experience a loss of professional opportunity with associated economic costs, psychological illness, unrelenting and mostly solitary labour, little appreciation or understanding by non-mothers of the nature of mothering tasks, and a perpetuation of dependence and powerlessness (Meyers 2001; Rittenour & Colaner 2012; Smart 1996). However, motherhood is also recognised as a source of feminine power, uniquely available to women, from which they may draw strength and self-definition (Rittenour & Colaner 2012; Smart 1996). For individual women, motherhood is experienced uniquely, and can be a source of both joy and distress (Arendell 2000).

Defining Mothers and Mothering

In many studies that examine mothering, the concept of mothering is often not defined or critiqued. One possible explanation for this may be the ordinariness of mothering as a concept (Abbey 2003; Jackson et al. 2004/5). Furthermore, many scholarly discussions are centred upon how mothering satisfies children’s needs, rather than on mothering from a woman’s perspective (Arendell 2000; Bell & Ristovski-Slijepcevic
What is important to recognise in discussions of mothering is not only the biological ability to conceive, bear and feed children, but also the ongoing care and emotional work inherent in raising them (Arendell 2000; Maushart 1997).

Although the most common definition of mother is a simple one, a mother being a female parent (Cambridge Dictionary 2011), the word mothering is frequently used interchangeably for care or nurture in the literature. That the word ‘mothering’ is used to refer to nurturing generally, regardless of gender, appropriates an essentially feminine domain and a deeply gendered construct.

Despite mothering being synonymous with nurturing, current definitions fail to capture the emotional intricacy inherent in the act of mothering. Walzer (2007, p. 1) defines mothering as “... the practices involved in taking care of children.” This definition makes no acknowledgement of the emotions that are invested in the act nor captures the intricacy of tasks involved. Hayes (2008, p. 61) did attempt to capture this complexity when she wrote, “mothering is a complex and continuous process that occurs across the lifespan and is of utmost importance for the growth and development of children.” Glen (1994, p. 3) defines mothering as “... a historically and culturally variable relationship in which one individual nurtures and cares for another.” Although Glen conceives mothering as an expanded role that occurs within a relationship between two people, the nature of the relationship between the individuals involved is not described, unless nurturing here is also implied as a synonym for mothering.

The lack of reference to women is striking in the definitions. Reclaiming mothering for women, Glen (1994, p. 22) wrote, “... pregnancy, birth and breast-feeding are such powerful bodily experiences, and the emotional attachment to the infant so intense, that it is difficult for women who have gone through these experiences and emotions to
think that they do not constitute unique female experiences that create an unbridgeable gap between men and women.” Given the uniquely female experience of birth, and the fact that all humans are birthed by women, it could be argued that the definitions of mothering that do not refer to women discount the unique position women occupy in the mothering role. The word itself implies that mothering would be an action undertaken by a mother. While mothering definitions appear to have been expanded so as to become synonymous with the concepts of care and nurture, it means that the definitions deny the origin of the word, and maternal actions are appropriated. Therefore, for the purpose of this thesis a mother is defined as a woman in an established parenting relationship with a child, with mothering being the enactment of an emotional caring obligation by the woman for that child.

Expectation of Motherhood

Women have always been bound by their relationship to others (Hoare 1967), and are united by motherhood across the world (Arendell 2000; Christian 1994; Maushart 1997). Despite demographic changes to the number of births per woman, age at first pregnancy (McMahon 1995), and access to and acceptability of contraception (Sevón 2005), the majority of women will inevitably become, and are expected by society to become, mothers (Jackson et al. 2004/5; Kirkley 2000; Maushart 1997; McMahon 1995).

For women it is almost impossible to escape the biological imperative of childbearing. The degree of choice women have regarding becoming mothers has been questioned by scholars who imply that becoming a mother is often simply considered an inevitable expression of becoming an adult female (Maushart 1997; Meyers 2001). Indeed, being born with a womb means that at some point all women must consider at least their
potential for motherhood (Gordon 1990; Sevón 2005). Furthermore, motherhood is a decision that cannot be fully informed, as the consequences are not apparent until motherhood is achieved (Meyers 2001; Sevón 2005).

It is estimated that at least fifty percent of pregnancies in Australia and the United States are unplanned (Keely & Rosene-Montella 2008; Read et al. 2009; Schwarz et al. 2007). The ‘choice’ of whether or not to continue with a pregnancy can also be influenced by religious and cultural beliefs. Alternatives such as terminating a pregnancy may not be viewed as an option for some women due to personal beliefs and values. Once pregnant a woman’s course is often set.

The notion of autonomous ‘choice’ also collapses for women who cannot bear children or access reproductive technology (Bell 2009; Speier 2001). There are also questions about the autonomy of women to reject motherhood, if their education or training precludes satisfying employment. Maternity may be considered an attractive alternative to unskilled low paying jobs (Meyers 2001; Speier 2001). Meyers (2001) also noted that decisions about conception often occur within the context of a partnered relationship and are therefore collaborative and influenced by the dynamics of the relationship. Although Meyers (2001) makes this point in the context of heterosexual relationships, thereby implying a gendered power imbalance, in homosexual relationships decisions regarding children would also be subject to couple psychodynamics.

When asked, women can have difficulty articulating their reasons for having children (Maher & Saugeres 2007; McMahon 1995; Sevón 2005). Some of the difficulty justifying having children is because the ‘choice’ to have children (unlike the decision not to) is rarely questioned by society (McMahon 1995; Sevón 2005). However, women
who have made a choice to not have children are more likely to have thought it through and developed an explanation to rationalise that choice (Maher & Saugeres 2007).

Childbearing is often seen as a natural life progression, and the desire to bear children has also been associated with “the culturally transmitted mythologies of rapturous motherhood” (Meyers 2001, p. 746). The desire to become a mother is more often than not entrenched in emotions rather than rationality, and thus not easily identified (Sevón 2005). Yet the desire to have a baby can be overwhelmingly powerful and compelling, stemming from the capacity to conceive and an appreciation for the possible relational opportunities of motherhood (Sevón 2005). For the majority of women, that they will bear children is a taken for granted assumption with only the timing and circumstances bought into question (Maher & Saugeres 2007).

Women are thought to bear children to satisfy maternal instincts or natural drives, to gratify a desire to nurture and to enter into a particular type of relationship, or in response to the awareness that the time of fertility is limited (McMahon 1995). In some cases women become mothers due to committing to an adult relationship. Having formed a lasting bond with another person, pregnancy and motherhood might seem to be a natural sequence of events (Maher & Saugeres 2007). It should be stated, however, that the societal expectation for women to become mothers assumes the ‘right’ conducive social, economic and sexual circumstances, otherwise women can be vilified for having children (Stenhouse & Letherby 2011).

*Always a Mother First*

Assuming the identity of mother is considered to be one of the most profound and abrupt identity constructions of adult life (Johnston & Swanson 2007; Maushart 1997). Furthermore, it is an identity that the majority of women will assume (Maushart 1997).
The mothering identity is reportedly more central to most women than either their role as a wife, or their professional identity derived from their occupation (Arendell 2000; Rittenour & Colaner 2012).

Some of the primacy of the mother’s identity is attributed to the degree to which the mothering role monopolises women’s time (Collett 2005). The identity of mother is inescapable. Women at work are more likely than men to spend time thinking about children, take time off work to care for sick children or be contacted by school or childcare about the children (Arendell 2000; Medina & Magnuson 2009). Mother as an identity may be even more significant to women from cultures that are highly invested emotionally in extended family (Arendell 2000), women from poorer socioeconomic circumstances (Hays 1996), or who have a lower level of education (Ex & Janssens 2000; Shtarkshall 1987). A higher investment in mothering has also been associated with lower levels of education providing less attractive career options for some women (Meyers 2001).

The identity of mother has often been examined from a problematic perspective. Feminist scholars, especially, have deconstructed mothering deploring the ‘patriarchal ideology’ in Western society, which has seen women subjugate the formation of primary identities external to that of mother and homemaker (Glenn 1994). However, Hays (1996) found that many women considered that the devotion they felt for their children still predisposed them to making mothering central to their lives. Likewise, in McMahon’s (1995) study, although women discussed the burden of the responsibility of mothering, motherhood also represented personal growth and development. McMahon’s (1995) argument centres upon the way social discourses impact upon the formation of self and identity, in respect to the ways women value the relationships they
have with their children. That is, women may be prone to defining themselves and evaluating their own worth based upon their capacity to care for others (Kayser & Sormanti 2002).

Mother as identity is intrinsically linked to gender identity. Whether or not a woman becomes a mother reflects upon her innate identity as a woman, and motherhood can be perceived as a reflection of femininity. Gender identity and behaviour are predominantly learned in childhood and modelled on the same sex parent (Peterson & Roberts 2003). A young woman’s self-image as a mother is closely related to her conception of her own mother (Ex & Janssens 2000). Thus, even when women disagree with certain aspects of how they were mothered, their own mothering is influenced by the behaviours they intentionally reject (Golden 2001). Women strive to be better mothers than their own mothers, instituting practices they appreciated as children, and avoiding those they felt were mistakes (Hays 1996). Gender identity as a mother is also subject to cultural interpretations based upon the dominant cultural ideologies of motherhood (McMahon 1995).

*Ideologies Create ‘Good’ Mothers*

Women’s beliefs about mothering are formed through a complex matrix of class, race, culture, religion, peers, experience, childhood memories and other factors. However, each woman’s unique perspective exists in reference to the predominant ideologies of mothering (DiQuinzio 1999; Hays 1996; Hequembourg 2007). An ideology is a collection of values, beliefs, and ideas produced in order to make sense of and provide standards of behaviours within a society (Johnston & Swanson 2006). The values, beliefs and ideas that form an ideology stem from the dominant culture within a society and function to maintain the privilege of that dominant culture (Lauster 2010; Rothman
As such, ideologies are political (Rothman 2000). Ideologies of mothering encompass societal beliefs about mothering and standards of mothering behaviour. Essentially, ideologies of mothering define the ‘right’ way to mother (Austin & Carpenter 2008).

Mothering as an exclusive and encompassing feminine occupation is based upon the ideal of White, middle-class, heterosexual, married mothers and their values (Arendell 2000; McMahon 1995; Sutherland 2010), positioning them as the norm of motherhood (Byrne 2006). This image of mothering excludes women of other races, sexual orientation, socioeconomic class and marital status (McMahon 1995). Although predominantly produced in the United States, the ideologies of Western mothering have been adopted in other Westernised cultures such as Australia and the United Kingdom. The adoption of comparable ideologies has been attributed to a common cultural and historical ancestry (Savvidou et al. 2003).

There are several mothering ideologies referred to in the literature, including scientific mothering (Apple 1995), essential mothering (DiQuinzio 1999), intensive mothering (Hays 1996), extensive mothering (Christopher 2012) and attachment parenting (Liss & Erchull 2012). ‘Scientific mothering’ stems from the increasing medical and ‘expert’ advice women are meant to draw upon when having and raising children (Apple 1995). ‘Essential mothering’ is predicated upon women’s biological capacity to bear children proposing that female nature and sexuality exists to serve procreation and perpetuation of the species (DiQuinzio 1999; Hequembourg 2007). Essential mothering dictates that not only do all women desire to become mothers but that it is only through motherhood that women can be emotionally and psychologically fulfilled (Hequembourg 2007).
The most pervasive ideology discussed in the literature is that of ‘intensive mothering’, which positions women in service to children (Hays 1996). In intensive mothering “… childrearing is construed as child-centred, expert-guided, emotionally absorbing, labour intensive, and financially expensive” (Hays 1996, p. 8). Central to intensive mothering is the tenet that only the biological mother possesses the necessary knowledge of the child and instinctive skills to undertake the work. In intensive mothering a good mother is self-sacrificing, subjugating her own needs for the good of her family (Arendell 2000; Baker & Carson 1999). The cultural standards of intensive mothering fervently connect the mother’s conscientiousness with the child’s appropriate development and wellbeing (Hays 1996; Sevón 2007).

‘Extensive mothering’ represents a shift in women’s adherence to intensive mothering (Christopher 2012). Christopher (2012), in a study of 40 employed Canadian and American mothers, found that participants delegated a substantial amount of the day-to-day care of their children to others. These women positioned themselves as being in charge of their children and fulfilled maternal responsibility through scheduling caregiving tasks and carers. Unlike working mothers in other studies who positioned their employment in terms of how it financially benefitted their children, women in this study emphasised the personal gains of being employed such as self-esteem, financial independence and utilising education (Christopher 2012). Some of the married women in this study expressed regret that they did not desire to be a primary carer and were hurt when their children developed strong bonds with alternative carers like nannies or au pairs. The author attributes this to the women still feeling accountable to the intensive mothering rhetoric even while rejecting it. Single working mothers were less ambivalent as they needed to work to support their children, so not engaging in intensive mothering was seen as less of a choice.
In contrast to ‘extensive mothering’, ‘attachment parenting’ as a mothering approach advocates for an especially intensive parenting style. Elements include natural birth, preferably at home, breastfeeding on demand until the child self-weans, treating babies as an extension of the parents’ bodies, carrying them and sleeping with them, and not leaving babies to cry (Etelson 2007; Green & Groves 2008). Although its title refers to parenting and there is scope for male parents to contribute to all attachment activities except for breastfeeding, the majority of primary caregivers in attachment parenting are biological mothers (Green & Groves 2008; Liss & Erchull 2012).

What mothering ideologies have in common is that they culminate in an ideal mother figure, often labelled the ‘good’ or ‘idealised’ mother. The ‘good’ mother represents a social construct that dictates unachievable levels of mothering (Arendell 1999; Dillaway 2006; Goodwin & Huppatz 2010b). Although in the past she has been predominantly White, married, middle-class, child-focused and financially dependent, the ‘good’ mother is historically and culturally malleable and is beginning to “appear as variations on a theme” in other mothering contexts (Goodwin & Huppatz 2010b, p. 2).

The ‘good’ mother in Western cultures is often aligned with commercial consumption (Clarke 2004). The ‘good’ mother can be identified by how she dresses herself and her children, how well she is groomed, the baby products she buys (Goodwin & Huppatz 2010a), the parties she hosts (Clarke 2007), and the house she lives in (Lauster 2010). This conspicuous consumption further alienates marginalised mothers from the ideal of the ‘good’ mother, as being a ‘good’ mother can require significant economic resources (Goodwin & Huppatz 2010a).

Although the sexualisation of mothers has received scant scholarly attention, phrases such as ‘yummy mummy’ (Goodwin & Huppatz 2010a) and ‘MILF’ (mother I’d like to
fuck) (Adams 2009) have become a part of the mothering vernacular. Such phrases represent the pressures to not only conform to standards of mothering but also represent the evolution of the mother figure from sacrosanct nurturer to sexual being.

An ideology represents an ideal, not reality, yet it is against these ideals that people in a society hold each other accountable (Johnston & Swanson 2006). Although women may be aware of the tension between mothering ideals and their actual achievability, they are still influenced by their self-expectations (Chase 2001; Goodwin & Huppatz 2010b). The dominant mothering ideologies are so pervasive that women may have difficulty not attempting to adhere to them. Choi et al. (2005, p. 169) state that it may be difficult for new mothers to resist conforming to the dominant ideology given the “... societal retribution for not performing one’s gender correctly.” Unfortunately, attempting to adhere to an ideology contributes to its perpetuation (Choi et al. 2005). Mothering ideologies thus represent “hegemonic motherhood” which involves mothers being regulated, controlled, defined and evaluated as nurturers of children (Arendell 1999, p. 4). Hegemonic mothering is perpetuated by women themselves who, having absorbed the prominent ideologies, unconsciously strive to achieve them, contributing to the propagation of standards by which they judge and are judged by other women (Arendell 1999; Austin & Carpenter 2008; Johnston & Swanson 2006). Thus, women are often unwittingly complicit in reproducing the cultural beliefs surrounding mothering even while these beliefs continue to oppress them (Austin & Carpenter 2008). It is difficult for women to resist conforming to the ideologies as they dictate what ‘good’ mothers do, and the majority of mothers want to be good mothers (Goodwin & Huppatz 2010b).

Women of different cultural backgrounds and lower socioeconomic status may redefine the idea of the good mother in order to be able to consider themselves as satisfying the
mould (Hays 1996). Likewise, women with disabilities might tailor their mothering efforts in an attempt to appear competent. In a qualitative study of women with disabilities, some of the participants reported attempting to make “extra efforts” to conform to the role of the ‘good mother’ (Malacrida 2009, p. 106). The women discussed taking their children on outdoor excursions despite being physically disabled, or dressing their children in designer clothes and paying particular attention to their grooming. A perception that they were subject to extra scrutiny on account of their disability caused the women to attempt to make their mothering skills more evident.

Resistance to or reframing of the ideal appears to be becoming more common, especially in samples of Australian women. In a study by Maher and Saugeres (2007), women without children were more threatened by the intensive mothering ideology. Women who had made a conscious decision to not have children, or who had postponed motherhood, described mothering as “... all-encompassing and potentially overwhelming” (Maher & Saugeres 2007, p. 5). Several of the women who were voluntarily childless also expressed more negative views of women who were mothers accessing childcare and returning to work. Contrary to this, women with children were more pragmatic and less invested in the idealised mother image. The majority of women in this study with children combined work and mothering. While they did stress the importance of being available to their children they tended to discuss the practical aspects of fulfilling maternal responsibility rather than subscribing to the rhetoric of intensive mothering. It has also been noted that women who have more than one child develop more agency, as during subsequent pregnancies they know what to expect and are more comfortable “cutting corners” (Choi et al. 2005, p. 177). Another emerging site of resistance exists in the online environment of chat-sites and blogs, where women share their experiences of mothering both positive and negative, and are able to position
their own experiences in relation to their peers (Hau-nung Chan 2008; Lopez 2009; Morrison 2010).

The significance of the ideologies of mothering is how they impact upon women’s feelings of value and self-worth. There is a dichotomy between the reality of women’s lives as mothers and the social, cultural and ideological images that depict mothering (Sevón 2005). The actual experience of mothering can be vastly different to the prescribed ideal, and this can lead to women feeling that they do not meet the standards (Andrews 2002; Liamputtong 2006; Malacrida 2009). This lack of fit between the ideal and reality has been attributed to causing women guilt and shame, stress, fatigue and mental and physical illnesses (Maushart 1997; Rizzo, Schiffrin & Liss In Press; Sutherland 2010). The societal expectations and ideologies of mothering can also make it difficult for women to express discontent, as ‘good’ mothers are supposed to be fulfilled and content in the mothering role (Hau-nung Chan 2008; Miller 2005; Sevón 2007; Shirani, Henwood & Coltart 2012). Therefore, ‘good’ mothers are supposed to be ‘happy’ mothers (Goodwin & Huppatz 2010b).

The Relentless Responsibility

The Western ideologies of mothering currently construct responsibility for children as almost wholly within the mother’s domain (Sevón 2007). A mother typically considers herself and is considered by others to be responsible for the health and wellbeing of her children (Collett 2005; Ruddick 1980; Seagram & Daniluk 2002). Children are the blank canvas upon which “the mother, custodian of the milky ink writes the foundational text” (Muller 2008, pp. 10-1). Despite the presence of other adults, a woman is still predominantly responsible for raising a child who can function well and be accepted by society (Dillaway 2006; Liamputtong 2006; Ruddick 1980). That
women are evaluated on their mothering, and their children appraised as a product of that mothering, highlights the way that motherhood is policed (Smart 1996).

Women are acutely aware that their mothering is scrutinised and that they are held responsible for any negative health, behavioural or social problems in their children (Jackson & Mannix 2004; Shirani, Henwood & Coltart 2012). Jackson and Mannix (2004) interviewed twenty Australian mothers to find that women reported being held responsible for such things as eczema or asthma in their child, with health professionals implying it was from a lack of adequate household cleaning, or not breastfeeding (Jackson & Mannix 2004). Mothers are implicated if children develop disorders as varied as schizophrenia, asthma, autism, epilepsy (Singh 2004), ADHD (Peters & Jackson 2008) and obesity (Jackson, Wilkes & McDonald 2007).

Fatherhood has avoided being typed and scrutinised to the same extent as motherhood (Goodwin & Huppatz 2010b). Fathers are often relegated to a secondary role and any threat or benefit they pose is either underrated or discounted. In the case of ineffective parenting it is invariably the mother who is targeted for intervention strategies (Greaves et al. 2004; Jackson & Mannix 2004; Taylor et al. 2009). Absent fathers are frowned upon, but ‘bad’ mothers attract particularly vitriolic moral judgement (Vincent 2010). The term parenting is often used interchangeably for mothering in research (Bell & Ristovski-Slijepcevic 2011; Greaves et al. 2004; Jackson & Mannix 2004; Taylor et al. 2009). Although this may be reflective of the expectation that parenting is a shared endeavour, it is actually a linguistic device that renders gender and the work of mothers invisible (Burnett et al. 2010; Jackson & Mannix 2004).

Implying that fathers contribute equally in parenting children defies findings in contemporary research. The expectation of shared care has progressed much more
rapidly than fathers’ actual involvement (Burnett et al. 2010; Milkie et al. 2002). In reality mothers are still bearing the majority of household and child-related chores (Burnett et al. 2010; McGuire, Primack & Losos 2012; Walters & Whitehouse 2012). In a telephone survey of 243 American parents, although both mothers and fathers expressed the view that there should be equal involvement in childrearing there was a discrepancy between how much fathers perceived they were doing compared to how much mothers reported they were doing (Milkie et al. 2002). A recent review of the literature on the work/life balance of white-collar, heterosexual couples with children in the United States and United Kingdom found multiple studies that confirmed inequalities in the amount of childcare and housework performed by fathers (Burnett & Gatrell 2010). Although the authors acknowledged that contemporary fathers were more involved in parenting than previous generations, mothers performed the bulk of domestic labour and childcare irrespective of their employment status (Burnett et al. 2010). In the studies reviewed, women performed between nine and eleven hours more housework and childcare per week than men (Burnett et al. 2010). Similarly, in a recent Australian study, although women were well aware of the inequality of the division of household labour they still assumed the bulk of domestic duties as they perceived their male partners to be incompetent to complete the household tasks to an acceptable standard (Walters & Whitehouse 2012).

Women are much more likely than men to sacrifice their income and time to be the primary caregiver. Many women stop work temporarily following childbirth, and frequently return to work on a part-time basis to facilitate childcare. This can be attributed to women generally having a smaller earning capacity, which reduces the ability to negotiate with a partner regarding work and childcare (Forssén & Carlstedt 2008). This is confirmed by Deutsch and Saxon’s (1998) study of working American
couples. Examining the division of household labour and childrearing duties among men who were blue collar workers and their employed wives, the researchers found a fairer division of household and childrearing tasks where the woman’s income was greater than the husbands. The authors concluded that higher earnings empowered the women to negotiate fairer divisions of labour.

Deutsch and Saxon (1998) also found that some mothers were possessive of their position as the primary nurturer, but that this was upheld by fathers, despite the fact that they often performed the same emotional and physical tasks for the children. Fathers in this study believed that they were merely substitutes for the mother, and were swift to identify themselves as such. The notion that fathers often perceive themselves as mothers’ ‘helpers’ is confirmed in more recent research (Burnett et al. 2010; Gatrell 2005, 2008; Maushart 2002).

In a longitudinal qualitative study of twenty-five Australian couples, Lupton (2000) found that women still expected to take responsibility for the majority of childcare. The women discussed wanting their husbands or partners to be supportive, helpful, understanding and forgiving as fathers. None of the women entertained the idea that childcare would involve an equal amount of care. Instead fathers were expected to assume the traditional role of full-time breadwinner while acting as a support person in their leisure time.

Other scholars have identified that mothers may unconsciously prevent increased father involvement in order to maintain maternal power and privilege (Allen & Hawkins 1999; Gaunt 2008). Although findings can also be attributed to a lack of paternal motivation to be involved, women with lower self-esteem, strong maternal identity and alliance to traditional gender roles are more likely to discourage fathers participating in childcare.
(Allen & Hawkins 1999; Gaunt 2008). Maternal gatekeeping is also correlated with a lower level of education and employment as well as some religious beliefs (Gaunt 2008).

All Mothers are Guilty

The ideologies of mothering are prescribed as every mother’s moral duty to fulfil; however, the bar is set very high and women struggle to achieve the standards (Eyer 1996; Malacrida 2009). Women’s self-esteem can be intrinsically linked to how well they feel they fulfil the mothering role (Forssén & Carlstedt 2008; Jackson 2000; Jackson & Mannix 2003). Yet there is little research that addresses the “... tremendous amount of invisible labour and self-discipline involved in compliance with dominant mothering standards from the perspective of those deemed as good mothers” (Avishai 2007, p. 136).

Not measuring up to the cultural expectations of mothering results in guilt, shame and feelings of inadequacy for many women. Sutherland (2010), while acknowledging that guilt is the more commonly used word, differentiates between guilt and shame. Guilt stems from a fear of punishment for a transgression, whereas shame is more about comparing oneself to others and perceiving that self as inferior (Sutherland 2010).

Ambivalence has been cited as a significant source of maternal guilt (Parker 1997). Women can find it difficult to admit that they both love and at times loathe their children (Nicholson 1983; Parker 1997). Although there can be overwhelming joy to be found in motherhood, there can be an equal measure of sorrow that stems from the burden of childcare, fatigue, self-sacrifice, and the curtailing of personal freedom and opportunity (Nicholson 1983).
That mothering entails guilt is a rarely contested concept (Seagram & Daniluk 2002; Sutherland 2010). The idea that guilt and shame are an intrinsic element of mothering is one of the most common findings in maternal research (Seagram & Daniluk 2002; Sutherland 2010). Acknowledging the pervasive guilt of motherhood, Rich (1986, p. 217) wrote: “the guilt, the powerless responsibility for human lives, the judgements and condemnations, the fear of her own power, the guilt, the guilt, the guilt”. Little has changed in the intervening years except that with the mass movement of mothers into the paid workforce, many more have opportunities to feel guilty and ashamed.

Seagram and Daniluk (2002) interviewed American women and found that guilt was experienced about nearly every aspect of mothering. As one participant summed up, “I feel responsible for every cell of his little body” (Seagram & Daniluk 2002, p. 67). These women felt constantly under surveillance by other mothers, friends, family and professionals. Expectations from others caused the women in the study to second-guess all of their parenting practices. These participants had obviously absorbed the intensive mothering rhetoric, resulting in a sense that only they possessed the necessary attributes to meet the needs of their children. This gave them a profound connection and possessive feeling of sole ownership of that child (Seagram & Daniluk 2002). However, attempting to live up to the impossibly high societal standards of good mothering was unattainable, causing them to experience guilt and a sense of inadequacy (Seagram & Daniluk 2002).

Women have many opportunities to feel guilt and shame regarding mothering. Even before conception, women are expected to prepare their bodies for the foetus, to cease smoking if a smoker, lose weight if overweight, and take vitamins prenatally (Van Der Zee & De Beufort 2011). During pregnancy, mothers are expected to abstain from all
social vices (smoking, alcohol), avoid all chemicals, not gain too much weight, avoid stress and eat a healthy diet (Van Der Zee & De Beufort 2011). Some scholars even go so far as to suggest there is a moral obligation to engage in prenatal selection of embryos to ensure a genetically advantaged child (Savulescu & Kahane 2009). Although all of these recommendations would assist in producing a healthy child, it is the moral tone of the advice that is objectionable. Bell et al. (2009) draw attention to the moral panic and scapegoating of mothers that occurs during public health messages regarding pregnancy, and how such messages victimise already marginalised women with no acknowledgement of the structural, environmental and contextual factors that constrain their ability to make healthier choices during pregnancy.

Once children are born, mothers face guilt over every aspect of their mothering from infant feeding (Elmir et al. 2012; Lee 2008) to their choice of school (Aitchison 2010). Mothers experience guilt if they go to work, and guilt if they do not (Hays 1996; Johnston & Swanson 2006).

Feelings of responsibility and guilt do not necessarily end when children are grown and independent. Dillaway (2006) interviewed 45 older women to find that the women still put their children first and suppressed their own needs. Even though their children were grown with families of their own, the women expressed feeling guilty if they attempted to meet their own needs first (Dillaway 2006).

Mothering as Performance Art

Mirroring theories of ideology, Goffman (1959) proposed that the way people present themselves to others is based upon cultural values, norms, and expectations. Drawing upon symbolic interaction, Goffman (1959) conceived people as actors who performed for one another. The objective of this performance is validation from the audience that
they fulfil the role. If the audience believes that the performance is constitutive of that person then the performance is successful. Goffman (1959) also divided life into the front stage where performances take place and the backstage where performances are prepared (Goffman 1959).

Goffman’s (1959) dramaturgical metaphor can be easily applied to the mothering role, as the performance of mothering is also watched and evaluated. The institution of motherhood includes “societal expectations, assumptions, laws and rules which govern how a woman is expected or, in some cases forced to mother her children (Porter 2010, p. 5). Due to their mothering being scrutinised, women are conscious of how they portray themselves as mothers in public. Wilshire (1982) suggested that in everyday life, humans are often acting, reacting to the people around them, altering their performance to seek outside validation.

How mothering is conducted in private is preparation for the public performance. Behind closed doors women may struggle with mothering. However, the picture they present to the world is rarely telling. Women may attempt to appear competent in their mothering role in order to avoid the public censure that can result when their performance is deemed to be wanting (Lauster 2010).

Performing mothering requires props. In an embodied example, breasts are props as breastfeeding is a visual performance of ‘good’ mothering (Speier 2001). Lauster (2010) discussed privileged performances of mothering in the context of houses as stage props. Other performance props include baby paraphernalia such as expensive prams and designer clothes (Goodwin & Huppatz 2010a).
Even women who do not fit the cultural stereotype of the ‘good’ mother will draw upon props to validate themselves in the mothering role. Using props to validate mothering is evident in Edin and Kefalas’s (2011) study of young, poor American mothers. The young women in their study discussed dressing their babies in designer clothes they could not afford in order to project the appearance of good motherhood.

Another conspicuous site of maternal performance can be found in the orchestration of children’s parties. In Clarke’s (2007) ethnographic study of English mothers, she documented the increasingly commercialised and elaborate nature of children’s birthday parties. Clarke (2007) positions children’s birthday parties as an opportunity for women to demonstrate what ‘good’ mothers they are through the choices of cake, food, decorations, theme and take-home gifts for visiting children. Parties also provide an opportunity to be validated as a mother by the hopefully gracious behaviour of their child as the guest of honour. Other children’s birthday parties offered a similar occasion for seeking validation, as women were evaluated upon the presents they brought, their child’s outfit, or costume if the party was fancy dress, and their child’s behaviour as a guest.

However, the children’s birthday party circuit could also be a source of marginalisation. For some women, children’s birthday parties represented “an overt form of social tyranny” (Clarke 2007, p. 90). Perpetuated by middle-class women, and a flourishing gift economy, ‘other’ mothers, those without the economic resources, or who were from different cultures and held different beliefs about children’s parties, could struggle to participate in the birthday party circuit. Not being able to participate due to scarce resources could cause the women to feel guilty that their children were disadvantaged.
In a study in California Blackford (2004) documented the way that women performed mothering for one another in children’s playgrounds. Being with their children in the public space of the playground brought the private issue of mothering into public view. Children’s playgrounds functioned as “ritual spaces” where middle-class mothers modelled social roles and engaged in thinly veiled competition and control (Blackford 2004, p. 234). Reflecting upon her study, Blackford (2004, p. 239) wrote: “The playground becomes a space in which those parenting requirements are performed, contested and reified by community. It is a public stage of a screenplay written by 19th-century domestic ideology.”

*The Love of a Mother’s Life*

The relationship between mother and child has been conceived as the closest possible bond between two people (Arendell 2000; Seagram & Daniluk 2002). Maternal love is the motivation of care and vigilance, despite fatigue and lack of a tangible reward (Noriuchi, Kikuchi & Senoo 2008). Yet maternal love has remained largely unexplored in the literature, either trivialised or not examined as it is an expected emotional response deemed unworthy of investigation (McMahon 1995). It has also been considered as proof of women’s greater emotionality, which is considered innately feminine (McMahon 1995). However, expressing these emotions and caring deeply for and about a child is an intrinsic part of mothering (Sevón 2007), and vital to the survival of humans as a species (Noriuchi, Kikuchi & Senoo 2008).

When McMahon (1995) embarked on a study of Canadian mothers to examine the relationship between the meaning of work and motherhood in women’s lives, she was unprepared for how central mothering and children were to the women. “Haunted by the data”, McMahon (1995, p. 6) reframed her study during the analysis so that it “...
became a study of the subjectively creative production of identity and social reproduction of cultural meanings associated with gender and motherhood” (McMahon 1995, p. 14). McMahon defines maternal love as “... commitment to an identity and sense of self that a woman vests in her relationship with her child. That is, the identity established and validated in the social relationships associated with motherhood is appropriated by the self as constitutional of self” (McMahon 1995, p. 22). The women in her study described themselves as surprised and overwhelmed by the emotions they felt, and the depth of love they were capable of, when they became mothers. They attributed their love for their child with making them better people, more responsible, less selfish, more reflective, more aware of global issues, having a larger stake in the world’s future and being more mature (McMahon 1995). While McMahon (1995) is swift to clarify that not all mothers experience this instant connection, the depth and all-encompassing nature of these women’s emotional response was such that McMahon (1995) felt compelled to redirect the focus of her inquiry.

Women can be unprepared and shocked for the depth of love they experience for their newborn children. In a paper that explored the experience of motherhood for academics, one author recounted how difficult she found it to be separated from her newborn infant (Buzzanell & D’Enbeau 2009). She recalled being told “it was abnormal to feel so much love for a baby” (Buzzanell & D’Enbeau 2009, p. 1205). Yet the connection between mother and child is often stronger, more intense and more durable than that between romantic adult partners (Rittenour & Colaner 2012; Seagram & Daniluk 2002). Sevón (2007) also found her participants overwhelmed by their emotional response to their infants. Participants were astounded that they had “... made such a marvellous thing ...” that their children were “... so beautiful and wonderful ...” (Sevón 2007, p. 6). One participant, despite having had a difficult time with a very sleepless baby still remarked
“... that she loved her child enormously and the child was the most important thing in
the world to her, and that she would be able to endure the loss of her husband better
than the loss of her child” (Sevón 2007, p. 6). This view was reflected in a study by
Seagram and Daniluk (2002, p. 73) where a participant stated she would not sacrifice
her life for her husband, but would not hesitate to do so for her child, “...that child is so
important, and so precious that I’m prepared to die for that child.”

For women without stable romantic partners, the relationship with a child can represent
emotional continuity and stability. Women in a study of young unmarried American
mothers viewed their relationships with their children as a haven from the sometimes
harsh relationships they had with adults (Edin & Kefalas 2011). The love of a child was
seen as redeeming, validating, pure and reliable, whereas love from men was viewed as
possibly dangerous and transient. Being loved and needed by their children made the
young women feel valuable and validated (Edin & Kefalas 2011).

The love of a mother for her child can exclude others. For example in Lupton’s (2000)
study, women spoke of the pleasure they gained from being the primary person in a
child’s life. The women enjoyed being recognised as ‘mother’ and their child displaying
a preference for them. This has been a common theme in other studies. In Sevón’s
(2007) study, women spoke of enjoying breastfeeding because it made them vital to the
baby, as breastfeeding is an act not easily relinquished to another person.

**Motherhood and Women’s Health**

There is a distinct lack of inquiry surrounding the everyday mothering of healthy
children, which has resulted in little being known about how mothering issues affect
women’s health (Forssén & Carlstedt 2008; Jackson & Mannix 2003; Thorne, 1990).
Furthermore, “health research has frequently overlooked gender differences and even
omitted gender, usually women” (Borrell et al. 2004, p. 1871). Much of the literature centres upon the stress inherent in combining work with mothering (Borrell et al. 2004), or upon mothering in the context of children’s various disabilities or conditions.

Women define health and wellbeing largely in terms of relationships (Kasle, et al., 2002). Mothering can provide health benefits in terms of increased self-esteem, through being able to provide for the physical or emotional needs of dependants, and access to close and affectionate relationships (Edin & Kefalas 2011; Fokkema 2002; Holton, Fisher & Rowe 2010). In a study of young unmarried American mothers, the authors credited motherhood with providing the women with a meaningful identity (Edin & Kefalas 2011). Poor and with little education, the women found mothering to be an area in which they could excel. Many of the participants in this study discussed making sure their children were always well dressed and clean in order to elicit positive comments from people, which bolstered their sense of worth (Edin & Kefalas 2011). Other work around self-esteem has shown that how well a woman feels she performs mothering has direct consequences for her sense of self and personal value (Forssén & Carlstedt 2008). In Forssén and Carlstedt’s (2008) study of elderly Swedish women, the women attributed mothering with having a positive influence on their health as it meant that they were loved, valued and needed. Even when their children had grown and had families of their own, the women found self-worth in helping to care for their grandchildren.

Yet an ethic of intensive maternal caring can be detrimental to women physically. In Forssén and Carlstedt’s (2005) study, women also described providing care to their children beyond their physical capacity. Women suffered “weariness in body and soul, as well as worry, burnout, physical ailments and injuries ... judged by the women to be
consequences of their excessive caring” (Forssén, Carlstedt & Mörtberg 2005, p. 660). The experiences of the women in this study prompted the researchers to develop the concept of “compulsive sensitivity” (Forssén, Carlstedt & Mörtberg 2005, p. 668). Compulsive sensitivity refers to an ethic of self-sacrifice, of being unable to resist responding to another’s needs, even if to do so is detrimental to one’s self (Forssén, Carlstedt & Mörtberg 2005).

When discussing the effect mothering has on women’s health, there is a need to consider it in conjunction with other variables, namely socioeconomic and education levels, family size and children’s ages, as well as individual personalities and coping styles (Artazcoz et al. 2004). Working for wages, looking after a family, and other daily responsibilities limit the hours women have available to rest and pursue healthy leisure activities (Artazcoz et al. 2004; Lewis & Ridge 2005). Time for sleeping and leisure is reported to be one of the first casualties of combining motherhood with full-time employment (Artazcoz et al. 2004). Time is considered a valuable commodity, and even when women ‘make’ time to exercise they often feel self-indulgent and guilty that they are neglecting maternal duties (Lewis & Ridge 2005). Lewis and Ridge (2005, p. 2300) relate this to mothering being an “undervalued social role” that causes women to feel the need to justify taking any time for themselves. It is also related to the traditional concept of mothers subjugating their own needs for the good of others (Lewis & Ridge 2005).

Juggling work and family may contribute to a woman feeling overworked and having no control over how she spends her time (Artazcoz et al. 2004). However, this is dependent upon a variety of factors, including the woman’s level of education and income, the type of work she undertakes, the number and ages of her children (Artazcoz
et al. 2004), and her marital status (Fokkema 2002). Full-time unskilled labour is found to be much more detrimental to women’s health than skilled work (Artazcoz et al. 2004) as it is more likely to expose women to hazardous working conditions (Borrell et al. 2004).

In a representative cross sectional sample of Spanish women in Catalonia (n=2866), Artazcoz et al. (2004) found that a higher level of education mitigated the possible negative health effects of combining mothering with work. Higher education levels correlated with more qualified employment positions and therefore greater economic resources to hire domestic help. In a similar study in the Netherlands, Fokkema (2002) found combining working with mothering was beneficial to the health of both married and divorced women whose children were over five years of age. The benefits of working were thought to be related to increased social contact and having a personal income (Fokkema 2002). In Fokkema’s (2002) study, women with children (on average) had better health than those without. This was especially true for married women who may have received more assistance from their husbands with domestic and childcare tasks.

**SUMMARY**

From the scholarship on mothering it is apparent that mothering is fraught with meaning and significance for women. Women’s identities, self-esteem, emotions, time and attention are heavily invested in their roles as mothers. Generally women express feeling great love for their children, feel responsible for their care and wellbeing, and are aware that they and others are continually monitoring their mothering performance. It is therefore intuitive that any threat to their capacity to mother their children could
have potentially devastating consequences for women’s sense of self-esteem and feelings of worth.

SITUATING MYSELF IN THE RESEARCH

I am a mother, partner, sister, cousin, aunt, daughter, Wiradjuri woman and nurse. My life has been shaped and defined by these highly gendered roles. I bring to this thesis my own personal experiences of being a working mother of two teenage children. As a mother, my adult life has largely been concerned with creating a stable, happy, healthy environment for my children. Despite being very aware of the Western cultural ideologies of motherhood, I find that I struggle to resist them, as it is very important to me that my children view me as a good mother. I have committed the full extent of my personal resources to what can only be described as intensive mothering.

I am the eldest of six children. For much of my childhood and adolescence I represented the maternal figure for my sisters. Our mother had mental health and substance abuse issues which resulted in a peripatetic childhood. We changed names, homes, schools and towns frequently. I have lived in hotels, caravans and some quite nice houses depending upon our transient circumstances. After I left home when I was seventeen, some of my siblings spent time living rough in tents. I believe that the disruption I experienced in childhood is intrinsic to my desire to provide my own children with stability and surety. My experiences of being inadequately mothered gave me cause to reflect deeply upon the nature of motherhood which in turn determined my own mothering style. Mothering was modelled for me by my Aunts and other nurturing older women. This was fortunate, as an Indigenous heritage often results in limited maternal capacity due to a history of dispossession and separation.
The spectre of maternal illness has haunted my family. My sisters, cousins and aunts have various conditions and diseases that impact (sometimes severely) upon their ability to care for their children. These illnesses include hypertension, diabetes, lupus, heart disease, epilepsy, cerebral palsy, iron deficiency anaemia, and protein c and s deficiency which has manifested in life-threatening clots. Despite their health challenges, they are all dedicated, devoted mothers.

I live with an extremely supportive partner. Although he is more than willing to help with anything I ask, we have assumed gendered roles. He will take over the housework and cooking if I am facing a deadline or buried in work, otherwise the bulk of domestic tasks and childcare is my responsibility.

As a nurse, being a mother made me especially sensitive to the plight of women patients with maternal responsibilities. I remember one woman, who after an extended period of hospitalisation for motor neurone disease, elected to be extubated rather than remain mechanically ventilated for the remainder of her life. Witnessing her distress while her children said their final goodbyes to her and their distress when she was extubated and swiftly died affected me profoundly. She was the first of many. There was another who died of ovarian cancer. Only a few days before she died she told me that she was going to beat the disease as she was determined to accompany her daughter to Kindergarten for her first day of school. While I was showering her, another very young mother with a debilitating and chronic lung condition asked me, “But I have little boys, how will I run and play with them? What kind of mother will I be?” It is experiences with patients like these, and my own experiences of mothering children and being mothered, that motivated me to undertake this study.
EXPOSITION

And the crown of her motherhood will be more precious than the diadem of a queen

(Harper 1892)

INTRODUCTION

Serious illness diminishes personal resources, and impacts upon finances and friendships, status and self-esteem, and fitness for life roles such as parent or employee (Miczo 2003). Illness can therefore threaten women’s identities as mothers both morally and existentially by interfering with their ability to care for their children (Wilson 2007). While pregnancy is a natural condition, at least 15-20% of women entering prenatal care have their pregnancies complicated by existing or emergent health issues (Keely & Barbour 2008; Lyerly et al. 2009). Furthermore, it has also been estimated that 20-50% of women with a serious mental illness live with children (Montgomery et al. 2006). Due to maternal status not being included in hospital separation statistics it cannot be determined how many mothers of older children, mother while experiencing illness. However, given that the majority of adult women do have children, or anticipate having children at some point in the future, it can be reasonably assumed that the mothering capacity of a vast number of women hospitalised or being treated for physical or mental illness will be affected. The purpose of this section is to draw conclusions about the current state of research regarding mothering disrupted by illness and define the need for this study within the wider discourses of mothering and health scholarship.

Databases including CINAHL, Scopus, Wiley Blackwell and Google Scholar, were searched regularly during the course of this doctoral degree. The literature included in
this review is the result of searches and alerts that included reference to mothers, illness and disruption published between 2000 and 2012. Some seminal work on disruption outside of this date range has also been included. Further search terms such as interrupted and disease were included as they functioned as synonyms for the main concepts. These search terms returned thousands of titles; however, a large majority of them examined mothering an ill child or focused upon how maternal illness impacts upon children. Other scholars investigating illness and mothering have found similarly (Bell & Ristovski-Slijepcevic 2011; Grant 2001; Montgomery et al. 2006). Discussing the prevailing discourses in the cancer literature, Bell and Ristovski-Slijepcevic (2011, p. 633) noted that researchers appeared “generally uninterested” in the impact that metastases had upon mothers, but rather how their children were affected. Studies that privilege children tend to discount the existential challenge that impending death or serious illness presents to women (Bell & Ristovski-Slijepcevic 2011).

Several papers that featured both mothers and fathers as participants were also included. Although these studies referred to parenting in illness, the vast majority of participants were mothers and the focus was therefore upon mothering. There appears to be a general lack of acknowledgement of the gendered composition of some studies. In a literature review of thirteen studies of parents with cancer, ten of the studies reviewed focused exclusively on mothering, and in another mixed gender study seven of the nine participants were women (Semple & McCance 2010b).

**Biographical Disruption**

Theorists have proposed that women position their relationships with others as central to their sense of self and wellbeing (Kayser & Sormanti 2002). Women evaluating themselves through their capacity to nurture others can have significant consequences
for their sense of self if that capacity is disrupted. Michael Bury’s (1982) seminal work on biographical disruption conceptualised chronic illness as a major disruptive event. Bury drew attention to the way that chronic illness challenged individuals to recognise the nature of their relationships with others and forced them to renegotiate terms of reciprocity and support. The disruption to social relationships and ability to mobilise material resources were intrinsic to the definition of disruption.

Although Bury’s (1982) participants were predominantly women, many of whom had children, his article focused upon disruption to their identities as workers and neglected to mention how chronic illness impacted upon their mothering capacity. Wilson (2007, p. 624) suggested that greater attention needed to be paid to incorporating “the cognitive and emotional significance of motherhood and of caring responsibilities more generally into sensitive explorations of the effects of illness.” In her own study, Wilson (2007) used biographical disruption as a framework when interviewing Scottish mothers who had HIV. During the interview, Wilson’s (2007) participants were committed to establishing their identities as good mothers despite the threat that both the stigma of the disease and the potentially fatal nature of the disease presented to this identity construction. As the women had mothering identities that pre-existed their illness, Wilson (2007) deemed the emphasis on motherhood in their accounts was a form of biographical reinforcement.

Bury’s (1982) biological disruption focused on chronic illness. However, illness can be disruptive and have long-term consequences even if it is of relatively short duration. How disruptive illness is perceived to be depends upon several factors; one of these is the woman’s stage of life at the time of illness (Fisher & O'Connor 2012; Grinyer 2007; Wilson 2007). For example, women who are gravely ill immediately following
childbirth may recover in a relatively short period of time. However, if their ability to
bond with their newborn child or establish breastfeeding was impaired during this time,
the ramifications for their identities as ‘good’ mothers could be long term (Elmir et al.
2012). Others have also noted that an illness does not have to be chronic to be
disruptive and a threat to personal identity (Hubbard, Kidd & Kearney 2010). I
therefore distinguish disrupted mothering from Bury’s (1982) biographical disruption in
that disrupted mothering focuses purely upon the maternal. By focusing upon the
disruption to mothering rather than biography generally, a greater understanding of the
effect illness has upon a woman’s capacity and experience of mothering will be
revealed.

Derivation of Disruption
Disrupted mothering has been previously defined in the literature as “a woman
perceiving that her maternal life has become disordered” (Vallido et al. 2010, p. 1435).
Disruption as a concept is increasingly being utilised in empirical research. Letteney
(2010) referred to disrupted parenting in her study that investigated how HIV impacted
upon women’s care giving capacity. However, the study examined deficits and the
focus was on disrupted parenting causing maladjustment in children. Similarly, Grant et
al. (2011) referred to disrupted parenting in their study of mothers with substance abuse
issues. Although they did not define disruption, in their study disruption referred to
periods of not having custody of their children. However, disruption to mothering can
take many forms and does not necessarily mean physical separation.

Drawing upon studies of the experience of infertility, stroke, mid-life disruption,
chronic illness and late-life transitions, Becker (1997, p. 7) conceived “disruption as a
part of the human condition.” Studying disruption from an anthropological perspective,
Becker (1997) maintained that in Western cultures, there is an innate assumption that our lives will progress upon a predictable path. Disruption is therefore viewed as chaotic as it makes it difficult to fulfil cultural ideals and ideologies (Becker 1997). Furthermore, Becker (1997) recognised that the inability to fulfil these ideals threatens a person’s ability to see themselves as a moral being.

Illness can be perceived as more disruptive for women who have children than for those who do not. Bell and Ristovski-Slijepcevic (2011, p. 634) found that Canadian women who attended a support group for metastatic cancer engaged in a “hierarchy of suffering” where women with dependent children were deemed to suffer the most, regardless of the type of cancer, metastases, disability or amount of pain. Childless women in the group or those who had adult children responded emotionally to the women who were going to die and leave their young still dependent children motherless.

Women experiencing greater empathy for ill mothers with young children was confirmed in Murphy et al.’s (2011) study of women with HIV. Participants whose children had grown before they became symptomatic valued the timing of the disease that had spared their children’s childhood. One woman commented, “If somebody is as ill as I am today and have little ones, I feel really bad for them because you can’t do anything. You are that zapped ...It takes a lot of energy to raise kids” (Murphy, Roberts & Herbeck 2011, p. 366).

Lack of energy, fatigue, feeling unwell or sedation from medications can severely impact women’s capacity to care for their children. Thomas and Kalucy (2003) investigated the way that mental illness and the medications used to treat it could negatively affect people’s motivation to actively care for and be involved with their
children. Although Thomas and Kalucy (2003) discussed ‘parenting’, twenty-eight of the thirty-five participants were mothers and only one quote from a father was included in the article. So although their focus was not mothering specifically, their study has still been included in this review. Many of the women in that study discussed difficulties resuming parenting after hospitalisation as they moved from an environment that demanded very little of them (hospital) into one that required a lot of organising and planning (home). The researchers suggested that significant cognitive deficits persist for several weeks after discharge and that people required assessment and rehabilitation in order to adequately cope with parenting responsibilities. This study did not reveal how women felt about their inability to mother their children adequately. Furthermore, Thomas and Kalucy (2003) neglected to acknowledge the cultural expectations that mothers are predominantly responsible for childcare. Acknowledging this would have made apathy in parenting from a father a far less reportable outcome.

Illness may not always be perceived as disruptive if women are asymptomatic or tolerating treatments. Murphy et al. (2011) interviewed women who were HIV positive about their ability to care for their children. These researchers concluded that disruption was dependent upon how well the mothers felt. Forty percent of their participants did not feel that they had missed activities with their children due to their illness as they were asymptomatic. However, women who experienced symptoms from the illness or antiretroviral medications detailed numerous losses in relation to maternal life. They reported illness causing them to miss out on school events and extracurricular activities, leisure trips and holidays. Regret was expressed over being too tired or sick to cook and clean or even just play with children. Intimacy was affected with some women reporting they were anxious about hugging or kissing their children as they were
frightened about transmitting the virus. Mental health issues stemming from the illness were also debilitating.

Hospitalisation is frequently reported as disruptive to mothering (Fisher & O'Connor 2012; Montgomery et al. 2006; Savvidou et al. 2003). However, it is mostly presented as an incidental finding and not named as a disruptive event explicitly. Being confined to a hospital bed leaves women with time to reflect upon their children, miss them and be concerned that the care they are receiving is not the same as the mothers provide (Fisher & O'Connor 2012). Even being visited by their children in hospital can be emotionally fraught for women. In Öhlén and Holm’s (2006) study of Swedish women who had breast cancer, one woman recalled her children visiting as desolating. Seeing the children in the hospital environment made her confront the tenuous nature of her existence and how her illness represented a threat to their future happiness. “I couldn’t breathe when I saw the children come in. When the children came into the sickroom” (Öhlén & Holm 2006, p. 26).

For women with mental illness, hospitalisation can threaten their ability to retain custody of their children (Montgomery et al. 2006; Savvidou et al. 2003). Six of twenty women participating in a study of mothers hospitalised for severe mental illness had no contact with their children at all (Savvidou et al. 2003). Despite this, the researchers described all of their participants reporting strong bonds with their children.

Having to travel to seek treatment can be a significant source of disruption. While investigating the needs of cancer patients that lived in rural and remote areas of Queensland, Clavarino et al. (2002) noted that some women required daily radiation treatment for a period of four weeks or more for breast cancer. One woman reported relocating her entire family into the city for her eight months of treatment. Another
stayed in the city with her partner leaving her two children aged 16 and 17 years at home alone. Women with no support had very limited options, having to either organise support from acquaintances or take children with them for treatment. Having no support also often equated with limited financial resources. In order to take her children with her for treatment, one participant in the study by Clavarino et al. (2002) sought funds from the Cancer Foundation.

Fatigue and the side effects of treatment can seriously impair a woman’s ability to care for her children. Participants in Savvidou et al.’s (2003) study stated that the sedating side effects of anti-psychotic medications could make it difficult to function. The medication caused difficulties with concentration, and lowered energy (Savvidou et al. 2003). Similarly, Poole et al. (2012) found that having the energy to listen and talk to children was among the more difficult aspects of mothering reported by women who had lupus erythematosus. For women who had undergone a hysterectomy following a post partum haemorrhage, fatigue impacted dramatically upon the women’s ability to care for their newborn children (Elmir et al. 2012).

The ultimate disruption to mothering is impending maternal death. Mothers aged 31 to 42 who had been diagnosed with breast cancer spoke of the fear of dying and leaving their children motherless being partially mitigated by planning for the event (Fisher & O’Connor 2012). One participant spoke of having a large life insurance policy that would enable her husband to spend quality time caring for their children in the event of her death and this was a source of comfort for her. However, often women cannot imagine their children’s lives without them and do not believe anybody else is able to care for their children with the love and devotion of a mother (Nelms 2005).
Women with terminal illnesses often consider their own impending deaths more in terms of loss for their children rather than for themselves. Yet the notion of children coping well after maternal death can be both a desire and a fear for dying women (Bell & Ristovski-Slijepcevic 2011). Women expressed fears that their children would suffer and grieve for them. Although the women did not wish their children to experience this sorrow, they also did not like to think that as mothers they might not be essential and would not be missed (Bell & Ristovski-Slijepcevic 2011).

‘Good’ Mothers Keep Mothering

Mothers are generally portrayed as an unassailable source of strength, nurture and permanency. The struggle to continue to mother despite serious illness can be related to the cultural belief that biological mothers are the most appropriate people to raise and care for children (Bell & Ristovski-Slijepcevic 2011; Blachman 2006). Cultural expectations of mothers to be self-sacrificing in order to be ‘good’ mothers are fairly inflexible. Research has shown that family members often assume women will continue to function in the role of mother at pre-morbid standards despite serious illness (Bell & Ristovski-Slijepcevic 2011; Hackl et al. 1997; Kayser & Sormanti 2002; Wilson 2007; Öhlén & Holm 2006). Women in Öhlén and Holm’s (2006) study revealed that during sick leave from work they were still expected to care for their homes and families. Despite being excused from work, exhausted and ill, the women expressed guilt if they could not continue to care for their children to the standards they had before becoming ill. Van Mens-Verhulst et al. (2004, p. 79) wrote: “Mothering is special in that it requires women to be either ‘on the job’ or available 24 hours a day. Moreover, a mother cannot stay off the ‘job’ for a long time for any reason.” Their study of mothers with asthma reported that mothers attended outdoor hockey matches or allowed their children to have pets despite knowing that these activities would aggravate the
symptoms of their illness. Participants in van Mens-Verhulst et al.’s (2004) study also recounted overdoing activities with their children on days when they were well, to compensate their children for times that they were not.

Before they become ill, women have often already imbibed the cultural expectations of motherhood. In Kralik’s (2002) investigation of women living with chronic illness women sought to minimise the disruption to others’ lives by attempting to maintain their pre-morbid levels of employment and housework. According to Kralik (2002), the women were aware that culturally they were expected to place other people’s needs before their own, and that they would be undervalued if they failed to conform to these cultural expectations. In order to fulfil the mothering role, some women recalled “powering through” despite debilitating symptoms and fatigue (Murphy, Roberts & Herbeck 2011, p. 368).

When attempting to fulfil the mothering role, women sometimes make choices that are detrimental to their health (Murphy, Roberts & Herbeck 2011). Motherhood trumped patienthood in a study of people who had multiple chronic illnesses (Townsend, Wyke & Hunt 2006). Participants discussed undertaking activities with their children that were difficult and damaging to their wellbeing in order to retain their sense of themselves as mothers. “The illness comes secondary to your family... and it always will” (Townsend, Wyke & Hunt 2006, p. 191).

The struggle to continue in the mothering role while ill is often described as balancing (Adams et al. 2011; Billhult & Segesten 2003). Women are reported to attempt to balance the symptoms of their illness with continuing to care for their children (Adams et al. 2011; Billhult & Segesten 2003). By carrying on as normal women seek to limit disruption to their children’s lives (Billhult & Segesten 2003). Finances are another area
of balancing, with women attempting to continue in paid employment during treatment in order to meet their family’s financial needs (Adams et al. 2011). Balance is also sought between keeping children informed regarding their mother’s illness and avoiding scaring them with information (Billhult & Segesten 2003).

Balancing can be difficult when mothers have a mental illness. Often the professional discourses reject women with severe mental illness as legitimate mothers, yet maintaining the identity of mother is very important to ill women (Montgomery et al. 2006). For women with a mental illness, motherhood provides an opportunity to assume an identity other than that of a patient. Motherhood represents a socially ‘normal’ role and is attributed with motivating women to continue to seek treatment in order to be well for their children (Montgomery et al. 2006; Rutherford & Keeley 2009). In their study of mothers with severe mental illness, Montgomery et al. (2006) discussed women masking their illness in order to portray themselves as competent mothers to others. Frightened that their children could be taken from them, participants reported continuing to care for their children despite debilitating fatigue and illness. The women discussed the difficulty of continuing to mother saying that they cared for their children like zombies, not expending any energy beyond completing the tasks that were necessary. However, as their symptoms worsened it was difficult to maintain even this facade.

*Mothering as Motivation*

Although the previous section described the difficulties associated with mothering during illness, there are also rewards for women. Children were described as a “metaphor for hope” in a study of women prenatally diagnosed with HIV (Kelly et al. 2012, p. 1559). Although they still worried for the health of their unborn children, after
being told the babies had an excellent chance of being born HIV negative, the young women in this study had something to live for. Similarly, in a study of women with breast cancer, women with children were more optimistic about their chances of survival than women without, as they could not countenance the idea of their children being left motherless (Boehmke & Dickerson 2006). This implies that motherhood itself can be a serious motivator to seek treatment and regain health.

Women will often strive to stay alive, or well enough to care for their children, until they perceive that their children are independent enough to cope alone (Elmberger et al. 2008; Wilson 2007). American women who had survived longer than 10 years with HIV attributed their longevity to their desire to continue caring for their children (Barnes & Kronenfeld 2008). Women report wanting to stay alive long enough to witness milestone events in their children’s lives such as marriage and graduation (Nelms 2005).

Although women attribute their children to giving them the will to live, their struggle can become moot if they perceive they are no longer needed by them. Women in Wilson’s (2007) study of women with HIV were determined to see their children reach independence. However, if they had achieved the time goal they had set for themselves, some women expressed a sense of uncertainty about their continued existence (Wilson 2007). This suggests that women’s personal identities are sometimes so entrenched in the mothering role that they can lose their motivation to live if they feel unnecessary to their children.

Mothering also assists women to cope with day-to-day living despite life-threatening or terminal diagnoses. Although maintaining normality for children is articulated as the reason women continue to try and carry on as normal, it has the dual outcome of
keeping women engaged with life despite illness (Bell & Ristovski-Slijepcevic 2011; Fisher & O'Connor 2012). Bell and Ristovski-Slijepcevic (2011) reported mothers with metastatic cancer saying that mothering distracted them from dwelling upon their illness and motivated them to keep seeking treatment and engage in everyday activities. This was in sharp contrast to young women in the study who did not have children, who discussed withdrawing from the world.

For women with severe mental illness, being a mother can be their primary motivation for seeking treatment (Montgomery et al. 2006). However, treatment can also expose the degree of illness they are experiencing and increase the chance of them losing their children. Montgomery et al. (2006) found that some Canadian mothers who were inpatients in a mental health facility had attempted to conceal symptoms of illness to continue mothering their children. Medications would help but not always.

_Disrupted and Dishonoured_

One thing that mothering and illness have in common is that they are both moralised conditions. Illness is increasingly being attributed to inappropriate lifestyle choices thus positioning good health as a virtue (Bury 2001; Ogle, Tyner & Schofield-Tomschin 2011). Therefore, being a mother with a stigmatised illness can be a significant source of guilt and shame. One mother in Wilson’s (2007) study reported feeling guilty for several reasons. Having contracted HIV from drug use she felt guilty that through her own “stupidity” her children would be motherless and would have to become independent at an earlier age (Wilson 2007, p. 621).

Guilt and grief can arise if a woman perceives she is not functioning as a ‘good’ mother should (Elmir et al. 2012). Women can be reluctant to express feelings of discontent regarding mothering in case it threatens their view of themselves as good mothers.
However, the reality of mothering while ill may severely test a woman’s patience with her children. One participant in a study of mothers who had asthma remarked “when you’re not feeling good and the asthma’s there, you need – it’s like you get very crabby and like, ‘Get away from me’, ‘I’m sick of you’. It’s like I just want some space, and so that’s like a rejection to them [the children] and it comes back as guilt to me” (van Mens-Verhulst, Radtke & Spence 2004, p. 81).

Guilt can be especially poignant if a mother considers herself a physical threat to her child. Ugarizza (2002) interviewed women who had experienced postpartum depression to find that eight of the thirty participants suffered profound shame and guilt recalling the urge to harm their babies. One woman stated, “I tried to avoid opening the kitchen drawer. Seeing the knife there made me scared even though I knew I wouldn’t use it.... I was so ashamed.... What kind of a mother was I?” (Ugarriza 2002, p. 231).

Women can hold themselves accountable for any hardships their children might face as a consequence of maternal illness even if such consequences are beyond their control. One young woman, in a study of women who had experienced gestational breast cancer, reported feeling a great deal of emotional distress that her son had been delivered pre-term so that her oncology treatment could begin. This distress was compounded by the infant needing to be placed in the neonatal unit (Ives, Musiello & Saunders 2011).

Being unable to do things for their children due to illness can be an intense source of grief and guilt for women. Feeling bad and feeling guilty can contribute to the women experiencing the symptoms of illness more keenly (van Mens-Verhulst, Radtke & Spence 2004). Guilt can be especially burdensome if the woman perceives that her illness is not taken seriously. One woman who had frequent asthma attacks reported her
son saying “It’s all in your head, Mom” (van Mens-Verhulst, Radtke & Spence 2004, p. 82).

**Invisible or Inappropriate Support**

Support for mothering in illness is intrinsic to women being able to continue to mother, yet although emotional or practical support is often raised in studies it is not elaborated upon. In their study of mothers with non-recurrent breast cancer, Billhult and Segesten (2003) stated their participants felt fully supported by partners, their children, friends, colleagues, health professionals and other patients. This was in contrast to participants in Fisher and O’Connor’s (2012) study of young mothers with breast cancer. These researchers reported that the young women consciously withdrew from their social circles and peers, perceiving themselves as ‘other’, isolated and different. Although the women desired support from other parents, they could sense that the visible signs of their illness such as hair loss and appearing unwell made others fearful of saying the wrong thing.

When considering whether or not to accept support, reciprocity can be an issue. Being unable to reciprocate is another barrier women face when trying to maintain friendships when they are ill. Grant (2001) reported mothers who had arthritis being wary of accepting invitations for play dates as they had difficulties transporting their children. Between not feeling able to accept invitations and not inviting others to their home, they found that the invitations ceased. However, very close friends were cited as a good source of support as accepting help from them did not leave the women feeling beholden.

Women’s partners are frequently cited as being a significant source of support yet the contributions that partners actually make are often not explored in studies of ill women.
In Murphy et al.’s (2011) study, women who were partnered were less likely to report missing out on their children’s activities, yet the support that they received was unexplored. Similarly, in a survey of mothers living with systematic lupus erythematosus, mothers with younger children reported less difficulty with mothering (Poole et al. 2012). This was contrary to what the researchers had hypothesised and they attributed it to the women being younger, better educated and more likely to be partnered compared to other participants. Yet again there was no indication of how the partners helped. This is significant as recommendations from these researchers include eliciting support with cooking, and playing with children outdoors. Support for their children was especially valued in Fisher and O’Connor’s (2012) study of young mothers with breast cancer. Women in this study discussed arranging for others to take their children on outings and make up for any shortcomings in the love, attention and new experiences their mothers could provide. Who these other people were was not revealed.

The activities of support people were well described in a study of new mothers who had experienced a postpartum haemorrhage requiring a hysterectomy (Elmir et al. 2012). In this study, husbands were described as either stiflingly supportive or unsupportive. Physically incapacitated following the birth and surgery, women had to relinquish the majority of the care of their newborn babies to others. Partners and female relatives stepped in to help; however, their support was sometimes detrimental to the women becoming comfortable in the mothering role. Some of the babies formed strong bonds with support people which caused the women to question their validity as mothers. Impaired bonds with babies sometimes became a source of friction between the women and their support people.
Elmir et al. (2012) and Grant (2001) both found that women could be reluctant to seek support fearing that it would cause them to feel inferior in the mothering role. One participant in Elmir et al.’s (2012) study was especially anxious about allowing her own mother to care for her children for this reason. Women were also frightened that alternative caregivers would replace them in the mothering role in Montgomery et al.’s (2006) study of mothers hospitalised for severe mental illness.

**Women Privilege and Doctors Discount Motherhood**

Treatment decisions in illness can be heavily influenced by motherhood and impending motherhood. Women who were diagnosed with gestational breast cancer were torn between a desire to protect their unborn baby and commencing treatment that would maximise their chances of a positive outcome (Ives, Musiello & Saunders 2011). For women who already had children, the priority was to survive to see these children grown although there was conflict regarding the child they were carrying. Women experiencing their first pregnancy were often prepared to delay or forego optimum treatment in order to protect the unborn child (Ives, Musiello & Saunders 2011). This willingness to privilege mothering over health is evident in later motherhood as well. Mothers with HIV reported ceasing or skipping medications that had unpleasant side effects if they had an important event to attend for their child (Murphy, Roberts & Herbeck 2011).

Breastfeeding can be another reason to forego treatment. Women in a study of mothers who had experienced postpartum depression were reluctant to take antidepressant medication, fearful it would be transmitted through breast milk, or that it would disrupt their milk supply (Ugarriza 2002). Already feeling that they were not ‘good’ mothers
due to their depression, the women did not want to feel that they had also ‘failed’ at breastfeeding.

Women can be very invested in their identities as mothers, which makes it important for health care professionals to acknowledge that a patient is also a mother (Davies & Allen 2007; Fisher & O’Connor 2012). Yet often when women are interviewed about their experiences of mothering while ill, health professionals are portrayed as unhelpful in facilitating mothering (Backman et al. 2007b; Elmberger, Bolund & Lützén 2005; Wilson 2007). Mothering is often invisible in health care (Kralik 2002). According to Kralik (2002, p. 147), there “is little acknowledgement of the social and family context in which women live with illness” which results “in women feeling overwhelmed, alienated and without voice within the delivery of health care”. Overwhelmingly, when health care professionals were discussed in the studies reviewed, they were portrayed as uninterested in the maternal concerns of their patients. Health professionals often focused upon the disease and its treatment and could be insensitive to the needs of women outside their roles as patients. Fisher and O’Connor’s (2012) participants described feeling objectified as cancer patients by health professionals. They found it difficult when they were given inflexible appointment times that did not take into account any obligations they may have had besides being a compliant patient. Mothers in this study perceived that health professionals assumed they would prioritise treatment over anything else in their lives. Similarly, mothers who had cancer in Elmberger et al.’s (2005) study stated that health care professionals neglected to ask how women were managing their mothering roles, resulting in the mothers feeling unable to broach the subject. In Ciambrone’s (2001) study of women with HIV, one participant discussed how she was defined by her illness by health professionals. When attempting to gain
support for her mood and her mothering, she was automatically referred to a HIV specialist.

I don’t want to be labelled, please. There’s other things, I worry about being a good mother, I worried about a lot of things! Geez, I’m normal, I have to do things! Shit! Because I don’t want to put that in every part of my life, no! (Ciambrone 2001, p. 526).

Likewise, women with serious mental illness reported health professionals showing a preoccupation with symptom management and little understanding of their experiences and needs as mothers (Montgomery et al. 2006).

Health professionals can also be guilty of drawing upon the social construction of the ‘good’ mother in their dealings with women (Breheiny & Stephens 2007). Women can be disempowered by professional discourses that deny their ability to be mothers (Montgomery et al. 2006). In Montgomery et al.’s (2006) study of mothers with severe mental illness, health professionals were reported to placate women or disregard their maternal desires. One participant recalled being told “your kids will grow up fine without you” (Montgomery et al. 2006, p. 25).

Discounting a woman’s maternal desires appears to be quite common in stigmatised illnesses such as HIV and mental illness. The women with HIV in Wilson’s (2007) study reported being subjected to punitive and insensitive treatment by medical and nursing staff. They described the unnecessary use of gloves, and open disapproval from nursing staff when they were giving birth to their children. One expressed sorrow that she had been denied any feelings of joy over the birth of her child (Wilson 2007). Women with arthritis in a study by Backman et al. (2007b) also reported being
discouraged by their doctors from considering motherhood. Some perceived a lack of understanding from health care professionals about the desire to become a mother, and difficulties in mothering when physically disabled (Backman et al. 2007b).

From this review, it is obvious that women tend to privilege their children’s needs over their own and seek to mitigate the effects that maternal illness has upon them. Yet from the literature it appears that mothers can have trouble eliciting professional help. Women often report being unable to raise issues regarding their children with health professionals (Öhlén & Holm 2006) or obtain assistance for their children who may be finding it difficult to cope with their mother’s illness (Elmberger, Bolund & Lützén 2005).

The importance of mothering to women and the impact that illness has upon their ability to mother needs to be acknowledged by health professionals. “The task for health professionals is to put aside elitist attitudes and their displays of power, abandon preconceived hierarchies of the importance of diseases, and take seriously women who seek assistance with illness” (Kralik 2002, p. 153). Nurses are well placed to provide support for families in crisis, given that they are the largest group of health providers, relatively cost efficient and have a presence in women's lives as mothers beginning prenatally with antenatal clinics (Jackson et al. 2004/5). Addressing issues related to patient’s mothering should be an integral part of assessment and nursing care, beginning with an inquiry regarding maternal status, validating the importance of maternal responsibility, and identifying referral pathways (Fisher & O'Connor 2012).

**CONCLUSION**

This review investigated literature that included reference to disruption in studies of maternal illness. Apart from studies that drew upon Bury’s (1982) theory of
biographical disruption (e.g. Wilson 2007), disruption was an incidental concept mentioned in the title or body of the articles. Even though it is not framed as a distinct concept in the literature, the thin thread of disrupted mothering extracted for this review highlighted several issues for mothers.

Disruption from illness was considered more significant for women with children than for those without. Mothering in illness could be difficult due to the debilitating effects of the symptoms of the illness, fatigue and side effects of the treatments. However, mothering was also credited with providing women with the motivation to live, to seek treatment and continue to be engaged in everyday life.

It was well recognised by researchers that illness resulted in conflict for women when they could not live up to the cultural expectations of mothering. Women were reported to attempt to ignore the symptoms of their illness and to try to continue to perform housework and childcare to their pre-morbid standards. If they were struggling to accomplish this, or felt that their children were in any way negatively affected, the women suffered feelings of guilt and shame.

Although many researchers have investigated mothering in the context of specific diseases, few have approached mothering in illness from a mothering, as opposed to a disease, perspective. Although this focus upon mothering in the context of specific diseases is valuable, it is less helpful when trying to discern the overall effect of illness on mothering. It would be therefore valuable to examine the disruptive nature of illness in the context of mothering generally.

The search strategy located many papers that were within the scholarship on HIV and breast cancer. The potential of these diseases to cause premature death is presumably
why researchers associated them with disruption. However, disruption was found to be more associated with symptoms from illness and treatment, so some women did not experience illness as disruptive if they were asymptomatic. Disruption was also found to be contextual, with women who had a history of disruptive life events being less perturbed by an illness diagnosis. This finding highlights that the concept of disruption in many of these studies has been teased out by researchers, rather than being raised by the participants explicitly. There is therefore a need for a study that reveals the experiences of women who specifically identify as having their mothering disrupted by illness to determine how women themselves conceive and experience disruption. The current study intends to fill that gap.

Furthermore, as the majority of literature regarding mothering disrupted by illness involved interviewing women in the acute phases of illness or early recovery, little is known about the long-term effects disruption may have on the maternal-child relationship. As women define health and wellbeing largely in terms of their relationships, it is important to ascertain what the consequences are for women disrupted in their mothering. Identifying common themes in women’s stories of disrupted mothering aims to allow insight into the emic perspective of women simultaneously coping with illness and motherhood. Further research into mothering disrupted by illness may also contribute to health providers considering a woman’s maternal status and responsibilities when providing health services, may highlight gaps in professional knowledge, and give direction to future research.

In order to build on the nursing scholarship regarding mothering and illness it is necessary to ask women about their experiences of mothering disrupted by illness. Further research in the area of disrupted mothering as a phenomenon would contribute
to developing strategies to support mothering in illness, regardless of the illness type. Also missing from the literature is how women think retrospectively about disruptions to mothering. Listening to the stories of women who have experienced disrupted mothering in the past would illuminate strategies they used to cope and highlight any far-reaching consequences.

AIMS OF THE THESIS

The broad objectives of this thesis were to explore the stories of women who identified that they had been disrupted (temporarily or completely) by illness in their experience of mothering a child to:

- develop insights into the phenomenon of disrupted mothering from women’s perspectives;
- discover the consequences disrupted mothering has for women’s self image and relationships;
- explore women’s experiences with health care providers to ascertain ways in which health care may be improved for women disrupted in their mothering;
- contribute to nursing’s body of knowledge about women’s health and provide directions for further research.
DIRECTION AND CUES

But in order to make you understand, to tell you my life, I must tell you a story

~ Virginia Woolfe

INTRODUCTION

It is evident from the preceding review that most women feel primarily responsible for their children, and experience guilt and shame when their ability to care for them is constrained by illness. The negative emotions women experience can be partially attributed to the oppressive ideologies of Western mothering, which position mothers within such cultures as the only suitable primary carers of dependent children. These ideologies are socially constructed and serve to legitimise existing social arrangements that often constrain and regulate the ways that women mother (Porter 2010).

Illness is also socially constructed. There are social and cultural assumptions regarding the way people are expected to behave and experience different diagnoses (Conrad & Barker 2010). Different diagnoses command different responses. For instance, sexually transmitted infections in women are often construed socially as ‘dirty’ and a result of immoral or promiscuous behaviour (East 2009). Human immunodeficiency virus and mental illness are similarly stigmatised in Western cultures. Yet the diseases themselves are embodied, it is the connotations attached to them by society regarding the character of the people who contract them that constitutes their meaning (Conrad & Barker 2010).

Given the oppressive nature apparent in the Western social constructions of motherhood and illness, this study was conducted within a framework formed by three intersecting theoretical positions: social constructionism, feminism and storytelling. Social constructionism and feminism both assert that motherhood and illness are historically,
culturally and socially constructed (Conrad & Barker 2010; Sardadvar 2010). Social constructionism and storytelling are equally concerned with the creation of meaning and reinterpretation (Crotty 2003; Frank 1995), with storytelling also revealing how personal experience is influenced by cultural values and ideologies (Daiute & Lightfoot 2004; Holloway & Freshwater 2007a; Smith & Sparkes 2008b). In addition, feminist and storytelling research are united in valuing participants and their lived experiences as legitimate and unique sources of contextual knowledge (East 2009; Peters, Jackson & Rudge 2008). The following discussion of social constructionism will be brief, but will serve to underscore the principle that meaning is made by storytellers; it is not pre-existing and waiting to be found by researchers (Crotty 2003). The feminist principles drawn upon in this study and the storytelling methodology will also be examined in more detail.

SOCIAL CONSTRUCTIONISM

The term social constructionism encompasses many different types of qualitative research and slightly differing beliefs about the nature of knowledge. Burr (2003, p. 2) captures this idea, describing social constructionists as having a ‘family resemblance’ to each other. Social constructionism is “concerned with explaining the influences upon and the processes by which people come to describe, explain and account for the world in which they live” (Holloway & Freshwater 2007a, p. 42). Thus research informed by a social constructionist understanding positions participants as meaning-makers (Shirani, Henwood & Coltart 2012).

Cultures contain pre-conceived assumptions (Schwandt 2000), and these assumptions form a framework for understanding the world (Berger & Luckman 1991). Whether or not they are aware of it, humans are influenced by those around them, their family,
friends, colleagues and other people with whom they interact (Holloway & Freshwater 2007a). This means that an individual’s definition of reality is characterised by the culture (and its history and language) within which it is situated (Berger & Luckman 1991; Davis & Gergen 1997; Gergen & Gergen 2004).

It is well documented in the literature that mothering is considered to be socially constructed (Porter 2010; Sardadvar 2010; Thorne 1990). Scholars have examined the social construction of mothering by analysing contemporary constructions and documenting the historical evolution of mothering practices over the years (Sardadvar 2010). It is the historically changing nature of mothering standards and practices that many scholars highlight when arguing that mothering is socially constructed (Arendell 2000; Hadd 1990; Hays 1996; Nakano Glen 1994). Furthermore, it is the social construction of mothering that defines it as a gendered role which culminates in a gendered division of labour (Guerrina 2001).

Challenging “taken-for-granted ways of understanding the world”, social constructionism calls researchers to regard all types of everyday phenomena with suspicion, and question existing perceptions of reality (Burr 2003, p. 2). Therefore, it is the perceived ordinariness of mothering that makes it an appropriate subject for a social constructionist critique. Social constructionist research into mothering rejects the notion that mothering is a biological imperative, but rather attempts to explain the ways that the dominant cultural ideals of mothering are created, maintained and moulded (Sardadvar 2010).

The notion that motherhood is not biologically prescribed is a belief shared by many feminists who seek to expose “the collusion between ideology and cultural practices” (Greene & Kahn 1991, p. 1). Feminist social constructionist research focuses upon
discourses perpetuated by socially dominant people and groups, viewing them as a source of oppression (Friedman 2006). Viewing oppression as a social construction is useful as it is then considered amenable to change (Friedman 2006).

**FEMINIST RESEARCH**

For the past three decades feminist theory has been well utilised in both nursing (Huntington 2002) and maternal research (O'Reilly & Bizzini 2009). Feminist theories represent ethically sound methods that are sensitive to issues of oppression, power differentials and socially constructed differences such as gender (Huntington 2002; Jackson 1997). These are important considerations in nursing research where the focus is often on the experiences of vulnerable and marginalised people.

Feminist theories are not homogenous and they incorporate differing perspectives and philosophies. Although in the past feminist scholarship has been dominated by North American women, there are increasing discourses from women of colour, women from developing countries and lesbian feminists (Sarkar 2004). However, diverse strands of feminism do intersect in several common tenets (Jackson, Clare & Mannix 2003). These tenets include an understanding that women are oppressed as a group, that their private lives are influenced by political forces, and being invested in consciousness-raising (Jackson, Clare & Mannix 2003). Feminist research recognises that women’s voices have been previously silenced in male-dominated research paradigms and seeks to reveal women’s ways of being in the world (Jackson 1997).

Although it is acknowledged that men have participated in feminist research (Jackson 1997; Peters 2006; Peters, Jackson & Rudge 2008), and undertaken it (Harding 2004), feminist research has traditionally focused on women (Glass 2000). One of the key principles of feminist research was that it was “research by, about, and for women”
(Gluck & Patai 1991, p. 2); that women’s personal experiences constitute their realities and, as such, are valid and worthy as legitimate sources of knowledge (Glass 2000; Jackson, Clare & Mannix 2003; James 1995; Stanley & Wise 1993). In particular, feminist research attempts to avoid positioning women as research objects (Landman 2006). Accordingly, Porter and Kelso (2008, p. xi) wrote “maternal scholarship must be grounded in maternal experiences, in the work and ideas of real mothers.”

After discussing feminism and mothering I will explore in more detail the particular tenets of feminism that guided the inquiry: ‘motherhood and oppression’, ‘the personal is the political’, and ‘consciousness raising’. However, before I proceed, it should be clear that I am not implying that all women are unaware of the political, cultural, social and economic influences on their lives and mothering. Mothering experiences are strongly influenced by social class, religion, ethnic background, and sexual orientation (Guerrina 2001; Sarkar 2004). Certainly many feminist scholars are mothers and conscious of the forces that impact upon mothering; yet unfortunately awareness of oppression does not negate it. Nor do I intend to imply that women are a homogeneous group. As Rhode (1992, p. 158) wrote: “There is no generic woman nor any monolithic woman’s point of view.” Instead I maintain that although women can, and often do, resist the political, cultural and economic influences that seek to shape their mothering, these forces nonetheless exist.

**FEMINISM AND MOTHERING**

In the past, motherhood has been a source of tension in feminist theory (Porter 2010). Radical feminists regarded motherhood as the root of women’s oppression and a fundamental cause of gender difference and inequality (Chodorow 1978; Holloway 2006). Motherhood was viewed as the means of keeping women socially and
economically subordinate to men, defined and confined by their reproductive capability (Porter 2010). This view of motherhood clashed with the perspectives of feminist mothers who accused early feminist theory of being anti-natalist (Porter 2010). The problem was formulating a political position that both valued women as mothers while still attempting to liberate them from patriarchal institutions (Everingham 1998). Adrienne Rich’s (1976) distinction between motherhood as a patriarchal oppressive institution and mothering as a source of empowerment and feminine power was fundamental in revolutionising the way feminists thought about mothering. Rich’s (1976) theorising in effect identified the institutions external to mothering as problematic, rather than mothering itself. Although the biologically-specific nature of birth means that women are required to continue to bear children, it is the heavily gendered nature of childrearing to which feminists object. Bearing children is not oppressive in itself, rather it is the societal values that have been attributed to motherhood that constitute oppression (Guerrina 2001).

Distinguishing between womanhood and motherhood and resisting the idea of motherhood as a biological imperative have been feminist priorities (Goodwin & Huppatz 2010b). The feminist movement has been instrumental in “making a wide variety of choices with respect to motherhood more available to and more socially acceptable for more women” (DiQuinzio 1999, p. vii). However, women are still subject to idealised notions of motherhood that pervade every facet of women’s lives (Goodwin & Huppatz 2010b). That these oppressive structures of mothering continue to exist, defies and challenges advances in women’s autonomy brought about by the feminist movement (Baraitser & Spigel 2009; Satz 2011).
Motherhood and Oppression

The central belief of feminism is that women are oppressed within patriarchal societies (Glass 2000; Stanley & Wise 1993). The women who participated in the current study responded to advertising that called for women who believed their mothering had been disrupted by illness. Identifying themselves in this way showed a common concern for the domestic matters of family life and how their location within this private sphere had been affected. Although the family could be considered a personal realm, feminists argue that it is in fact a social institution shaped by culture and society, within which women are constrained in their opportunities and choices (Satz 2011). As Birke (1986, p. 105) wrote, “a woman’s biology, and her experience of it, do not exist in a social and political vacuum, but in a society which is criss-crossed by social divisions of all kinds.”

Social life is largely governed by gender and in Western societies women are socialised to care for and feel responsible for others (Reger 2001). This means that regardless of their outside interests or obligations, women perform the majority of childcare and housework (Burnett et al. 2010; Milkie et al. 2002). Being primarily responsible for the domestic realm also has connotations for women’s opportunities to generate income, advance professionally for self-sufficiency in later life and the loss of leisure time (Meyers 2001). Feminist scholars believe that women have been disadvantaged by this inequitable share of domestic duties and childcare (Guerrina 2001; Stanley & Wise 1993; Stenhouse & Letherby 2011; Whelehan 1995). Thus, this disadvantage is both a source of oppression and a site of potential feminist activism (Reger 2001).

Some scholars believe that women can be largely unaware of the systems that serve to constrain them in the course of their everyday lives (Holloway & Freshwater 2007a;
James 1995; Kralik 2002), and “accept societal and familial gender inequities as both inevitable and natural” (O'Reilly 2010, p. 25). Yet some studies of women in Western cultures have indicated that women are aware of the oppressive nature of mothering, and the effects of caring on their health, although they may not frame it as such. Walters (1993), in a representative study of Canadian women, found that participants suffered stress, anxiety and depression as a consequence of caring for others. The demands to be self-sacrificing and continually put other people’s needs first were illustrative of the pressure to conform to gendered caring roles (Walters 1993). Although the participants recognised the detrimental effects caring had upon their health, they normalised mental health issues such as stress and anxiety. Health problems for women as a consequence of gendered caring continue to be apparent yet there is still little evidence that this is adequately addressed in public policy.

**The Personal is Political**

Informing this study is the feminist tenet ‘the personal is the political’. Coined by the feminist activist Carol Hanisch in 1969, the word *political* originally referred to power relationships generally, and implied that the majority of women’s problems and difficulties were caused by gendered oppression (Hanisch 2006; Stanley & Wise 1993). Feminists in the early 1970s encouraged women to reveal personal problems to other women as this was considered a political act that exposed the oppressive and constrained nature of women’s lives (Hanisch 2006). Feminists theorised that if problems and difficulties were a result of structural and social forces (the patriarchal system), exposing the effects was the basis of effecting change (Stanley & Wise 1993). The slogan has evolved to become one of the fundamental themes of feminism, acknowledging the way that systems and social structures impact directly upon private lives (Jackson, Clare & Mannix 2003; Peters 2006; Stanley & Wise 1993).
Women are less able to separate their public and personal lives than men due to their continued association with the tasks of childbearing and childrearing (Jackson, Clare & Mannix 2003). While it might be assumed that mothering would constitute mostly private experiences, women are in fact subject to scrutiny of their mothering from conception to throughout the life of the child (Goodwin & Huppatz 2010b; Jackson & Mannix 2004). The continuing regulation of mothering is a consistent finding in recent Australian research. For example, Cutcher and Milroy (2010) found young mothers were regulated financially through government policies of welfare and maternity payments; Peters (2006) discussed the regulation of reproductive rights in the context of access to assisted reproductive technology; and Blaxland (2010) revealed the way government policy aligned ‘good’ mothering with entering the workforce for mothers who were recipients of welfare under the Work for the Dole scheme.

Regulation of mothering represents the incursion of the political into the personal realm (Satz 2011), and is especially apparent in the lives of women who mother while ill. For instance, illness may change contraceptive and conception decisions for women. What is normally a private and personal decision between a woman and her partner about becoming pregnant is turned into a more public experience as health professionals may need to be consulted (Payne & McPherson 2010). Women with a mental illness may be vulnerable to other people making reproductive decisions for them including being coerced into terminating a pregnancy or surrendering the infant (Coverdale, McCullough & Chervenak 2010). Having a mental illness also increases the risk of surveillance and custodial interference from authorities (Frieder 2010). Women with physical disabilities or chronic illness can face opposition to becoming mothers, be judged as inadequate and incapable, and have difficulties accessing services (Backman et al. 2007a; Blackford, Richardson & Grieve 2000; Prilleltensky 2003; Thorne 1990).
The opposition women with illness face as mothers stems from the ideologies and cultural narratives of mothering, and the idea that women with illness cannot satisfy the tenets of the ‘good’ mother. As social forces, these ideals constitute elements of the ‘system’ that serve to constrain the personal lives of women (Baraitser & Spigel 2009).

**Consciousness Raising**

In order to effect change and continue to challenge the dominant and oppressive ideologies of motherhood, there must be awareness of the ‘systems’ that influence and shape women’s lives. A fundamental task of politicising the personal for feminists is consciousness raising. Consciousness raising began in the 1960s, when a group of radical feminists alleged that topics deemed by others as petty or not political, such as housework and mothering, were actually sources of oppression (Sarachild 1978). Consciousness raising involves encouraging women to recognise injustices in their social positioning and reassess their personal lives (Whelehan 1995). Through recognising and exploring the way that their lives are constrained, women can gain insight and a new perspective on their lives (Sarachild 1978; Stanley & Wise 1993). It is thought that this kind of evaluation leads to the development of more autonomous identities (Whelehan 1995). Consciousness raising is not a singular event, but rather an ongoing lifelong process (Sarachild 1978; Stanley & Wise 1993). Furthermore, by developing awareness of the issues that concern women, aspects of gendered oppression can be examined and challenged (Jackson, Clare & Mannix 2003).

According to Cook and Fonow (1986, p. 8), “only when there is a rupture in the ‘normal’ life of a woman ... is there a chance for her to become conscious of her condition.” Much as storytelling is an opportunity to reflect and come to find meaning in experience (Frank 1995; Williams 2009), the consciousness raising potential of
feminist research exists when women who participate have an opportunity to reflect upon their experiences and make connections between their lives and the systems that influence them (Brayton 1997). It was anticipated this study could contribute to consciousness raising in the women who participated, and the women who read literature arising from the study. This thesis also represents reflection upon the nature of my own situation and identification of oppressive elements in my personal and professional life. According to Stanley and Wise (1993), having your own consciousness raised is an inevitable consequence of undertaking feminist research.

STORIES

*What are Stories?*

To be human is to tell stories; it is in our nature to do so (Holloway & Freshwater 2007a). Every day people share and listen to stories. What constitutes a story has been the subject of much debate amongst narrative researchers who have proposed various criteria encompassing structure, content, plot, progression and sequences of events. However, for the purpose of this thesis a story has been simply defined as “an account of happenings” (Carter 2009, p. 477). While this definition might be considered less prescriptive than some of the more structured definitions offered in the literature, it captures the idea that stories are simply told by people. As such, stories may be fragmented, contextual, and confused (Carter 2009; Frank 2002). Storytellers are selective in which aspects of the experience they emphasise or suppress, combine or add (Carter 2008). Stories are an interpretive, subjective, selective depiction of human experience (Nelson 2001), and therefore should be respected and not unnecessarily subject to academic criteria (Carter 2009). Within this thesis a story is constituted through the woman’s account regardless of its structure, continuity of plot or
progression. These stories have been collected in order to discover knowledge that was held by the storytellers, thus each woman’s account represents a gift, the voluntary sharing of something personal and precious.

**Story and Narrative**

Scholars have debated at length the distinction between story and narrative. However, people do not tell each other narratives, they tell each other stories (Frank 2000). Wiltshire (1995) points to the structured reflection, sophistication and formality of narratives when distinguishing them from stories. He further states that nursing narratives should be “not merely anecdotal, casual accounts, but involve a blending of theoretical with empirical or experiential materials” (Wiltshire 1995, p. 81). Thus this thesis is conceived as a narrative of mothering disrupted by illness, as it blends the stories told by participants with empirical literature, and epistemological and methodological theories, within a structured and formal academic text.

**Stories have Functions**

Stories have functions; they are the building blocks of society and culture. It is through stories that experiences, thoughts, and feelings are shared, validating and affirming personal experiences, exposing differences and similarities, and allowing bonds to form between people (Atkinson 2001; Carter 2009; Holloway & Freshwater 2007a; Lekoko 2007; McAdams 1993). Through everyday stories people come to know themselves and impose order upon their experiences (Atkinson 2001; Miller 2005; Smith & Sparkes 2008b). They assist people to interpret, find meaning and sense in experiences; express, enhance or confirm identity; establish the teller as a moral being; and confirm group consciousness through shared cultural narratives (Holloway & Freshwater 2007a).
Through Stories Meaning is Made

Stories are often told and retold as the storyteller attempts to find something of worth in their experience (Holloway & Freshwater, 2007a). To create understanding from experience, experiential information about what has occurred needs to be organised and linked, and interpreted into what has been termed a pre-narrative (Labov 2006; Williams 2009). Once constructed into narrative form the experience can be reflected upon, and further developed for cohesion. Reflecting upon the event assists to situate the experience within the larger life story; links it to previous experiences; contributes to understanding why and how it occurred; and reconciles the experience with the emotions it evoked (Williams 2009). Although this is a largely unconscious process, people will retrospectively make inferences and embrace or reject details in an effort to achieve coherence (Baumeister & Newman 1994). Turning an experience into a story is the first step in making sense of it and is necessary in order to be able to integrate events into the sense of self (Baumeister & Newman 1994).

Finding meaning is a significant issue for people confronted by serious illness. Illness can cause a person’s personal story to suffer from incoherence, and the construction of a new story that allows disjointed thoughts and feelings to be integrated into the life narrative can contribute to healing (McAdams 1993; Williams 2009). Sharing stories of illness can also reduce feelings of isolation and fear (Miczo 2003; Williams 2009). Frank (1995, p. 53), citing Judith Zaruchs, wrote, “stories have to repair the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going.”

It should be noted, however, that it is not always possible for people to reconcile experience and find meaning, and if meaning cannot be made, distress and frustration
can occur (Baumeister & Newman 1994; Williams 2009). Although some professionals recommend helping people to construct stories to assist them to come to terms with their experiences of illness (Williams 2009), Frank (1995) suggests unresolved stories (which he calls chaos narratives) should be honoured. Researchers need to develop an enhanced tolerance for chaos, incoherent or non-chronological stories in order to respect participants’ right to tell their stories their own ways (Frank 1995; Smith & Sparkes 2008b).

*Identity is Created Through Story*

Identity is defined as “a complicated interaction between one’s own sense of self and others understanding of who one is” (Nelson 2001, p. xi). Stories are one way that identity is expressed, claimed and constituted (Atkinson 2001; Kreisworth 2000; Nelson 2001). In each story told of the self, new layers of identity are added and the teller’s identity is created anew (Daiute & Lightfoot 2004; Freeman 1999; Frid, Öhlén & Bergbom 2000; Holloway & Freshwater 2007a). Retrospective stories of experiences or actions guide future actions and the construction of new stories in the future (Nelson 2001).

To claim a certain identity, people tell stories about themselves to positively influence the way that they are perceived. According to Frank (2010), storytellers engage in interpretation, gauging reaction and shaping their story in order to appeal to the listener to view them as a worthy person. This can be attributed to people needing social recognition and validation from others to claim a particular identity (Baumeister & Newman 1994; Nelson 2001). Much of the recent scholarship on mothering involves studying how women claim the identity of a good mother (Collett 2005; Hadd 1990; Johnston & Swanson 2006). Nelson (2001) attributes the preoccupation with identities
related to personal relationships being more central to our narrative self-conception than other roles.

As well as seeking to establish a particular identity, people can have unwanted identities conferred upon them. A diagnosis of serious illness calls upon a person to assume the identity of a patient (Frank 1997a, 2010). The majority of people assume the patient identity due to the need for treatment. However, the patient identity is rarely sought on purpose and is often reluctantly and ambivalently assumed (Frank 1997a). It is through stories that people defy and resist imposed identities by detailing conflict, opposition, minor noncompliance and resistance to being classified and categorised by their disease (Frank 1997a).

**Societies Share Stories**

People’s stories do not exist in a vacuum; rather they are predicated upon shared cultural narratives (Frank 2010; Kirkman 2001; Smith & Sparkes 2008a). Similar to, and indeed often treated as synonymous with ideology (Porter 2010), cultural narratives prescribe how people in a society relate, understand, and behave toward each other (Gergen & Gergen 1993). Cultural narratives provide a benchmark of what is expected in terms of behaviour, actions, and moral standards in a particular society (Austin & Carpenter 2008; Bamberg 2004a, 2004b; Birmingham 2010; Gergen & Gergen 1993). The dominant Western cultural narratives of mothering make no allowances for differences (such as illness or disability) and create the assumption that there is only one way to mother (Greene & Kahn 1991; Porter 2010). Stemming from the dominant social group, cultural narratives may also be constraining and oppressive, and contribute to perpetuating unhelpful stereotypes (Romero & Stewart 1999). With their inherent social, cultural and moral contexts, cultural narratives impinge upon what
mothers feel they can say about mothering (Miller 2005). Although people do have the power to resist conforming to cultural narratives, they are often not consciously aware of them (Birmingham 2010; Frank 2002, 2010). Mott and Condor (1997) argue that sometimes people are too close to a situation and therefore cannot appreciate the systems of inequality that impinge upon their lives. A lack of insight into oppressive elements in a culture or community may be common. People may be unaware of the aspects of their life histories that they have in common with other people (Holloway & Freshwater 2007a).

Counter-narratives are narratives that are constructed to make sense of experience when personal narratives are incongruent with the cultural narrative (Bamberg 2004a). Austin and Carpenter’s (2008) study of women with children who had ADHD and Birmingham’s (2010) study of mothers of children who had autism both involved narratives that countered the norms. Participants in these studies reported feeling judged as mothers because of the aberrant behaviour of their children. The women could not offer their children’s achievements as proof of good mothering given the behavioural disturbances they had. Clashing with the cultural narrative of mothering caused these participants to mediate between their own experiences and the cultural narrative of mothering and develop stories that challenged what actually constituted good mothering in the context of mothering children with these diagnoses. These findings are confirmed in other studies. Jackson, Wilkes and McDonald (2007) found similarly in a group of mothers who had obese children, as did Peters and Jackson (2008) in their study of mothers of children with ADHD.

The inclusion of counter-narratives in research reports may allow what Frank (2000, p. 363) calls the “the inconvenient facts” of unheard stories to be revealed. Alternatively
the researcher can use them to reveal what is taken-for-granted in society (Holloway & Freshwater 2007a). However, counter narratives may still contribute to perpetuating cultural narratives as they draw upon general understandings and cultural assumptions (Holloway & Freshwater 2007a). Even if people do consciously resist the dominant cultural narratives, their stories are still told in reference to them (Austin & Carpenter 2008; Daiute 2004; Kruger 2003; May 2008; Somers 1994).

*Through Stories a Moral Being is Made*

Each society has standards of moral behaviour to which individuals must adhere to if they wish to be acceptable to that society (May 2008). Western societies have high expectations of mothers to be moral. The ethic of care for children is gendered and pervasive, representing a non-negotiable moral obligation that results in women putting the needs of their children before their own (Elmberger, Bolund & Lützén 2005; May 2008; Ribbens McCarthy, Edwards & Gillies 2000).

For mothers who are ill, the illness threatens their capacity to satisfy this ethic of care and can therefore imperil their perception of themselves as moral beings. The moral obligations to be both a good mother and a good patient can be difficult to reconcile (Elmberger, Bolund & Lützén 2005). Elmberger, Bolund and Lützén (2005) found that mothers who had cancer experienced guilt and worry that they were neglecting their moral responsibility to their children. The women resolved their moral dilemmas by both redefining the expectations of themselves as mothers, and ‘rising to the occasion’. According to Frank (1997b), ‘rising to the occasion’ is a moral challenge of serious illness. In effect ‘rising to the occasion’ means living the best life possible given the circumstances.
In Frank’s (2002, p. 116) words: “moral life, for better and worse, takes place in storytelling.” Through sharing stories, people with illness negotiate moral issues (Frank 1997b) and find ways to define themselves as good and decent members of society (Bamberg 2004a; May 2008; Miller 2005). Stories allow people to articulate justification for transgressing acceptable conduct which assists them to preserve a positive social identity (May 2008).

**Stories and Nursing Research**

The stories included in this thesis differ from everyday stories, in that they were elicited for the purpose of this study. Although women with children have a pre-existing motherhood story (Kirkman 2002), telling the story in reference to a specific research question can alter the priority of events and experiences discussed (Miller 2005). Stories used for research are therefore viewed as co-constructions between the researcher and participant. Reciprocal by nature, storytelling requires a storyteller and a listener (Simmons, 2006). Storytelling therefore represents the intrinsic relationship between the listener, the events and the teller, and, as such, places the burden upon the researcher to ethically and compassionately engage with the story (Frank 2000). Being listened to has been described by several scholars as a gift, as all people crave to be heard and understood (Ellis & Bochner 2006; Frank 2004; Simmons, A 2006). Having their story heard can make people feel valued and validated (Holloway & Freshwater 2007b), and give them the sense that somebody is genuinely interested in what has happened to them (Ellis & Bochner 2006).

As storytelling is a collaborative endeavour, participants can be validated by their experiences being recognised and respected, which also reflects feminist research goals (East 2009; Holloway & Freshwater 2007a). Malacrida (2009, p. 104) agreed, writing:
“narrative methods ... have the power to reclaim and refashion knowledge by making oppressed people’s stories public and thus offering individuals an opportunity to bear witness to their experience, to affirm personal perspectives, and to challenge dominant ideologies.”

Nursing is about caring for patients; consequently understanding their worlds should be central to constructing nursing knowledge (Repper 2000). Stories hold immense value for researchers to gain intimate insight into the reality and internal world of another being (Carper 1978; Kirkman 2002; Smith & Sparkes 2008b). Storytelling allows for the holistic examination of people’s experiences, identities, social and cultural influences (Daiute & Lightfoot 2004), while retaining the complexity of experience within the context of their lives (Vezeau 1994).

Whereas many types of research favour examining outcomes, storytelling focuses upon the totality of the experience (Bell 2002). A greater understanding of the patient experience could enhance the provision of empathetic and appropriate care through highlighting the issues that are important to the patient (Holloway & Freshwater 2007a). When retold by health care professionals, patients’ stories of illness are reconstituted as the professional narrative of the patients’ experience, thus becoming part of the professional discourse (Frank 1997a; Peters 2006).

Collecting women’s stories of mothering in illness was intended to reveal how women experience disruption to determine how distress might be alleviated for other women in similar circumstances. Storytelling is a particularly suitable research approach when collecting stories from women, as it can capture the complexity of multiple concepts introduced around a central topic which is a characteristic of feminine narration (Overcash 2004). Feminist scholars also consider storytelling a powerful means of
regaining a sense of self-worth for women through naming and articulating experiences (Banks-Wallace 1999; Grassley & Nelms 2009). As the goal of feminist research is to expose women’s subjectivity, listening to women’s stories is appropriate. Soliciting stories that include discussion of health and illness reveals women’s innate knowledge of their own bodies, positions them as experts on themselves and can empower them to be more proactive in seeking health and health care (Banks-Wallace 1999).

METHODS

The Story Sought

As the aim of this research was to explore women’s experiences of mothering disrupted by illness, women over the age of 18 who had cared for at least one child in a mothering capacity and identified that at some time they were disrupted in their capacity to care for that child by illness were sought. There was no upper age limit as it was anticipated that women with now adult children could provide valuable, retrospective stories that would reveal the long term consequences of disrupted mothering.

Although the study was originally restricted to women living in Australia, several women from the United States of America [USA] asked to participate. Therefore the inclusion criterion was broadened to allow women from other countries to participate in the study. Although there are socio-political differences, and Australians receive much higher levels of government support in the form of health care and costs associated with childrearing (Rezac 2007), other researchers have found more similarities than differences when undertaking cross-cultural research with participants from Australia and the USA (Anshel & Weinberg 1995; Rezac 2007). Both countries have Western individualistic and egalitarian values and subscribe to ideologies of Western mothering (Gomez & Rohner 2011). Furthermore, Australia has been infiltrated by American
culture through the media and globalisation of American brands and businesses (Bell & Bell 1998). During the interviews there were no discernible differences in the women’s experiences that could be directly attributed to country of origin, with all of the women sharing similar ideas about their responsibilities as mothers.

Finding Storytellers

In order to be as inclusive as possible, and to facilitate participation of women affected by illness and childcare obligations, the recruitment advertisements offered women the choice of sharing their stories face-to-face, via the telephone or through an email exchange. Due to the varied story collection strategies, the study was advertised through several different channels. Initially a press release was formulated and distributed to local newspapers across the Sydney metropolitan area [Appendix 1]. This proved to be problematic; as the press release was severely condensed by the majority of the papers and lost meaning in the translation [Appendix 2]. One of the local papers misrepresented the research and advertised a study that was seeking mothers of ill children. This misunderstanding resulted in a flood of calls from women who were very disappointed to find that the study was in fact seeking mothers affected by illness as they were very interested in sharing their stories of mothering an ill child.

As well as the press release, printed posters [Appendix 3] were displayed in chemists across several Sydney suburbs. It seemed reasonable to assume that women who were affected by illness would visit chemists regularly. Additionally, mothers frequent chemists as they seek health products and medicines for their children. The study was also promoted on the internet through social networking sites, and on several illness support group websites with the same illustration and information as the paper posters. It was through one of these internet support groups that the American participants
became aware of the study. The advertisement also appeared in one professional publication which was distributed to general practitioners’ offices.

The recruitment advertisements invited women to make contact by either telephone or email. Those who were interested and fulfilled the inclusion criteria were provided with an information sheet [Appendix 4], and a list of free counselling services [Appendix 5]. Upon receiving the documents women were advised to read the information and make an informed decision as to whether they wished to be involved. When they made contact for the second time, any questions they had regarding the study were answered, times for face-to-face meetings or telephone calls arranged, or the time frame for email exchanges discussed. During this conversation, the aims of the study were clarified, and the voluntary nature of participation, their right to withdraw without prejudice at any time, and the assurance of anonymity were all emphasised in order to ensure informed consent was obtained.

**Gathering Oral Stories**

Participants had the choice of sharing oral stories in a private room at the University, in their own homes or via the telephone. Although the word ‘interview’ is endemic in the narrative literature, it is incongruent with the spirit of storytelling, as it implies a more interrogative approach (Holloway & Freshwater 2007a). In recognition of the connotations of the word ‘interview’ some scholars have preferred to use the terms ‘conversation’ or ‘encounter’ (East 2009; Marshall et al. 2009; Peters 2006). Similarly I arranged times for participants to ‘tell me their story’. Framing the meeting more casually rather than as a formal interview is intended to put the participant at their ease, invoke feelings of equality and facilitate the telling of the story (East 2009; Marshall et al. 2009; Peters 2006).
The participants who preferred to tell their story in person all chose to do so in their own homes within business hours. With their permission, their stories were recorded on a digital recording device. I placed the recording device on a surface near us and it appeared to be soon forgotten. Although the introductions and signing of consent forms could be awkward, I believe that a genuine rapport was cultivated during the encounters as women revealed things to me that contravened the social constructions of ‘good’ mothering, such as alcohol abuse and screaming obscenities at children. I was concerned that the interviews might be burdensome to them; however, I came away feeling that my genuine interest in their stories was appreciated. I had the sense that many of the women had not had a previous opportunity to tell their stories of how disrupted mothering had affected them personally to such an interested listener.

For participants who chose the telephone option, a time was arranged and I called from inside a locked, private, soundproof office. After seeking permission from the participants I put the telephone on loudspeaker and recorded their stories. Although using the telephone to collect qualitative data has been deemed inferior to face-to-face interviews as visual cues are absent (Holt 2010), telephone interviewing has several positive aspects. Apart from the documented advantages such as the convenience and safety of participants not having to travel, the low cost, a lower burden of inconvenience for the participant, flexibility, and the ability to include difficult to access populations (Holt 2010; Sturges & Hanrahan 2004), I found it quicker to build rapport with participants than in a face-to-face interview or email exchange. Not being able to see me seemed to make the interaction less intense. Much like internet interviewing (which will be discussed shortly), I perceived that participants were more relaxed talking on the telephone and that it represented less of a burden for them. Participants do not need to ‘dress’ for a telephone interview or clean their home in
anticipation of a stranger visiting. A further advantage was the ability to take notes during the conversation unseen by the participant, a process which can interfere with the flow of conversation in a face-to-face interview (Sturges & Hanrahan 2004).

Once initial conversational formalities were over, whether on the phone or in person, participants were asked to tell me their story of mothering disrupted by illness. Including the research theme (i.e. disrupted mothering) in the open ended question lent itself to eliciting an account about the phenomenon of interest without excluding other ideas or tangents which may have emerged (Kirkman 2002). Ideally a story should emerge without too much direction or prompting from the researcher; however, several of the participants required guidance about where to start their stories, or other details to include. If they were unsure about starting, participants were asked to “start at the beginning, what came first the children or the illness?” Once they started talking, participants tended to relax and tell their story. Questions were kept to a minimum until it was perceived that the story had come to a natural conclusion, in order to not disrupt the flow of introspection (Simmons, 2006). Other clarifying or probing questions were then asked to further illuminate their point or perspective.

Stories from the Inbox

The internet is increasingly being used to conduct qualitative research (Beck 2005; East et al. 2008; Mann & Stewart 2000). Apart from the well reported benefits of decreased cost, reduced time pressures (no travel required), and the eradication of distance as an obstacle to participation, the internet is proving especially useful for including vulnerable or sensitive populations (Beck 2005; East et al. 2008; Elmir et al. 2011). Utilising the internet allowed access to women who were geographically diverse, who would otherwise have been difficult or expensive to communicate with due to travel
and associated costs, or who were unwilling or unable to meet face to face. Removing the requirement of an essential physical meeting was especially relevant for this study where illness and childcare imperatives could have prevented participation.

Internet interviewing has been described as participant friendly (Mann & Stewart 2000). East et al. (2008) propose that using email interviews can increase the disclosure of information, as being in a location removed from the researcher facilitates a sense of privacy. Others assert internet interviewing enhances the sense of anonymity, and removes the sensation of being under inspection or judged on physical attributes (Kralik, Koch & Brady 2000). A sense of anonymity is attributed with reducing reticent responses influenced by social desirability (Beck 2005). Email interviews may also contribute to increasing participant autonomy as they can respond at their leisure (East et al. 2008).

The time allowed by typed correspondence means that many responses may be more articulate, well thought through and possibly more reflective and comprehensive than verbal responses in a face to face interview might be (East et al. 2008; Kralik, Koch & Brady 2000; Murray & Sixsmith 2002). While internet interviewing has been criticised in that it excludes the illiterate, those of poorer socioeconomic circumstances and without access to computers or the internet (East et al. 2008; Murray & Sixsmith 2002), the women in this study had the alternative options of choosing face-to-face or telephone interviews. All data collection options potentially exclude someone, so offering three different options to share their stories was designed to improve women’s opportunities to participate.

Online communication has also been criticised as an inferior method of data collection as nonverbal cues are not conveyed (Beck 2005). Researchers who have utilised
internet interviews dispute these limitations stating that the use of icons can assist to convey emotion (Beck 2005; East et al. 2008; Kralik, Koch & Brady 2000; Murray & Sixsmith 2002); however, it is unlikely that the full range of human expression could be captured in a series of emoticons.

In the current study the effectiveness of internet interviewing varied. Although several women were obviously quite comfortable corresponding and produced lengthy, in-depth stories (one woman’s account was referred to as War and Peace by its author), other women provided very brief responses. The ability to cultivate rapport with women was also more variable. Whereas some women seemed to respond with pleasure to elaborating and probing questions in subsequent emails, others limited their further answers which discouraged further questioning. One notable advantage of email interviewing was that it gave me time to reflect upon the women’s stories and compose more thoughtful responses. This time for reflection was less apparent during face-to-face and telephone interviewing, where the participant and I took turns at talking, and their remarks required more immediate responses.

From Talk to Text

Of the 27 women who participated in this study, 15 sent their stories via email; nine told me their stories over the telephone; and three elected to have face-to-face encounters in their homes. Emailed stories were copied and pasted into Microsoft Word documents. The internet stories were on average six pages each, ranging from two to ten pages. Stories collected via telephone averaged fourteen pages each, ranging from six to twenty-three. Stories collected face-to-face averaged sixteen pages and were from fourteen to nineteen pages each. The internet stories were typically collected within three to four email exchanges. Each of the telephone interviews took approximately an
Face-to-face interviews varied from an hour to over three hours and included other elements that increased the time such as a grocery delivery and tour of the garden.

Both Riessman (2008) and Sandelowski (1991) raise the issue of the non-verbal aspects of a face-to-face qualitative interview disappearing in the transcribing due to an inability to retain the real oral expression in text. To help counter this, long pauses, emotional responses, very loud or soft speech, emphasised words and so on were noted in the transcript. I personally transcribed all of the conversations, which meant that I had the advantage of also having been privy to the original telling. Transcription occurred within days of the interview in order to be able to retain and transfer to the text as much detail as possible.

**NARRATIVE ANALYSIS**

Before describing the method used to reduce hundreds of pages of women’s stories into neatly presented themes, it is necessary to acknowledge that the analysis of the data in this study began during the literature review and has been ongoing throughout the entire course of study. Although there was a particular period of time that was devoted solely to analysing the stories and writing the findings, the analysis has continued to evolve. Mauthner and Doucet (1998, p. 124) have also recognised the ongoing nature of analysis, writing that “data analysis is not a discrete phase of the research process confined to the moments when we analyse interview transcripts. Rather it is an ongoing process which takes place throughout, and often extends beyond, the life of a research project.”

In line with the feminist philosophies that guided this study, I acknowledge that the narrative in this thesis represents a co-construction. I make no pretence to being merely an interested observer, and instead situate myself as a part of the stories that were told
to me. The stories were told in the context of participating in a research study and shaped by the storyteller in response to the research question. These stories have then been analysed and reshaped and woven through the narrative of this thesis. Therefore, as a researcher I am an active agent in the construction of the stories (Abma, 2002). By exposing the private spheres of women’s worlds, I am also involved in the social construction of motherhood albeit for an academic and clinical audience.

I further acknowledge that the interpretation of the women’s stories was subject to my own historical, cultural and social influences (Creswell, 2009), and that I assumed an empathic stance to the women’s stories. I am therefore “accountable and vulnerable” to the reader for my interpretation and presentation of the stories of others (Abma, 2002, p. 18; Gergen & Gergen, 2004). This is as it should be given the tension between my own agenda of gaining a doctoral degree and the generosity of the women who have offered their personal stories for public consumption. Like the women who shared their stories with me, I share my own story within this thesis exposing my own vulnerabilities, understandings and experiences of the world.

To combine the participants’ experiences into the narrative of this thesis, interpretation had to occur. As Riessman (1993, p. 43) wrote, “it is naive to think one can ‘just present the story’ without some systematic method of reduction”. The varying sources of data collection led to distinctively different styles of storytelling, which posed a challenge when choosing a method of narrative analysis. When considering alternative approaches as to how to manage the data, narrative analysis approaches such as thematic, content, structural and interactional were considered. Thinking about the focus of the women’s stories being experiential where the emphasis was upon the content of the stories (what was talked/written about), rather than upon linguistic
structures or the use of language, it was decided to interpret the stories thematically. However, the scripts that were produced for each sub-theme also represent a form of content analysis in that they identify common elements in the women’s accounts and are presented as the thread of a collective story (Holloway & Freshwater 2007a).

**Thematic Narrative Analysis**

As previously described, I transcribed the oral stories myself. Transcribing involved listening to each of the digitally recorded stories countless times; this was the beginning of a period of data immersion. After the recordings were transcribed I spent more time listening to the recordings while reading and re-reading texts, gradually developing a sense of the work, and beginning to determine shared concerns, experiences and patterns in the women’s stories.

While other researchers using storytelling have rejected the use of qualitative data analysis programs as incompatible with the human nature of storytelling (Peters 2006), or used manual means of coding such as coloured highlighters or pens (East 2009), I found the NVivo 8 (QSR International Pty Ltd 2008) computer program invaluable in the early stages of analysis. The computer program does not identify themes but rather allows sections of text to be highlighted by the researcher, named and saved as nodes. Nodes are preliminary categories of text which in this study related to ideas, emotions and outcomes that recurred across women’s stories. The same sections of text can be coded repeatedly into different nodes to assist the identification of close or overlapping concepts. Transcripts remain intact, yet all of the text coded with the same node can be retrieved simultaneously, allowing for concepts to be examined across transcripts.

The original NVivo coding produced 62 nodes. To subject these simple nodes to a deeper level of analysis, I employed a form of data display. Data displays use visual
means to organise and compare data (Miles & Huberman 1994). The node names were each placed in a text box in a Microsoft Office Word program. These boxes were then shifted and sorted into lists of like concepts or affinity groups. Once sorted, similar nodes were collapsed into one another and subthemes and themes began to be identified. Using this method eliminated the identification of participants’ single words or phrases as standalone themes. Single words or phrases represent more simple categories or single units of analysis (DeSantis & Ugarriza 2000). Instead, themes are more abstract, serving to unite these lower levels of analysis into overarching meanings. Once identified, themes were regarded cautiously until the end of data collection and writing up of the findings, when they were verified through the constant comparison of data and discussion with supervisors. The final list of themes underwent at least ten stages of evolution in their transformation from nodes to the final Acts and Scenes [Appendix 6].

RIGOUR

Rigour refers to the trustworthiness of the data, and how accurately the researcher portrays the reality of the participants and describes the study methods and decision making processes (Riessman 2008), in order to substantiate the findings (Speziale & Carpenter 2007). Methods of demonstrating rigour should be compatible with the theoretical underpinnings of the research study (Jackson, Daly & Chang 2003). Therefore, in keeping with a social constructionist epistemology, rigour is discussed here in reference to the ethical and professional conduct of the researcher (Riessman 2008). Furthermore, in discussing rigour, I attempt to convince the reader that the data are authentic, and my analytic interpretations of them are conceivable, logical, and persuasive. As recommended by Guba (1981) and Guba and Lincoln (1994), the
operational techniques of credibility, dependability, confirmability and transferability were considered when designing this study.

*Credibility*

Credibility is described as a quality criterion to assess whether a study has effectively described a phenomenon and produced believable findings (Cresswell 1998; Polit, Beck & Hungler 2001; Speziale & Carpenter 2007). Byrne (2001) states that to be credible a researcher should elaborate on their background and qualifications and discuss their preconceived assumptions and philosophical influences. In the personal positioning section of this thesis I exposed the forces that have acted in my life to lead me to this topic, and I have revealed the philosophical influences and reasoning behind the choice of methodology and method at the beginning of ‘Direction and Cues’.

Although member checking (returning transcripts and findings to participants for verification) is a commonly recommended technique to increase rigour, it is also controversial (Riessman 2008). For the purpose of this study, I chose not to do this. Oral stories are transformed when transcribed into a different form and may appear foreign to the participants, as the text is divorced from the context within which it was generated (Riessman 2008). Furthermore, I agree with Riessman (1993, p. 67) that:

> They [participants] may not even agree with our interpretations (so it is important, whenever possible, to clearly distinguish between our views of subjects’ lives and their own). In the final analysis, the work is ours. We have to take responsibility for its truths.

The decision not to use member checking also avoided threats to the collected data as participants with the luxury of hindsight might have sought to edit their accounts.
Stories are time and context bound; each story only existed in its form for the time it took to tell. Subsequent retellings would be slightly different as with temporal distance tellers gain perspective and apply new layers of meaning (Sandelowski 1993). The story they shared was their personal truth at that time, and to subject it to further scrutiny would be to dishonour the original telling and threaten the trustworthiness of the study (Sandelowski 1993). Having shared their story, participants may have achieved some form of closure (Hutchinson, Wilson & Skodol Wilson 1994). There is the further risk of intensifying participants’ emotional distress by picking over their account a second time, as well as the increased burden upon their time and resources.

Rather than engaging in member checking I endeavoured to ensure that the exact words used by participants were correctly transcribed and retained in the quotes used in the findings section (with the exception of identifying data). I also made certain that the essential meaning of the stories was retained and continued to take precedence throughout the multiple versions that comprise qualitative work. If participants were to read the thesis or articles arising from it they should easily be able to recognise their own stories. This is in keeping with Guba and Lincoln’s (1981) statement that a credible study is one in which individuals can recognise their own experiences.

**Dependability**

Dependability refers to the truthfulness and constancy of the data findings (Polit, Beck & Hungler 2001) and is reliant upon credibility (Speziale & Carpenter 2007). Lincoln and Guba (1986 p. 19) state that dependability can be determined by an appraisal of the research by a competent outsider. Each step of this study has been described in detail in this thesis to allow the reader to understand all aspects of the research; from the selection of the method and methodology to the evolving categories and themes and the
reasoning behind their selection. Due to the supervisor/student relationship inherent in a PhD doctoral study, I was also supervised from the original proposal to this final thesis by my PhD supervisors, who are academic researchers. Peer review or debriefing occurred as my supervisors challenged and questioned everything from my methods to my conclusions throughout the course of this study. The discussions with them during the analysis subjected my interpretations to a continuous critical gaze (Byrne 2001).

**Confirmability**

Confirmability is, in effect, a process audit (Speziale & Carpenter 2007). As recommended by Byrne (2001) confirmability was achieved by creating an audit trail, in the form of a researcher journal, and keeping original data such as audio recordings, transcripts and observation notes, early versions of data interpretation and communication with participants. As per the UWS Research Code of Practice Policy all of these items will be stored until the ethical requirement to store data for five years following publication is met, at which point they will be destroyed (University of Western Sydney 2011).

In this thesis confirmability is demonstrated, for example, by documenting how data analysis was performed, and how the conceptual categories, themes and sub-themes were arrived at (Jackson, Daly & Chang 2003; Polit, Beck & Hungler 2001). Polit, Beck and Hungler (2001) further state that providing excerpts of participants’ stories enhances confirmability of findings. Extensive excerpts of participant stories are included in the research findings to support the conclusions of this thesis.

This study will be replicable in that all steps are well described, allowing other investigators to replicate it (Lincoln & Guba 1985; Sandelowski 1986; Speziale & Carpenter 2007). However, given the context-specific nature of narrative research, this
does not mean that if another researcher followed the same methods they would come
to the same conclusions or interpret data in the same way.

Transferability

While qualitative studies are by nature not easily generalised, they must be transferable
in order to be of use to nursing practice (Polit, Beck & Hungler 2001). Transferability
refers to whether the findings can be applied to similar people in similar settings
(Holloway & Freshwater 2007a). In order to achieve a measure of transferability some
scholars recommend including thick descriptive data when writing up in order to
provide context for comparison to other studies (Lincoln & Guba 2004). In this thesis
an effort has been made to provide as much information about the study as feasible,
including the underpinning theories, recruitment strategies, participant characteristics,
story collection and interpretation.

Transferability can also occur through the findings of the study being drawn upon by
other researchers for journal articles and theses, as this is a functional and pragmatic
test for a piece of work (Riessman 2008). The transferability of the current study can be
confirmed as sections of this thesis that have been published in peer reviewed scholarly
journals have already been cited by other scholars.

ETHICAL ISSUES

Feminist research is often focused upon revealing and challenging issues of oppression
and marginalisation. Conducting research that draws upon feminist theories should
therefore not contribute to the marginalisation of participants (Jackson, Clare & Mannix
2003). Instead, feminist research subscribes to a caring approach that is cognisant of the
relationship between the researcher and participant. The researcher’s interpretation of
events can be seen as authoritative, which can compromise participants’ understanding
of their own experiences (Smythe & Murray 2000). Therefore research design, analysis and reporting must be respectful and sensitive (Holloway & Freshwater 2007a). To ensure that the research proposal for this study satisfied ethical considerations for the use of human subjects, permission was sought from and granted by the University of Western Sydney’s Human Research Ethics Committee [Appendix 7]. Ethical issues will be discussed under the headings of ‘Gaining Consent’, ‘Ensuring Participant Privacy’, ‘Emotional Considerations’ and ‘Self Disclosure.’

**Gaining Consent**

At first contact, participants were given, emailed or posted the study information sheet [Appendix 4] and consent form [Appendix 8] as well as a list of counselling services [Appendix 5]. This gave them time to read the information and consider whether they would like to participate. At the beginning of interviews and email exchanges the nature of the study was explained and any questions participants raised about the study were answered. It was clearly explained to potential participants that involvement was entirely voluntary and that they would be free to withdraw at any time without any explanation. Face-to-face participants were asked to sign a consent form. For women who participated in the telephone interviews, study documents and a stamped self-addressed envelope were posted to them in advance. Once they had returned the signed consent form via the self-addressed envelope, a time to conduct the interview was arranged. Those women who participated in the email exchanges received the documents electronically and were informed that consent was implied by their continued correspondence.
Ensuring Participant Privacy

The promise of confidentiality is the assurance that participants will not be identified in research or other publications and that their identity will be closely guarded by the researcher (Polit, Beck & Hungler 2001). Confidentiality was addressed by the participants’ real names only appearing on the consent forms. Whilst care was taken not to alter meaning, during the transcription the names of people and places were removed or replaced with pseudonyms. Participants were asked to choose a pseudonym that started with a letter corresponding to the order in which they joined the study. For example the first participant chose a name starting with A, the second a name starting with a B. When the end of the alphabet was reached, the twenty-seventh participant chose a different name starting with A.

In line with the UWS Research Code of Practice Policy (University of Western Sydney 2011), emails were stored in a password encrypted computer only accessed by the researcher. Hard copies of emails and transcriptions of stories and audio recordings were kept in a locked drawer in a secure area of the UWS Campbelltown Campus. Five years after publication computer files will be deleted and hard copies and transcripts of stories destroyed.

Emotional Considerations

Sensitive issues in research are those that have “the potential to cause physical, emotional or psychological distress to participants or the researcher” (Elmir et al. 2011, p. 12). Revealing events about which they are saddened, embarrassed, or regretful increases the possibility of emotional discomfort for participants. Being a mother with an illness has great potential to be a sensitive issue, as being unable to mother to a particular standard contravenes societal expectations, which may elicit feelings of
shame. However, people who volunteer to tell their stories to a researcher are the best people to judge whether or not they are emotionally ready (Hutchinson, Wilson & Skodol Wilson 1994). Those who do agree to participate may also consciously choose which information that they share or withhold, or how they contextualise information, in order to protect themselves emotionally (Hutchinson, Wilson & Skodol Wilson 1994). Furthermore, the perceived sensitivity of a particular topic will vary. What may be a highly sensitive topic for one person may not be perceived as such by another (Hutchinson, Wilson & Skodol Wilson 1994).

Many participants are reported to appreciate having their story valued and taken seriously (Dyregrov 2004). Telling stories has also been attributed with participants gaining resilience (East et al. 2010; Jack 2010), and insight, making sense of emotions (Jackson & Mannix 2003), and feeling validated (Hutchinson, Wilson & Skodol Wilson 1994).

It is frequently reported that although some participants can become emotionally distressed during an interview, the release of feelings and sharing of information can have a cathartic effect that participants often consider beneficial (Borbasi, Jackson & Wilkes 2005; Dickson-Swift, James & Liamputtong 2008; East et al. 2010; Elmir et al. 2011; Holloway & Freshwater 2007b; Hutchinson, Wilson & Skodol Wilson 1994). However, Carter (2008) refutes the notion of storytelling necessarily being cathartic, pointing to a lack of evidence. She also urges researchers to acknowledge that if storytelling can be cathartic, telling stories could also be potentially damaging for participants. In order to help counteract any negative effects of sharing their stories, all participants in this study were provided with a list of free counsellors on recruitment, in case they needed to access professional help [Appendix 5]. When they had finished
telling their stories, participants were reminded about the list and encouraged to contact the counsellors if they felt the need.

Self-Disclosure

The researcher sharing their own thoughts and experiences on a topic can contribute to making a participant feel more comfortable sharing their story (Reinharz & Chase, 2001). Self-disclosure can also contribute to equalising the power differential between the researcher and the participant (Sword 1999). However, the amount of self-disclosure should be carefully monitored as it is the participant’s viewpoint that is sought, and too much personal information about the researcher can skew the tone and direction of their story (Reinharz & Chase, 2001).

In the beginning I was undecided whether or not to reveal that I worked clinically as a nurse as it may have altered the participants’ disclosures regarding experiences with health professionals, or it could have skewed the conversation to a general discussion of their illness, disease or disability, or even caused them to seek health advice (Sword 1999). Acknowledging that you are a health professional can also affect the quality of the data as respondents may assume you have pre-existing knowledge of their issues which can lessen the chances of unexpected insights being revealed (Sword 1999). However, rather than hide my roles as a nurse and a mother I finally chose to reveal the multiple roles in my life. I considered that sharing my insider’s awareness of mothering and that I had witnessed serious illness, albeit from a nurse’s perspective, was both appropriate and reciprocal since I was asking them to share their experiences with me.

SUMMARY

Although scholars have examined mothering in the context of specific diseases and there has been recognition of the disruptive nature of illness, none have sought the
views of women who actually identify that their mothering has been disrupted. For these reasons this study employed a storytelling approach guided by social constructionist and feminist principles.

Ethics approval was gained from the University Ethics Committee before recruitment began. Women were recruited via posters, flyers and advertisements in newspapers and on internet bulletin boards. Following procedures of informed consent, women’s stories were collected through face-to-face and telephone conversations as well as email exchanges. I personally transcribed all of the interviews and interpreted the stories thematically. A theatre metaphor was applied to the findings and then extended throughout the thesis. The next four Acts contain my interpretation of the women’s stories supported by quotes from the transcripts.
DISRUPTED MOTHERING IN ILLNESS:
A DRAMA IN FOUR ACTS

This mask represents the conception we have formed of ourselves – the role we are striving to live up to – this mask is our truer self, the self we would like to be

(Park 1950, p. 250)

PRESENTATION OF THE FINDINGS

Long before Shakespeare wrote ‘All the world’s a stage’, philosophers explored the idea of people as actors. The presentation of this thesis has been heavily influenced by dramaturgical concepts. Themes and sub-themes are Acts and Scenes, titles draw upon theatrical terminology, each Scene is preceded by a script and quotes are presented in script form. Before introducing the participants and their stories, the rationale and use of this theatre metaphor will be explored as well as the justification for certain language choices used throughout the Findings section. Summaries of Scenes appear as codas at the end of each section of text.

Theatre as Metaphor

While ruminating upon sources of support, I identified the women’s partners as understudies to the mothering role. Although not normally in the lead they were able to follow the script and deliver the necessary lines. The naming of this one sub-theme ‘the imperfect understudy’ generated a process of reflection upon the rest of the findings. If the partner represented the understudy, then the woman being replaced in the role could be conceived as the lead actor. The idea of the women as actors also resonated with the literature that implied mothering was often a public performance. As Wilshire (1982, p. xv) suggested, “since theatrical or theatre like concepts such as role are already
embedded in ordinary language for ordinary life, why not deliberately and scientifically extend a group of concepts to offstage life?” Further to this, when drama occurs in people’s lives, life does in fact become theatre-like (Wilshire 1982). The experience of illness that is severe enough to disrupt a woman’s ability to mother her children is surely such an occurrence.

Extending the metaphor of the theatre to all of the findings was a process of metaphor mapping which is applying an unrelated concept to a disparate context (Lakoff 1992). Applying metaphor can contribute to altering how a subject is considered (Wood 2002); provide fresh insight into data (Aita et al. 2003); assist in explaining complex realities by reducing them to schema (Kangas, Warren & Byrne 1998); reveal hidden facets of a phenomenon; and provide a creative way of structuring results (Carpenter 2008). Thus the metaphor has been used in this study to provide cohesiveness to the thesis by drawing upon theatrical concepts for the thesis and section titles, themes and subtheme names.

The theatrical metaphor also prompted the inclusion of scripts at the beginning of each sub-theme in order to summarise the essence of the women’s experiences of disrupted mothering. An attempt was made to capture the main ideas in each sub-theme and present these distilled into a single page of script. Unlike the Acts and Scenes which constitute the themes and sub-themes, these scripts are presented chronologically in that they are a single story, following a woman from early to late motherhood. Although they are an amalgamated representation of the women’s stories, the scripts provide a concise overview of the predominant findings of this study and thus represent a narrative thread within the thesis.
Although some studies report using a metaphor identified early in the research process to unearth themes (Aita et al. 2003; Dexter & LaMagdeleine 2002; Kangas, Warren & Byrne 1998), in this study the themes were fairly developed before the metaphor was conceived. Having well developed themes before applying the metaphor has allowed me to avoid certain dangers such as manipulating the emerging data to fit the metaphor or disregarding findings that did not entirely mesh with the metaphor (Carpenter 2008). However, the consequence of applying metaphor to developed findings is that some themes and sub-themes were more readily adaptable to the theatrical concept than others.

It is important to note that the use of the theatre as a metaphor for the findings of this study in no way intends to trivialise the women’s experiences, or imply that they were not sincere in their good intentions for their children. Indeed, the intent was to instead create a powerful re-telling of the women’s stories. It must be kept in mind that these stories are not fiction; rather, they are the sometimes painful, heartfelt experiences of real women. As Goffman (1959, p. 9) wrote: “The stage presents things that are make-believe; presumably life presents things that are real and sometimes not well rehearsed.”

Although the theatre metaphor was not completely definitive of the women’s experiences, it was useful to provide cohesiveness to the findings, which by their nature are limited by the interpretation and other tensions inherent in producing a conceptual piece of research. Research findings are superficially representational of human experience given that the research process tends to explore one aspect of people’s lives to the exclusion of countless others. I acknowledge that the themes presented in this thesis are but one interpretation of what are potentially hundreds of themes. From my
consideration of the women’s stories, four dominant themes (Acts) and twelve subthemes (Scenes) emerged. The Acts are numbered I-IV, with each Act containing three Scenes (Table 1).

Table 1: Acts and Scenes

<table>
<thead>
<tr>
<th>Acts</th>
<th>Scenes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Playing the Part</strong></td>
<td>Reconciling roles: The patient mother</td>
</tr>
<tr>
<td></td>
<td>The show must go on: The relentless responsibility of mothering</td>
</tr>
<tr>
<td></td>
<td>Adlibbing: Doing the best she can</td>
</tr>
<tr>
<td><strong>The Health Care Subplot</strong></td>
<td>Reading different scripts: Nurses misunderstanding mothers</td>
</tr>
<tr>
<td></td>
<td>The heartbreak scene: Mothering from hospital</td>
</tr>
<tr>
<td></td>
<td>Receiving good direction: Supportive health professionals</td>
</tr>
<tr>
<td><strong>The Supporting Cast</strong></td>
<td>The imperfect understudy: Partners in the spotlight</td>
</tr>
<tr>
<td></td>
<td>Women in the wings: Friends and female relatives</td>
</tr>
<tr>
<td></td>
<td>Behind the scenes: Helpful others</td>
</tr>
<tr>
<td><strong>Reviewing the performance</strong></td>
<td>Plot resolution: The consequences for mother/child relationships</td>
</tr>
<tr>
<td></td>
<td>A performance with poor reviews: Critics, guilt and blame</td>
</tr>
<tr>
<td></td>
<td>Rewriting the script: The mostly happy ending</td>
</tr>
</tbody>
</table>

Choice of Language

Adopting a feminist stance in this study meant that particular attention had to be paid to the way that language was used, as language can contribute to the oppression, exclusion or marginalisation of groups (Jackson, Clare & Mannix 2003). Therefore at all times I endeavoured to use language that was sensitive and respectful to the women and their stories. Within the Acts and Scenes there is the occasional reference to unborn children
or babies. Although the words unborn child were criticised by an anonymous reviewer as being too emotive, this phrase and other perceivably emotive words and phrases have been retained within this thesis. The women themselves used such words to describe their offspring and these words therefore facilitate understanding the women’s stories on their own terms. Furthermore both mothering and illness are experiences that evoke strong feelings, and as such affective words were appropriate to retain the feel and mood of the stories. To substitute clinical terminology such as foetus would have contributed to medicalising and diminishing the women’s experiences. Assuming an expert tone in the narrative would have been anathema to both the storytelling methodology and feminist stance assumed in this study.

I decided to refrain from referring to the women who shared their stories as participants within the findings section in order to remain consistent with the theatre metaphor. Therefore the words mother, mothers, woman, and women were used. When referring to women in this section, reference was being made only to those women who shared their stories for this research study, and not women generally.

**INTRODUCING THE LEADING ACTORS**

The twenty-seven women who participated in this study were all unique and individual with their own specific experiences and perspectives. However, they shared some key characteristics. They were all White women from Western countries who spoke fluent English. All of the women believed that at some stage their mothering had been disrupted by illness or injury. The range of illnesses they had experienced was diverse, with several women having multiple diagnoses. Fifteen of the women had been diagnosed with a physical illness or injury, seven with a psychiatric illness, and five had been diagnosed with both physical and psychiatric illnesses. The women had between
one and six children each, aged from five months to fifty-five years, and were themselves aged twenty-five to seventy-five years old.

Due to the nature of the data collection procedures, the stories told by the women varied widely in length. While the face-to-face and telephone interviews resulted in up to twenty pages of transcript per story, some of the emailed responses were as short as two. Although story length did not correlate with ‘completeness’ or ‘depth’ of experience, and some of the shorter stories were incredibly powerful, this explains why some women have been featured more frequently in the findings. Regardless of transcript length, each woman who participated was moved enough by the subject of the study to share her own story, and I have endeavoured to do each woman’s story justice, and feature them wherever possible in the following Acts and Scenes. Following is a brief introduction (Table 2: The Leading Actors) of the women who were generous enough to share their experiences.
Table 2: The Leading Actors

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Nationality</th>
<th>Diagnosis</th>
<th>Marital Status</th>
<th>Highest Education Attended</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Alice</td>
<td>34</td>
<td>Australian</td>
<td>Long medical history, including pulmonary fibrosis, postnatal depression, and a brain tumour (ependymomas).</td>
<td>Married</td>
<td>University</td>
<td>A 6 year old daughter and 4 year old son.</td>
</tr>
<tr>
<td>2. Bailey</td>
<td>34</td>
<td>Australian</td>
<td>Dilated cardiomyopathy.</td>
<td>Married</td>
<td>TAFE</td>
<td>A 12 year old daughter, and 2 sons aged 7 and 4.</td>
</tr>
<tr>
<td>3. Cate</td>
<td>45</td>
<td>Australian</td>
<td>Crohn’s disease.</td>
<td>Married</td>
<td>High School</td>
<td>3 daughters aged 22, 19, and 17, and a son 10 years old.</td>
</tr>
<tr>
<td>4. Dee</td>
<td>47</td>
<td>Australian</td>
<td>Crohn’s disease, which led to right hemicolecotomy, ileostomy, proctectomy, also iritis and rheumatoid arthritis.</td>
<td>Separated</td>
<td>TAFE</td>
<td>3 daughters aged 28, 25 and 22.</td>
</tr>
<tr>
<td>5. Eliza</td>
<td>35</td>
<td>Australian</td>
<td>Postnatal depression, pneumonia, deep vein thrombosis.</td>
<td>Married</td>
<td>TAFE</td>
<td>A 5 year old daughter and 2 year old son.</td>
</tr>
<tr>
<td>6. Farrah</td>
<td>65</td>
<td>Australian</td>
<td>Borderline personality disorder and agoraphobia.</td>
<td>Divorced</td>
<td>University</td>
<td>6 adult children.</td>
</tr>
<tr>
<td>7. Ginger</td>
<td>31</td>
<td>American</td>
<td>Lyme disease, fibromyalgia, chronic fatigue, hypothyroidism.</td>
<td>Married</td>
<td>University</td>
<td>2 children aged 5 and 9. One child is a son, the sex of the other child was not revealed.</td>
</tr>
</tbody>
</table>

1 TAFE stands for Training and Further Education. TAFE is Australia's largest provider of vocational education and training.
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<tbody>
<tr>
<td>8.</td>
<td>Heather</td>
<td>25</td>
<td>American</td>
<td>Bipolar disorder.</td>
<td>Engaged</td>
</tr>
<tr>
<td>9.</td>
<td>Isabella</td>
<td>32</td>
<td>American</td>
<td>Ulcerative colitis resulting in removal of colon and ileostomy, plus seizures following a head injury.</td>
<td>Married</td>
</tr>
<tr>
<td>11.</td>
<td>Karina</td>
<td>59</td>
<td>Australian</td>
<td>Depression.</td>
<td>Divorced</td>
</tr>
<tr>
<td>12.</td>
<td>Lilly</td>
<td>57</td>
<td>Australian</td>
<td>Bipolar disorder.</td>
<td>Divorced</td>
</tr>
<tr>
<td>13.</td>
<td>Maggie</td>
<td>51</td>
<td>Australian</td>
<td>Lupus and haemorrhagic stroke, resulting in left sided hemiplegia.</td>
<td>Married</td>
</tr>
<tr>
<td>14.</td>
<td>Nora</td>
<td>44</td>
<td>Australian</td>
<td>Breast cancer resulting in a mastectomy, chemotherapy, and radiation</td>
<td>Married</td>
</tr>
<tr>
<td>15.</td>
<td>Olivia</td>
<td>75</td>
<td>Australian</td>
<td>Two bouts of tuberculosis one as a child aged 13, a second as an adult and mother.</td>
<td>Widowed</td>
</tr>
<tr>
<td>16.</td>
<td>Pearl</td>
<td>40</td>
<td>Australian</td>
<td>Cholecystitis, pancreatitis and Cholecystectomy.</td>
<td>Married</td>
</tr>
<tr>
<td>17.</td>
<td>Quin</td>
<td>75</td>
<td>Australian</td>
<td>Viral myocarditis.</td>
<td>Married</td>
</tr>
<tr>
<td>18.</td>
<td>Rachael</td>
<td>26</td>
<td>Australian</td>
<td>Ulcerative colitis, resulting in two separate stomas and bowel reconnection, plus depression.</td>
<td>Married</td>
</tr>
<tr>
<td></td>
<td>Name</td>
<td>Age</td>
<td>Country of Birth</td>
<td>Condition</td>
<td>Marital Status</td>
</tr>
<tr>
<td>---</td>
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</tr>
<tr>
<td>20.</td>
<td>Tanya</td>
<td>Not Supplied</td>
<td>Australian</td>
<td>Postnatal depression that evolved into pre-menstrual psychosis.</td>
<td>Married</td>
</tr>
<tr>
<td>22.</td>
<td>Veronica</td>
<td>40</td>
<td>Australian</td>
<td>Crohn’s disease resulting in two bowel resections and depression.</td>
<td>Married</td>
</tr>
<tr>
<td>23.</td>
<td>Winter</td>
<td>49</td>
<td>Australian</td>
<td>Breast cancer resulting in mastectomy, chemotherapy and radiation.</td>
<td>Married</td>
</tr>
<tr>
<td>24.</td>
<td>Xanthia</td>
<td>45</td>
<td>Australian</td>
<td>Hyperparathyroidism.</td>
<td>Married</td>
</tr>
<tr>
<td>25.</td>
<td>Yasmin</td>
<td>44</td>
<td>Australian</td>
<td>Severely prolapsed discs.</td>
<td>Married</td>
</tr>
<tr>
<td>26.</td>
<td>Zeta</td>
<td>43</td>
<td>Australian</td>
<td>Cholecystitis and cholecystectomy.</td>
<td>Married</td>
</tr>
<tr>
<td>27.</td>
<td>Adelaide</td>
<td>37</td>
<td>Australian</td>
<td>Dural headache and torn ligament post caesarean.</td>
<td>Married</td>
</tr>
</tbody>
</table>
There is something unspeakable in day by day living – unspeakably particular and private – and all art can do is to show in revealing ways that and how there is the unspeakable; it cannot live it in the way we must offstage

(Wilshire 1982, p. 211)

INTRODUCTION

The women in this study did not audition for the patient role, but were cast unwillingly into it. The patient role impacted on the mothering role, which in turn influenced women’s treatment choices. This resulted in conflict for the women as they endeavoured to manage their illness while minimising the effect that the illness had on their ability to mother their children. Women were forced to make decisions in an effort to balance the different demands placed upon them by the conflicting roles. The trade off between mothering and treatment decisions is examined in ‘Act I, Scene I: Reconciling roles – The patient mother’.

There was little doubt that despite their illness, the women in this study considered the mothering role to be a priority and still felt primarily responsible for the physical and emotional care of their children, and maintenance of the household. As a consequence of the debilitating nature of their illnesses, some of the women experienced a profound sense of detachment and a loss of joy in mothering, yet they continued caring for their children. The daily struggle to mother during illness is shown in ‘Act I, Scene II: The show must go on – The relentless responsibility of mothering’.

‘Act I, Scene III: Adlibbing – Doing the best she can’, describes the way in which the women in this study altered activities they engaged in with their children in order to
mother to the best of their ability despite illness, injury, or its consequences. Although they strove to be good mothers, some still expressed feelings of inadequacy. The women also discussed missing out on sharing some experiences with their children.
Script. Act I, Scene I: Reconciling roles – The patient mother

Setting

A lounge room in a suburban house. The room is messy, littered with toys. A young woman is sitting on the couch talking on the telephone. She looks tired and distressed. A young boy is playing with his toy trucks on the floor beside her. He pauses occasionally to look at her, listening to her conversation. A baby is asleep in a bouncer.

Character Dialogue and Stage Directions

MOTHER I don’t know Mum, she’s asleep at the moment, but she’s been so unsettled. I don’t know if she’s getting enough milk. I don’t know if it’s the meds affecting the milk, or her, or both.

(She pauses, listening)

MOTHER I know, I’m back on the meds now but since I’ve had her it’s the worst it’s ever been. Maybe because I cut them back so much when I was pregnant. I don’t want to go back to hospital, not now, but I don’t know how much longer I can stand it. I’ve doubled one of them, I guess I just have to wait and see if it helps.

(She pauses, listening, the baby starts to stir)

MOTHER No don’t come yet. Let’s just see if it settles. I’ve got to go she’s waking up. Okay bye.

(Putting the phone down she awkwardly gets to her knees and picks the baby up out of the bouncer. Holding her with one arm, she uses the arm of the couch to pull herself back up. Once seated she puts the baby to her breast)

LITTLE BOY Mummy, are you going back to the hospital today?

MOTHER I hope not baby, Mummy took some medicine. Let’s hope it makes me feel better, okay. Then I can stay home with you.

(Reaches out to ruffle his hair)

LITTLE BOY Don’t go okay Mummy, stay home with me. I don’t wanna go to Nanny’s house to sleep over again. I just want you to stay home with me. Okay Mummy?

(His eyes brimming with tears)

MOTHER I’m trying honey, but I don’t know. We’ll see okay. If the medicine works. It’s not so bad at Nanny’s is it? She always tries to do fun things with you.

LITTLE BOY Stay home Mummy...please, please, stay home this time!

(The baby releases the breast and starts to cry)

MOTHER I said I’d try hun, now be a good boy and go get Bubby’s snuggly for me. It’s in her cot.

(The little boy runs out of the room, the mother switches the baby to the other breast)

MOTHER I know Bubby, see if there’s any in that one.

(Lights fade)
ACT I, SCENE I: RECONCILING ROLES – THE PATIENT MOTHER

The women’s stories were marked by the conflict they felt between their ability to mother to their ideal standards and to answer the demands made upon them by their illness. Whereas the mothering role invariably represented self-sacrifice and putting the children’s needs first, the patient role (in terms of dealing with symptoms and adhering to treatments) required the woman’s health needs to be met as a priority. This first scene examines treatment decisions women made while attempting to reconcile these disparate roles.

Although the stories are retrospective, with some occurring fifty years ago or more, in each case the diagnosis of illness or the injury occurred during the woman’s childbearing years. In nineteen of the stories the diagnosis was made just before, during, or just after a pregnancy. This caused internal conflict for several women who had to make difficult decisions either about falling pregnant or remaining pregnant, while considering their own health, the desires of their partners, and any possible teratogenic threat from the illness or treatments.

In attempting to reconcile their desire to become mothers with their illness, several of the women sought to resolve conflict by privileging one role over the other. Choosing motherhood over treatment, they opted to discontinue taking their medications during conception and pregnancy, in order to avoid damage to the unborn baby. However, this left these women vulnerable to the symptoms of the illness for the duration of the pregnancy. Unity, who had schizophrenia, very deliberately set out to become a mother, discontinuing her anti-psychotics to protect the conception and prenatal development of her child.
Unity: When I was 32 I wanted desperately to get pregnant and have a child. I had been on medication but I took myself off medication to get pregnant. Now, I was not well mentally, because I was off my medication [...] I got pregnant, but I was mad, I was totally insane.

Whilst Unity was resolute in her desire to become a mother, others were not convinced that she could cope with the mothering role in light of her illness, and she had to defend her right to give birth in court. This was despite being willing to relinquish the baby after giving birth if the mothering role proved totally irreconcilable with her illness.

Unity: The psychiatrist who used to come around regularly noticed that I was insane. So I was hospitalised and that’s when they found out that I was three months pregnant. They decided that because I was not stabilised, they were going to take me to court [...] there was a lot of pressure for me to have this child terminated [...] But because I’m able to talk even when I’m psychotic - I was able to reason with them. I told them that if worse came to worst, that I would surrender the baby. That was my idea, but their idea was to not let me have her. That is court ordered abortion [...] I don’t know how they get around it [...] Even if a woman is, quite crazy at the time, like I was, how dare they!

Unity was able to remain pregnant, which she attributes to being articulate enough to argue her case despite her symptoms, a sympathetic judiciary member, and threatening to contact the media and the Right to Life Organisation[^2]. While Unity’s overwhelming desire to become a mother guided her choice to stop taking medication, others knew

[^2]: **Right to Life** is an Australian organisation that campaigns against abortion, infanticide, assisted suicide, euthanasia, mercy killing and the disposal of embryos created for invitro fertilisation.
that for their own health and wellbeing they would not be able to forego treatment. Tanya had two children when she was diagnosed with depression which evolved into pre-menstrual psychosis. Although her husband desired more children, Tanya was conflicted. Coming from a large family herself, she would have liked to accommodate his wishes, yet she knew that her illness was so debilitating there was no possible way she would be able to manage without medication. Not taking her medication would also have further impacted upon her ability to mother the two children she already had. So in order to retain her existing capacity to mother her children, she had to remain compliant in the patient role, adhere to her treatment regime, and relinquish the idea of any more children.

Tanya:  *I would have had to withdraw from my medication and have none, to be able to go through with nine months of baby. However, I knew deep down I would have no chance of getting through that time without it. I knew by the time I had my son there was no way I could go off my medication because if I missed a day, I’d be shot. I’m a wreck. That’s how bad I am.*

Although having a stoma [as a consequence of ulcerative colitis] made Rachael self-conscious and caused her to withdraw from her social networks, she postponed an operation to have the stoma reversed and her bowel re-joined, as she was worried about how the operation may impact upon her ability to conceive.

Rachael:  *I was told there was a risk of not being able to have children after the second operation to perform the pouch, so we decided to put it off until after.*
However, in addition to decisions regarding timing of a pregnancy and treatment, Rachael was also faced with fertility issues. Her inability to conceive naturally resulted in further medical intervention and the threat of having to make morally fraught decisions regarding selective termination.

Rachael: With a bit of help from a drug to produce eggs, which I over reacted to. My only chance at this stage without IVF [unaffordable] was to get pregnant coming off it. And I could not conceive more than one baby or it would have to be terminated as I wouldn't have been able to carry more than one.

Where women knew they were pregnant, they attempted to protect the development of their unborn child to the best of their ability. However, women were not always aware that they had conceived, which meant that a baby could have been unwittingly exposed to treatments and medications. Alice was hospitalised with pulmonary fibrosis, on a transplant waiting list, and not expected to survive to see the New Year when it was discovered that she was pregnant. Facing death for herself, but with new life inside of her, Alice experienced profound conflict. She originally considered termination, but abandoned the idea when she realised she was already halfway through the pregnancy.

Alice: I was expecting to be only about 4-8 weeks, so an abortion was definitely on my mind. When we found out I was 20 weeks this changed things considerably. It felt like hell, I was in a panic at first. The more I thought about it [being pregnant and not expected to live] the scarier it was.
After being treated with an experimental drug, Alice survived without receiving a heart and lung transplant. However, she later wondered if the treatments she underwent while pregnant contributed to her child having autism.

Alice: *I spent some time early in the pregnancy in hospital not knowing I was pregnant and it makes me cringe as to the amount of x-rays etc I had during that time and I often wonder if that is what caused my baby girl to have problems later.*

The women carefully weighed and balanced treatment decisions so that they could manage their illness with minimal disruption to the mothering role, and with the child’s safety as a priority. Despite this, children were often still in danger of harm which resulted in maternal guilt. Yasmin had originally delayed pregnancy as she wanted to avoid potentially teratogenic effects that could have resulted from her need for analgesia required for a severe back injury. However, having found what she considered a fairly safe alternative in the form of epidurals, Yasmin could not have anticipated all the possible threats and her unborn child was still at risk.

Yasmin: *I could read the automated BP machine in recovery and my BP was really low and they wouldn't let me lie on my side so baby could get better blood supply. For over half an hour the nurses did nothing, wouldn’t get my Dr until I made a fuss, then I got some IV meds to bring up my BP. My baby stopped moving during this and I did not feel her move for three days. My obstetrician reassuringly let me listen to her heart beat, but no one could tell me she did not get hypoxic. The remaining few weeks were full of guilt that I had not protected my unborn babe.*
Despite maintaining her blood pressure within safe limits clearly being the responsibility of the treating team, as a mother, Yasmin still held herself responsible. Motherhood was such a powerful motivator that despite the potential for guilt, some women were willing to risk a child’s health to enter the role. Where women had no choice but to continue to take medication during pregnancy, they had to weigh the odds of their developing child being negatively affected.

While on medication to prevent seizures Isabella became pregnant. Due to hormonal changes and the increase in blood volume that occurs during pregnancy, what had been a previously stable dose now required frequent monitoring and titrating to ensure that therapeutic serum levels were maintained. The drugs in question were known to be teratogenic. However, if Isabella ceased taking the drugs the unborn baby was also at risk of hypoxic injury if she had a prolonged seizure. Isabella lived in fear throughout her pregnancy that the anti-seizure medication could affect her developing child. While she made every attempt to counteract the effect of the drugs, the worry that Isabella endured impacted upon her subsequent fertility choices. In pursuing motherhood, Isabella felt like she had gambled on her son’s health and won, and she refused to tempt fate a second time.

Isabella: *It was worse because two of the meds could cause birth defects, but those effects can be counteracted with high doses of folic acid so I took that, and luckily it all worked out. I did worry about the meds, a lot, and that is part of the reason we decided not to have any more kids [...] I wanted him to have a sibling, but I didn’t want to risk it. I felt selfish in risking it the first time.*
The mothering role was difficult to reconcile with the patient role, as women privileged the mothering role, attempting to put their children’s needs and safety before their own. Where possible they resisted succumbing to illness, tailoring medication and treatment decisions to better accommodate their mothering. Cate discussed increasing her own steroid medication and switching to a clear fluid diet to avoid being admitted to hospital for Crohn’s disease, as her absence distressed her son so much. Pearl had herself prematurely discharged from hospital the day after a surgical procedure, as she was breastfeeding an infant, had a toddler at home with chicken pox and little support apart from her husband. Despite being ill enough with postnatal depression to be hospitalised, Alice’s first thoughts were for the safety of her daughter, and her inability to protect her in a strange environment. This caused her to refuse admission to the mother and baby unit of a private hospital.

Alice:  *On the day I went there, it was very dark inside. Being a psychiatric hospital I did not feel safe as the maternity section was just another ward where any patient could just enter [...] It was really scary. I feared more for my baby’s safety. I did not feel as if I was in the right state of mind to be responsible for her in that environment. So we went home instead.*

Both Quin and Olivia also resisted hospitalisation on the grounds of their maternal responsibilities, and in both cases they were convinced to stay by doctors appealing to them as responsible mothers in order to convince them to accept treatment. Olivia’s son was two when she had a recurrence of childhood tuberculosis which resulted in eight months of isolation in a sanatorium and a lobectomy.
Olivia: So I went before the board of doctors and I said ‘Look here, I’m not having this, because I’ve got a son to get back to and I just need you to give me something to fix me’ [...] And he said ‘That’s a bit sad, because if you don’t have this operation, he may not have a mother.’

Like Cate, Pearl, Quin and Olivia, Lilly also resisted hospitalisation so that she could continue to care for her children: I would be very, very unwell when I went in because I would try to hang on and not go there. Being a typical mother I would try to pretend that everything was fine both before and after admission. ‘Hanging on’, however, sometimes left Lilly and her children vulnerable to the manifestations of her mental illness. Lilly had taken her two young daughters on holiday when she began to experience suicidal and homicidal thoughts. While she did seek help, she was unwilling to follow certain avenues for fear of losing custody of her children.

Lilly: I could envisage taking the children down to the swimming pool one at a time and drowning them and [...] then drowning myself. So that was very scary because I was a long way from help. I was alone with the kids, but I did speak to a friend who is a very senior nurse therapist [...] She contacted me with resources for help, but I didn’t contact them because I thought they would take the children away. So I rang my psychiatrist who increased my anti-depressant [over the telephone].

Sometimes illness and medication also interfered with a woman’s ability or choice to breastfeed her baby. It was obvious that the public promotion of breastfeeding has had some success, with women assimilating breastfeeding into their view of what a ‘good’ mother does for her child. This made some of the women feel inferior as mothers if they could not breastfeed their child. Olivia, who against medical advice had conceived and
bore her son, was given instructions not to breastfeed him. While her desire to have a child made her disregard medical advice, the innate desire to keep that child safe meant that she was compliant regarding his feeding. This made her feel flawed as a mother, despite the fact that she was protecting her child from possible harm.

Olivia: Because I’d had TB I wasn’t allowed to breastfeed him. [...] So again, I felt very inadequate. And I thought, my God, nothing is ever right with me! Everything to do with having a baby, which I thought was a simple sort of thing, well it was all wrong.

In some cases it was not the risk of harm to the child that prevented breastfeeding, but rather the effects of the illness impacting on the milk supply. Not producing sufficient milk also left some of the women feeling deficient and lacking as mothers.

Jayne: I lost my breast milk supply in the meantime. That was so, so, so hard, realizing that I wasn’t going to be able to nurse my son any longer and I was going to have to rely on formula. I felt like I’d failed him, failed to be able to produce the ‘perfect’ food, etc. My poor body just couldn’t keep up with breast milk production because I was losing so much from the diarrhoea.

Unlike Jayne, Isabella was not particularly disturbed that she could not breastfeed, yet she felt judged by others. It is noteworthy that Isabella stated strangers felt they had the right to comment on how she fed her child with no knowledge of the circumstances. Although Isabella understood that she had no choice in the matter, her perception of herself as a mother still suffered.

Isabella: Because of the meds, I wasn’t able to breast feed, so that was something that I didn’t get to do. I didn’t mind not being able to breastfeed, I didn’t
get much milk in so may not have been able to anyway. What did bother me was people constantly judging me because I wasn’t breastfeeding. Just random people would say oh it’s so much better for the baby, and it’s pushed so much on TV, that it made me feel like a bad mother that I didn’t.

The decision whether or not to breastfeed was made more difficult when health professionals could not agree whether it was safe for the child or not. Professional disagreement regarding the toxicity of their breast milk meant the women had to make decisions about their child’s welfare based on conflicting medical advice.

Alice: My friends would always say how my baby was such a content baby, but deep down I put that down to the depression drugs she must have been getting through the breast milk. Different doctors had different opinions and that made it very difficult.

CODA

The theatre is portrayed symbolically by the twin masks of the smiling muse Thalia and the weeping muse Melpomene. Similarly, the women in this study attempted to find pleasure in motherhood despite the tragedy of illness. Being pregnant while ill overshadowed what is normally a time of joy with fear and concern for the baby. Several women had to make difficult choices regarding treatment, foregoing medications and threatening their own health to protect the unborn child, or continuing with medications and gambling upon the baby’s health in order to achieve motherhood. The tension that resulted from attempting to reconcile treatment for illness and motherhood caused several women to abandon the idea of future pregnancies.
Although some women still breastfed while using medications, they were generally guided by doctors and specialists about whether this was safe or not. However, making decisions about what was best for their child was sometimes difficult due to conflicting medical advice. If they withheld breast milk for the child’s safety, or were not able to breastfeed due to the illness, some of the women felt like they had failed or were not ‘good’ mothers. These negative feelings were further compounded by the judgement of others.

The women often resisted the sick role and privileged mothering over their own health. They tailored treatments, avoided hospitalisation, and discharged themselves early in order to continue, or resume caring for their children. For these women, occupying the dual roles of patient and mother had consequences for length of hospital stay, compliance to treatment, drug regimes, timing of procedures and their emotional engagement with the mothering role.
Script. Act I, Scene II: The show must go on – The relentless responsibility of mothering

Setting
A kitchen in a suburban house. A man is making sandwiches. A woman is sitting on a stool at the sink washing up dishes.

Character Dialogue and Stage Direction
MOTHER You’ll have to toast it. He likes the cheese melted.

FATHER But it’s fresh bread! Let’s just try him. I’m sure he’ll like it.

(He exits stage right with one of the sandwiches on a plate. Voices can be heard onstage)

LITTLE BOY But it’s not melted Daddy. Mummy always melts it and makes the bread to toast.

FATHER Just try it mate, the bread’s nice and soft.

(The man enters stage right with the sandwich on a plate, he rolls his eyes at the woman)

MOTHER Told you so.

(She smiles wanly at the man, who takes a sandwich press from a lower cupboard and plugs it in)

FATHER How’s the pain? Do you think it’s getting any better? I’ve got that job on tomorrow and we need the money this week.

MOTHER I think it’s a bit better. Hopefully it will settle. I tell you, I’m struggling though. I barely got them dressed this morning. I considered just making it a pyjama day... for all of us. It would have cut down on the washing too, the laundry’s a mess. I can’t deal with this much longer, we’re living in squalor. And the poor kids, I’m just going through the motions.

FATHER Don’t worry about the house hun; I’ll help on the weekend.

MOTHER I know, but I feel bad. You’re working and helping me with everything. He got really upset today when he thought I was going in. It took everything I had to pretend I was okay. If I do go in you’ll have to take him to your mum’s.

FATHER Can you pack his bag in case? Last time I packed the wrong shoes and all hell broke loose.

MOTHER I know, doesn’t matter how hot it is, he still wants to wear his Batman sneakers.

(Climbing gingerly down from her stool the woman exits stage right. Lights fade)
ACT I, SCENE II: THE SHOW MUST GO ON – THE RELENTLESS RESPONSIBILITY OF MOTHERING

The commitment to the mothering role was exemplified in Scene I through the women privileging mothering over their own health needs. Scene II: The show must go on, further demonstrates this commitment, and illustrates the daily struggle of continuing to care despite debilitating illness. Women in this study considered themselves irreplaceable to their children, believing that as mothers they bought something unique to parenting. Indeed, even though they were ill, it still fell to the women to comfort others and help the entire family to cope with the diagnosis. Although the majority of women in this study were partnered, they still considered themselves the primary carer of the children, and assumed the bulk of responsibility for physical and emotional childcare. There was also evidence that they were still regarded as primarily responsible for the care of the children by other people.

The majority of women in this study included housework and cooking in their descriptions of mothering, implying that they viewed domestic chores as a part of the physical enactment of the mothering role. As maintaining a certain standard of housework and cooking was considered to be a part of their responsibility to their children, the women were distressed if they felt their house was not clean, or the meals they produced were substandard. This was an added stressor for the women, as it meant that they placed very high demands upon themselves, and they were upset when they did not meet their own expectations. Coping with the relentless responsibility of mothering, housework, and their illness, left many of the women in this study grieving that at times they were not able to enjoy the mothering role.
Even during the diagnosis and treatment of their illnesses, the women did not willingly relinquish their primary carer role. Instead they struggled on regardless, believing that ‘the show must go on’. However, as Alice discovered while she was being treated for a brain tumour, sometimes they simply could not physically meet the demands that motherhood placed upon them.

Alice: *Stupidly I opted to have the chemo and radiation together, kept working and looking after the kids. Unfortunately I collapsed in the car park one afternoon with my kids and was rushed to hospital to have a full blood transfusion. I really thought I was strong enough to do it all.*

Unity, too, struggled on in the mothering role, believing that the severe and debilitating fatigue she was experiencing was related to the medications she was on to treat schizophrenia and epilepsy. She made the care of her small daughter a priority, until physically she could not carry on anymore. Even then, barely conscious, she would listen to her little girl playing in an effort to provide parental supervision.

Unity: *But I tried so, so, so hard. I tried so hard. Whenever I could spend five minutes, 20 minutes, a half an hour - anything - I would. I made sure she ate; I made sure she was washed and I made sure she was dressed. Before the last couple of months, when it was just beyond my ability, then I would sit there and mind her with my head down.*

Unbeknown to Unity at the time, her condition was not caused by her psychiatric and neurological medications but by an undetected and untreated thyroid condition. One of the reasons that her condition remained undiscovered for so long was that in an effort to retain custody of her daughter, Unity was drinking copious amounts of coffee in order
to appear alert to the social worker and doctor who visited her once a week. Her quest to appear responsible nearly cost her life.

Unity:  So I spent a year and a half with my thyroid packing up and then the doctor finding me, one day, nearly dead [...] I was doing what I should do, as much as possible, but I wasn’t enjoying it [...] but at the same time I also loved my daughter, so it was all very confusing. I did a lot of things, just simply by automatic behaviour.

Illness sometimes decreased the pleasure that could be derived from mothering, reducing it to duty and responsibility. Like Unity, several other women in this study described going through the motions of physically caring for their children while failing to find any pleasure in them. Although they were physically present and performing the chores of mothering, they were emotionally absent and disengaged.

Although her family were willing to care for her children when she was hospitalised, Karina, who had experienced bouts of major depression for much of her life, had difficulty obtaining practical support with the care of her children when she was at home. Her husband was often absent due to his profession, and her family struggled with an understanding of psychiatric illness and believed her to be attention seeking. This misconception left her very ill and isolated, yet still responsible for the full care of three small children. Struggling to mother them, Karina sought to protect them from her illness by ‘acting’ love.

Karina:  And I had no emotional connection with the children, because I was dead. The only feeling I had was overwhelming sadness. I would pretend. I would bath them and do their hair and do what I knew I had to do, in the most
loving manner, hoping that they didn’t pick up that I couldn’t feel anything

[...] And the times I’m remembering the most were when I was on my own. I
had no pleasure in life; there was nothing that gave me pleasure, even my
own beautiful children.

Where Karina found no pleasure in mothering as a consequence of endogenous
depression, Alice thought that emotionally withdrawing might be a protective strategy.
Despite still assuming the majority of childcare and housework, Alice found herself
removing herself emotionally, disengaging from her children to protect them, so that in
the event of her death there would be less of a sense of loss for them.

Alice: When I am home I find it very hard to enjoy being with my kids. I don’t know
why this is and I am embarrassed to even say it. I love my kids very much
and tell them all the time but the simple task of sitting down and playing with
them I find extremely difficult. It is almost like I need to keep some distance
maybe to make it easier when I may no longer be there.

In several of the stories women discussed still being responsible for the organisation
and running of the household, even where they were physically unable to carry out
much of the actual work. Even when she was separated from her children and the
family home through hospitalisation, Alice felt responsible for organising everyone.
Her husband and mother’s dependence on her was sometimes frustrating when she was
lying in a hospital bed.

Alice: I hate being away from my kids [when in hospital]. They are my world. I
have to let my Mum and husband take over. They don’t know where anything
is and that drives me crazy. It feels like parenting via telephone.
Often mothers considered their intimate knowledge of their children made them irreplaceable. Veronica stated that while her husband was very supportive, and had assumed much of the care of their children, she had a better understanding of the children’s needs and wants and had to provide him with direction.

Veronica:  *I know where everything is so I have to; you know I might get everything out and say this is what he’s going to need. If he has to make lunch or whatever, I tell him well give him this because this is what he likes but don’t give him that.*

Maggie stressed how important it was to her that her children were self-sufficient, stating: *I was determined to make mine independent [...] Giving them a gift*. Yet despite Maggie framing independence as a gift, there were multiple references to herself as pivotal to the smooth running of the household in her story.

Maggie:  *But the kids suffered. They went a bit feral. There wasn’t the regularity at home, everything was in disarray. Everyone helped as best they could but it still wasn’t right. My son put on a get well card “Things weren’t the same without you”. Well they couldn’t be, the central person is Mum.*

Maggie seeing herself as accountable for the children was evident in the responsibility she assumed for her daughter struggling with literacy. It also indicated that other adults saw her as primarily responsible for the children despite her illness. In the following passage of text she blames herself for not drawing attention to the fact that she could not assist her daughter with reading due to losing her sight; however, there is no mention of the fact that there were two other adults in the house (Maggie’s husband and brother) who could have assumed this task.
Maggie:  *I did try to help by listening to her reading the readers that came home* [...]  
*And then I went blind as a side effect of the steroids and I got cataracts. Really nasty ones so I couldn’t continue that. This is how stupid I was. I should have let the teacher know that I had gone blind and she [daughter] wasn’t getting the support at home with the reading. I mean it was so obvious; I genuinely kick myself over that one. Because they have mothers who go up to the school to help with reading, or the bigger kids.*

Despite being described by her doctor as ‘Crohn’s crippled’, Dee had no doubt that her husband considered her fully responsible for their children.

Dee:  *My husband was not good at handling my illness, he still expected me to be able to do it all even when I would just get out of hospital* [...]  
*I was married to a man that seemed to think since we had daughters it was my job to do everything with them and whenever I was really ill he would take off to play his lawn bowls or fix a mate’s car and leave me to take our daughters to their dancing lessons, swimming lessons, volleyball and so much more.*

Even where partners were supportive, they were considered ‘helpers’ and not expected by the women to assume the full care of the children. Xanthia spent years dealing with the symptoms of hyperparathyroidism that was not properly diagnosed until her youngest child was four years old.

Xanthia:  *It was just so much effort to make even the bed. When the girls awoke, I had to push all feelings aside and push myself to get them going, make the beds, make their breakfasts and lunches, oversee them getting dressed and ready, before doing those same things for myself. It was*
a struggle but I pushed myself. I didn't have time to wallow or be idle and self-indulgent [...] My husband would help as much as he could and as my condition went on, he helped more and more with everything.

As well as providing the majority of physical care, women were also largely responsible for relaying their diagnoses to their children, and helping them cope emotionally. This included comforting and reassuring children as well as dealing with the consequential behavioural issues that some of them experienced. Winter, who underwent a mastectomy, chemotherapy and radiation for breast cancer, discovered that her teenage son had started smoking marijuana. It was left to her to counsel him, reassure him regarding her illness, and keep watch over him for further evidence of drug use.

Winter: He told me that he started using about 1 month after my diagnosis. That he needed something to help him cope. He said that he was feeling out of control, angry a lot and smoking calmed him down. He also said that he was glad that I had found out, because he wanted help in stopping. He did not know how to tell me, and he did not want to give me extra stress [...] He was also aware that I had to tell his dad. My husband just called him a “dickhead” and that was the end of the subject.

Even though it was Winter who had to deal with the illness and treatment firsthand, she felt responsible for helping the entire immediate family cope with the stress of her diagnosis.

Winter: All of the kids and my husband say that the reason that my diagnosis has not affected them as badly as they thought was due to me. That as I was OK with everything, that I still yelled at them, that I still had my warped sense of
humour. So after going through all this it is my firm belief that yes my family look to me to hold everything together. They take their lead from me.

CODA

The production revolved around the performance of the leading actors. Even when they were offstage, they prompted the lines and action. As mothers they felt that they were irreplaceable, fundamental to their children’s wellbeing and the smooth running of their households. They assumed, and believed it was assumed by several of their partners, that despite the sometimes debilitating symptoms of illness they were coping with, the children’s physical and emotional wellbeing remained their responsibility. Even where women were physically incapable, or separated by hospitalisation, they were still called upon to provide direct care. While the women in this study strove to meet their perceived responsibilities, they sometimes struggled to be emotionally present and mothering could be a joyless and exhausting activity.

Setting

A lounge room in a suburban house. The room is messy, littered with toys. A young woman reclines on the couch; a baby asleep on her chest. A young boy is driving trucks up and down her legs.

Character Dialogue and Stage Direction

LITTLE BOY Can we go to the park Mummy and play on the swings?

MOTHER I wish we could mate, but Mummy feels too yuck to go out. How bout we watch Finding Nemo again? You love Dory.

LITTLE BOY Come on Mummy… you said that we could go to the park if it was sunny today and it’s sunny allllll dayyyyy.

(Whining loudly)

MOTHER Give me a break kid. I feel sick. I said NO!

(There is silence for a little while; the little boy sullenly driving his trucks along his mother’s shins)

MOTHER I’m sorry Mate. I know I’m a crap Mum. How bout I read to you for a while?

LITTLE BOY Will you read me the Dr Seuss? Can I have two of them?

MOTHER You can have as many till the Bubby wakes up.

(The little boy runs off returning with an armful of books. He hands one to the woman, puts the rest on the coffee table amidst toys and the dirty plates from his lunch, pulls a small plastic chair next to her and sits down. The woman opens the book above the sleeping baby and begins to read)

MOTHER I am Sam...Sam I am...That Sam I am...That Sam I am...I do not like that Sam I am. Do you like green eggs and ham?

LITTLE BOY Am Sam… am Sam … That Sam I am … I am … don’t like

Sam I am … DO YOU LIKE GREEN EGGS AND HAM!

(Light fades)
The women in this study strove to fulfil the mothering role in any way they could despite illness, injury or separation. Due to illness or injury many of the women found that they could not participate in many of what they considered to be ‘normal’ mother-child activities, especially those of a physical nature. Missing out on activities with their children left some of the women feeling flawed and envious of well mothers and their abilities. Phrases like ‘the mother I wanted to be’, ‘the mother I should have been’, and ‘the mother I could have been’ occurred frequently in their stories.

The women discussed missing experiences, opportunities, and potential memories with their children through separation, hospitalisation, or as a consequence of limited physical or emotional ability or reserves. Where they were restricted in activities they could undertake with their children they still strove to be the best mothers they could be, and substituted other (generally more sedentary) activities. Yasmin, who had a severe work-acquired back injury, was limited in the types of activities she could undertake with her daughter, yet she actively sought out pastimes that they could share.

Yasmin: While I found swimming worsened my pain with turning to breathe, once she learnt how to snorkel, we did that together as I did not have to turn my head [...] I also found a bike design that worked for my back, it has great shock absorbing qualities - we could then ride to school [...] I tended to do quieter things with her like painting, crafts, cooking, reading, drawing, looking at plants in gardens, taking her to parks where she could play, and of course play time with other kids [...] If I had had an energetic boy, life would have been terrible for him.
Yet despite pursuing every activity that she could possibly engage in with her child, Yasmin still perceived herself as an inadequate mother, dwelling upon the things she could not do.

Yasmin: *The feelings of inadequacy that I couldn't run with her, roller blade with her, I couldn't be bothered cooking healthy meals every night. I felt that I was failing her as a mum on so many levels and with so many things. Picking her up sometimes was impossible.*

Isabella was also limited physically by her illness in her interactions with her child and her ability to amuse him. She was resentful that her illness had denied her sharing more experiences with her child, especially those ‘firsts’ that could not be recaptured.

Isabella: *I couldn’t even take him outside to play sometimes, and I felt like he should get to do that. There were times that I couldn’t even get out of bed and he would just play on the floor. The first time he went to the beach and actually played in the water, I was in the beach house sick. I missed a lot of stuff with him, because I was too sick.*

Cate also had many regrets regarding the limitations placed on her mothering by her illness. As she was in remission from her disease for approximately five years when her eldest two daughters were small, she also regretted what she perceived as an unfair distribution of her mothering amongst her children.

Cate: *For my older two children I have been there for all their milestones – graduations, award ceremonies, sporting achievements etc. My younger children have seen me miss events such as carnivals and assemblies.*
Several of the women in this study judged themselves harshly comparing their own mothering capabilities with that of ‘normal’ mothers. Cate’s view of what mothering is, and should be, was affected by her being ill, with the limitations placed upon her making her rationalise and measure the way she mothered her children.

Cate:  *I would just like to add that I live with guilt every day of my life, because I think that being chronically ill has made me less of a mother and I envy those mothers that are able to do the things with their children that I am unable to. I think that my being sick puts a lot of pressure on me to act normal and wanting to do the things that I think mothers should do with their children […] If I was asked what I feel was the most affecting thing in mothering with illness, I would have to say being unable to be an active mother, physical play, such as kicking or throwing a ball.*

Like many of the women in this study, Cate spent a lot of time with her children engaged in more sedentary activities. What is notable is that the alternative activities they engaged in were nearly always educational and this was of benefit to the children: *My children are all good readers as reading to them and listening to them read to me was sometimes the only thing I could manage to do with them* (Cate). Despite stating that she felt she had met her child’s needs, Isabella also compared herself unfavourably to other mothers. However, she recognised the educational benefits that could be found in more sedentary activities.

Isabella:  *I still managed to stay up all night if he needed me, and to manage to do whatever he needed, it was just so tiring; it was so hard for me. And I*
know it was hard for him [...] I think me being sick gave me more time to work with him on things. We spent hours and hours on letters and colours and all that good stuff. If I had been well we probably would have gone and done more things and not concentrated on that so much.

While Unity thought that her child might be missing out on some experiences, she comforted herself that reading to her little girl fulfilled her mothering obligations to a certain extent.

Unity: \textit{I read to her, and I read to her, and I read to her [...] until she wouldn’t let me read to her any more, when she was eleven or twelve. But it was the best – it was the only thing I could do. So I did it and I thought, okay, I'm not giving this kid enough going out experiences, but she is getting something from me.}

Being ill sometimes resulted in women being confined not only in their homes, but also to their beds or bathrooms. This caused issues with their ability to supervise small children who for their own safety also had to be kept close so that their mother could watch them. Although Isabella’s illness was dormant during her pregnancy, it returned immediately following the birth of her son. She spent a lot of time sitting on the toilet due to the nature of her illness. Often alone in the house, she had no choice but to keep her baby with her in the bathroom where she could watch him.

Isabella: \textit{He really didn’t mind being in the bathroom, he had a bunch of toys in there, and some of those crayons for the shower (that are supposed to wash off, but don’t!) and he coloured all over my shower! I tried washing it off after I was better, but decided to leave it so if I got}
depressed about having an ileo, I could look at that and remember why I did it.

Isabella was not the only woman to spend time in the bathroom with her child; both Jane’s and Veronica’s illnesses meant their children were also mothered in the bathroom some of the time: *Heck, I had to keep a towel on the bathroom floor to lay him on when I had to use the bathroom when my husband was at work* (Jane).

Veronica: *We did a lot of reading, a lot of drawing and like play dough sort of stuff. We did do a lot of indoor stuff [...] I wasn’t confident going out with him on my own. I think that was the main reason because I was worried that if I had to go to the toilet... If we did at times have to go out on our own and I did have to go to the toilet he’d just sit in the cubicle with me and just chat.*

As a consequence of inflamed joints from lupus, Maggie sometimes found it difficult to get out of bed. This meant she had to find ways to amuse her daughter within the confines of her bedroom.

Maggie: *And my daughter who was two or three, she’d get this cream and massage my leg to help Mummy. What she was really doing was playing with the cream* [laughs], *finger painting Mummy. I wanted her where I could see her, and she was happy to massage Mummy’s leg to make her better.*

While commonly the women in this study recounted difficulties caring for their children secondary to their illness, for several women it was not the illness that made it difficult to care, but the fact that they were physically absent from their child. Separated by
hospitalisation or custody issues secondary to mental illness, these women maintained contact with their children in any way they could. Lilly was frequently hospitalised to treat bipolar disorder when her children were small. Although the children were brought to visit twice a week, it was vitally important to her that she maintained some type of daily contact.

Lilly: *As far as the mothering is concerned throughout all of those hospitalisations when they were little, there must have been ten occasions at least. I would write them a little letter each, each day, and on different pretty papers and with pretty stickers told them what I’d had to eat. They used to love knowing what I had had to eat. And I would speak to them every day on the phone.*

It was also very important to Lilly that as much as possible her children had a normal childhood, despite the frequent absence of their mother. In an attempt to convey maternal presence and create childhood memories, despite being confined to the hospital, Lilly still managed to celebrate one of her little girl’s birthday within the facility.

Lilly: *On one occasion when they were little, one of them had a birthday coming up and one of the patients got permission to use the craft room which was normally locked at the weekend. So we painted all sorts of pieces of paper and made them into cones for their dollies at the party and they loved that.*
However, when she was very unwell and her children were visiting, it was sometimes beyond Lilly’s capability to play with her children. For her, mothering was then enacted by closeness and spending quiet time together.

**Lilly:** *A friend’s husband had a TV and radio business, and she bought me in a telly that would take a video and so when they came in at weekends we would all lie on the bed together and have a cuddle and watch a video. And that was helpful for me because often when they’d been to visit I was absolutely drained, it meant I didn’t have to talk as much to entertain them, but could still be close.*

Lilly had frequent contact with her children even when she was hospitalised; however, Samantha, who was diagnosed with schizophrenia, had very infrequent contact with her two sons. As the boys were in her mother’s custody, and living in another state, Samantha was not only separated physically from her children by distance, but legally by court orders. Her only recourse was to try and stay in touch by telephone, to remind her children daily that she was their mother and that she loved them. However, even this tenuous contact was threatened by further restrictions.

**Samantha:** *I have no idea what Mum tells the boys about me. I don’t even think they talk about me. I have made it my passion in life to ring the boys virtually every day. I get a $29 cap, which is $150 worth of calls, and I just spend all that on talking to the boys. I talk to them as often as I can. My mother and the DHS have been trying to restrict that to only Wednesdays and Sundays and only between six and eight.*
Samantha was very aware that she was missing seeing her boys grow, and attempted to capture some of their childhood in photographs by providing them with a camera. However, this still resulted in only occasional glimpses of her children.

Samantha: To put it bluntly, I’m numb 90 per cent of the time and I am missing the boys dreadfully […] I’ve missed so much, especially with my mother. She doesn’t record anything. She doesn’t keep us in the loop, nothing. We gave them a camera for Christmas. On the email that my younger son sent, he sent a photo of himself. Every now and then I might see something.

Where the women felt inadequate about one aspect of mothering, overcompensating in other ways was commonly discussed. As Cate wrote: I think I over compensate when I feel well and overdo things with them. Once when Samantha’s children were allowed a brief visit, Samantha and her husband bought them a motorbike, despite not having very much money.

Samantha: We actually went out and bought them a motorbike. Just for the access visit […] Everyone took their trail bikes and even my step son; he came out with all of his mates and all their bikes. They all went riding together and had a great time. We try to give them something cool to do with us.

Heather recognised that in her manic periods she attempted to compensate for the times she was depressed and unresponsive to her young son by being ‘super mum’. However, she also realised that this confused him, and it was a consequence of her illness. Heather also mourned the loss of what might have been.
Heather:  *When I’m manic if I’m not too ‘high’ I am super mom, amazing home-cooked meals twice a day, playing with my son on his level, teaching him to play violin, working on preschool worksheets and flashcards, getting messy with paints and crafts. But I quickly can get too "high" and be irritable, yelling at him; very impatient […] I’ll drag him around shopping with no regard for his nap or meals. Thankfully, I am not manic very often. But at the same, time, he misses out on the mom that I should be, that I would be without this disease.*

Unity also compensated for perceived failures as a mother. While she had found it very difficult to mother her daughter when she was small due to an undiagnosed thyroid disease (which was in addition to pre-existing schizophrenia and epilepsy), Unity revelled in her ability to indulge her child once the thyroid condition was treated and her energy levels increased.

Unity:  *She knew I loved her, and she knows now I love her […] she’s always known. When I started getting better - if she didn’t like something I’d made, I’d go and make something else. My brother complained that I was at the stove from five o’clock to nine o’clock and he couldn’t get there because I’d be spoiling her, making her different things.*

**CODA**

When the normal script of motherhood was disrupted by illness, the women improvised, altering the activities they shared with their children to those that they could perform despite their illness. Women separated from their children attempted to continue mothering through maintaining daily contact. For those living with their children, it
often meant reading to them or engaging in other fairly sedentary activities that did not tax the mother too much and were educational for the children. Some of these activities occurred in the confined spaces of bedrooms and bathrooms as illness precluded the women from even moving throughout their own homes freely. Although these activities were of benefit to their children, the women felt that their ad-libbed performances of mothering were inadequate. This feeling of inadequacy was especially apparent when the women compared themselves to other apparently well mothers.

Despite doing all they could to entertain their children, the women were well aware that they and their children were being denied experiences. When they were able, the women attempted to compensate for their perceived shortcomings as mothers by doing extra things for their children. There was a pervasive sense of loss as the women mourned for the mothers they might have been, and the performance of motherhood they could have enacted.
ACT II – THE HEALTH CARE SUBPLOT

In the sick room, ten cents worth of human understanding equals ten dollars worth of medical science

(Fischer 1944)

INTRODUCTION

Exploring women’s experiences of physical or mental health care, ‘the health care subplot’ title continues to reflect upon the theatre as metaphor framework. Severe or chronic illness in Western countries invariably involves some form of medical intervention, and the majority of women in this study had at some time either been admitted to a general hospital or a mental health facility. All had received some form of treatment as an outpatient. ‘Act II - The health care subplot’ encompasses their experiences with health professionals, as well as the way being hospitalised affected their interactions with their children during the period of confinement.

For the women in this study, being hospitalised was a disruptive and often demoralising event. Several women with breastfed infants attempted to retain the care of their children by having them admitted into hospital with them. This resulted in clashes with nursing staff, who did not seem to understand that the breastfeeding woman considered herself irreplaceable to the child. When these women were unsuccessful in keeping their baby with them, issues emerged around maintaining a milk supply and contact with their child. The problems surrounding nurses facilitating early mothering in the acute care setting are elaborated upon under ‘Act II, Scene I: Reading different scripts – Nurses misunderstanding mothers.’
Being cast into the role of patient sometimes meant mothers were physically separated from their children, with the accompanying issues surrounding children visiting on medical, surgical, and psychiatric wards, arranging alternate care, and missing significant events and milestones. Being visited in hospital by their children could be as much a source of anguish as one of joy. As well as coping with the symptoms of the illness, and their own fears regarding their ill health, the women who were hospitalised worried for their children. It was often distressing for the children as well, which caused further worry and sadness for the women. ‘Act II, Scene II: The heartbreak scene – Mothering from hospital’, explores women’s experiences of being separated from their children through hospitalisation.

Although there were many negative experiences for women hospitalised for an acute illness or exacerbation, in the transcripts there were also stories of empathetic health professionals who provided the women with support and validation. In the main, these stories involved doctors and psychiatrists who had a long association with the women, who the women felt ‘knew’ them, and understood what was important in their lives and their domestic situations. These findings are discussed more fully in ‘Act II, Scene III: Receiving good direction – Health professionals supporting mothering.’
Script. Act II, Scene I: Reading different scripts – Nurses misunderstanding mothers

Setting

In a six bedded room in a hospital emergency ward. A woman is sitting in a hospital bed holding a baby and a phone. She looks pale and unwell. A small boy sits at her bedside. There is a harried looking nurse in scrubs, holding a clipboard standing at the end of the bed.

Character                       Dialogue and Stage Direction
NURSE                          Have you managed to get a hold of your husband yet?
MOTHER                         Yes, he’s on his way. He just stopped at home to pick some stuff up for me and the baby.
                                (Handing the phone to the nurse)
NURSE                          Great, has he got someone to help him with the kids?
MOTHER                         Well, my Mum can take my son while he’s at work. But I’m breastfeeding so I have to keep the baby with me.
                                (The mother rearranges the baby’s position, bringing her closer to her chest)
LITTLE BOY                     Awww not to Nanny’s house, can’t I stay too?
                                (The mother puts a finger to her lips, indicating that he should be quiet)
NURSE                          I don’t think that will be possible. We’re not set up here for babies to stay. I’ll have to speak to the Nursing Unit Manager.
                                (Frowning)
MOTHER                         But what if the baby were sick? She’d be staying then and so would I.
                                (Raising her voice)
NURSE                          Yes but then she’d be the patient. We can’t be liable for a baby who’s not a patient. I’ll talk to my NUM. I don’t want you to get your hopes up though.
                                (The nurse walks off briskly. The woman looks at the little boy and raises her eyebrows. He folds his arms and looks cranky. Lights fade)
ACT II, SCENE I: READING DIFFERENT SCRIPTS – NURSES

MISUNDERSTANDING MOTHERS

Mothering took on a new context when the woman was hospitalised for acute illness, and the transition from mother to patient was often abrupt and unexpected. In the hospital the focus was on the woman as a patient, and the treatment of her illness or injury. Women were expected to put their maternal responsibilities aside and co-operate with whatever treatments and medications were prescribed for them. However, the women in this study would not, and could not, simply relinquish their responsibility to their children. From the transcripts it became evident that within the hospital arena, a woman’s dual role of mother and patient was often misunderstood and not facilitated by nursing staff. This sometimes resulted in tension between the women and the nurses caring for them, as the women sought to reconcile their mothering responsibilities with their treatment.

Women who were breastfeeding when they were hospitalised were faced with the immediate dilemma of what to do with a dependent infant. An acute illness left no time for planning, for storing breast milk, or for coming to terms with the possibility of having to give a baby infant feeding formula. Pearl, who describes herself as a bit of a *nursing* Nazi insisted upon having her eight-week-old baby with her as a baby boarder, when she was admitted to hospital with pancreatitis from gallstones. However, she was acutely ill and totally responsible for the welfare of her baby, despite being hampered by intravenous lines and medical machinery, on strong painkillers, and with unstable blood sugar levels from the pancreatitis and not being permitted to eat. Although she

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3 In this context, when Pearl says ‘nursing’ she is referring to breastfeeding.
was allowed to keep her baby with her, she felt that the lack of support she received was almost punitive, and placed the baby at risk of harm.

Pearl:  
I got no help with the baby. I was nil by mouth for a week and I have these horrible memories of walking up and down the corridor dragging an Imed\(^4\), and a screaming eight week old [...] there are legal implications and the staff are told not to touch your baby, which was fine, she was my responsibility. But at one point I had a hypo and I could barely stay conscious. I had this baby screaming next to me and the staff wouldn’t touch her because she was a boarder, she was not the patient.

Although Pearl was successful in keeping her child with her during that admission, she felt she was fighting a constant battle with some of the nursing staff and ward management. The nursing staff failed to recognise that as a mother, it would be difficult to simply relinquish the care of a fully breastfed child. While Pearl was supported by her medical specialist to keep the baby with her, and keep breastfeeding, the nursing unit manager made it very clear to her that they would prefer the baby to go home with her husband. Pearl was also subject to individual nurses’ opinions regarding her infant feeding choices:

Pearl:  
I had a supportive specialist who was of the opinion there was more benefit to gain by her having the milk than there was risk of having the antibiotics. A lot of the nursing staff were very critical of me for continuing to feed with the massive antibiotics I was on. Some of them were very open about that.

\(^4\) An Imed is a pump used to deliver intravenous infusions.
Due to the difficulties that she had encountered boarding her baby, when Pearl was re-admitted to another hospital six weeks later for surgery, she allowed her husband to take the baby home. This admission was planned, so she was more prepared on this occasion.

Pearl:  *I was more comfortable with him [husband] going home with the baby after the surgery as I’d had six weeks trying to get a bit of a store up of milk. But with an acute attack, you don’t have that opportunity [...] she was a child that wouldn’t take formula. She was a child that didn’t like bottles. So even with breast milk, she wasn’t that keen. But she... You could spoon it into her.*

Zeta was also rushed to hospital unexpectedly with cholecystitis. Like Pearl, Zeta had a two-month-old baby who was fully breastfed, and she too sought to have her baby admitted with her. However, her request was denied and her husband and mother were left to cope with a baby that had never fed from a bottle before. Zeta was still emotionally distressed four years later when she recalled being separated from her child. Although she admitted that there were no long-term consequences for her relationship with her daughter, it was the loss of autonomy as a mother that upset her the most. She was disempowered in the mothering role and bewildered that others had the power to separate her from her dependent infant.

Zeta:  *But I did ask the nursing unit manager if I could have the baby in with me. Apparently there were lots of discussions... I’m not sure between whom. But it was decided that I was not able to have her [...] I feel a bit emotional thinking back to that, them not allowing me to have her! [...] The lack of control... you’re normally in charge of your own baby. You’re the parent.*
You’re the only one that can supposedly breastfeed her. Someone else can give her that milk but it’s not the same. That is part of your rights. You’re supposed to have and maintain that bond.

During her interview Zeta also expressed concern for the lack of any sort of psychosocial assessment of the home situation. She felt that the hospital made a superficial judgement call, believing that from their outward appearance, the family were equipped to cope with a fully breastfed newborn. Although the family did cope, Zeta was indignant that it was just expected that she would be willing to send her baby home with her husband, as this was the most convenient option for the hospital staff: What I’m trying to say, in a jumbled way is that the family looked all right so it was not their problem, send her home (Zeta).

The fact that she was a new mother was not really acknowledged. A nurse herself, Zeta was interested enough to acquire and read her own progress notes from the time she was hospitalised. She commented in the interview on the lack of documentation regarding her request to keep the baby with her, or that she was a breastfeeding mother attempting to maintain her milk supply. Zeta felt particularly abandoned by the hospital midwives, as despite the pressure women are put under to breastfeed in the acute antenatal period, there was no breastfeeding support available to new mothers when readmitted to other non-maternity wards. While one of the nurses did arrange the loan of a breast pump from the postnatal ward, she was provided with no education on how to use it. This implies that it is only in maternity and paediatric wards that women and babies are treated as a dyad and breastfeeding is actively encouraged.
When Eliza was taken to hospital with a severe deep vein thrombosis in her leg, there was discussion with hospital staff about admitting her with her breastfeeding infant into the maternity ward. However, once it was determined that there was no room in the maternity ward she was told the baby would have to go home. She was unaware of the hospital’s baby boarding policy and just accepted that her baby could not stay with her. She was then faced with choosing between treatments, both of which impacted upon her as a mother.

Eliza: I could have had one medication, that I injected myself, came home and been with the baby, but not breastfeed, or, stay in hospital, safely breastfeed, but not be with him. So that was a, very, teary, emotional experience.

Although she was admitted multiple times for day procedures, and did not stay overnight at the hospital, Yasmin also took her baby to hospital with her. Like Pearl, Yasmin had difficulties with some nursing staff imposing their own parenting values upon her, which she stated contributed to her developing a form of post-traumatic stress disorder.

Yasmin: I started to get physical symptoms at the thought of having to go to hospital, my heart would pound, sweaty palms and I just dreaded it wondering how bad would today be? In all I've had about 120 procedures.
In common with other women in this study Yasmin had no support other than her husband who also had health issues. She was also unwilling to be separated from her child, which again was supported by her treating doctor, but not by many of the nurses who cared for her. Like Pearl, Yasmin was also a nurse; however, the severity of her work-acquired back injury meant that she could not practise nursing.

Yasmin: *We have no family in the country and in all honesty I did not want to be away from my baby and insisted she stay with me. I don't think my Dr was brave enough to argue with a protective mum [...] some nurses though were absolute bitches. They imposed their parenting values on to me. I felt like imposing my nursing values on to them.*

Yasmin’s transcript contained numerous descriptions of nurses expressing judgement about her mothering choices. There were negative comments made to her regarding her bringing her baby to hospital with her, her decision not to use formal childcare, and her choice to continue breastfeeding. The criticism that concerned her the most, however, involved questioning either her choice to become a mother in the first place, or her ability to be a good mother to her child, given the nature of her injury.

Yasmin: *Another charming nurse hinted at notifying dept of human services saying I was not able to care for her [infant]. She said if you have this much pain that you need nerve blocks are you really able to look after your daughter properly, we have an obligation to report any child that is at risk. It was a very definite threat. I felt guilty that I had had her that maybe I wasn't good. I did not really resent her [infant], rather the nastiness from staff about having her. I don't think that type of conflict is helpful or healthy.*
It was not just ward or theatre nurses who were criticised by the women for misunderstanding their need to care for their children. Midwives were also felt to have failed to facilitate mothering. The disappointment in the care received from midwives was especially poignant given that midwifery as a profession generally espouses the importance of mother-child bonding and initiating and continuing breastfeeding.

Adelaide had a protracted and severe dural headache as a result of her dura mater\(^5\) being punctured during an epidural injection when she was in labour. To stand for any length of time was extremely painful and difficult. Her distress was compounded by the fact that her baby daughter was born with a heart defect and was in the neonatal intensive care ward, while she was admitted to the postnatal ward. Here she felt entirely ignored by the midwives. *And I hardly saw the midwives. It was like well, she doesn’t have her baby in there with her so she doesn’t need us* (Adelaide).

Already feeling distressed by the medical incident and subsequent severe headache, Adelaide spoke of numerous incidents where she was neglected by the staff. However, what really disturbed her was the lack of compassion she received as a new mother of a critically ill child. Due to the dural headache, Adelaide needed physical assistance to get to the neonatal unit. Her requests for help were not met by hospital staff, and family members were required to locate a wheelchair to assist her in visiting her child.

*Adelaide:* *I really didn’t get to see her [infant daughter] that much. I think I got to hold her maybe three times. And I was asking a midwife ‘can somebody take me down to see my baby’? And she said ‘we’re far too busy to be*

\(^5\) During epidural anaesthesia the dura mater is not meant to be pierced. The resulting headache is due to cerebrospinal fluid leaking from into the epidural space, which causes decreased hydrostatic pressure in the subarachnoid space and traction on the meninges.
doing that, we can’t leave the ward!’ So I said ‘well could you call an orderly?’ And she said, ‘we’ve only got one orderly for the whole hospital.’ It was just all too hard. So I thought ‘well stuff you!’ And I walked the length of the hospital [...] with a dural headache, because nobody would take me to see my baby.

At five days post-delivery, Adelaide’s baby was transferred to a larger paediatric hospital in another city to undergo heart surgery. Here she suffered a cardiac arrest and spent five days on a heart and lung bypass machine. The next time Adelaide got to hold her daughter was after she had been disconnected from life support and had passed away.

Adelaide: [Sobbing] I didn’t know... I just didn’t know that [...] I wouldn’t have that chance again. If I had known I would have just... I still feel bad about it because, I said to Mum ‘I should have held her more’ But Mum just looked at me and said ‘But you were so sick, I think you forget how sick you were!’

Like Zeta, Adelaide was disempowered by a system that did not recognise the importance of the mother-baby dyad. While other women who participated in this study were separated from their children for a short time and had an opportunity to mend any damage caused by the separation, Adelaide never had that chance. In addition to feeling badly let down by the midwives, Adelaide also held herself responsible for the lack of physical contact she shared with her daughter before her death.
Although this Scene contains predominantly negative depictions of interactions between women and nursing or midwifery staff it should be acknowledged that not all of the nurses discussed in women’s stories were portrayed in a negative light. For example Yasmin reported that the theatre charge nurse was lovely and when discussing midwives she said:

Yasmin: They are not controlling and overly opinionated. They seemed to be happy to accept you as a person rather than a condition or no.3 on the theatre list. They also loved that my baby was fully breast fed - scored points with them for that, and they seemed to value my desire to be with my baby and saw it as a positive, that I was a good mum who had bonded really well with her baby.

However, when nurses or midwives were deemed to be caring or compassionate it was rarely elaborated upon. What was remembered, discussed at length and deeply felt was when nurses or midwives were perceived to be callous or uncaring. This does not necessarily indicate that the majority of nursing care received by mothers hospitalised for illness was lacking compassion, but rather that women recalled times that they felt misunderstood or threatened as mothers much more readily than times they felt supported.
CODA

The women and nurses were reading scripts from different plays. In the women’s scripts, their babies were central to the storyline. However in the nurses’ scripts, the women were cast as patients, expected to follow directions and abandon other roles. Hospital-based nurses who cared for some of the women in this study failed to understand the importance that the women placed on their ability to continue to care for and breastfeed their infants, whom several of the women sought to have admitted into hospital with them. This was despite infant admission as baby boarders being supported by treating specialists and doctors and hospital baby boarding policies.

Where women were prevented from keeping their children with them, they reported that efforts to maintain their milk supply were not facilitated or considered to be a priority. One woman also commented on the lack of documentation regarding her breastfeeding status. Considering that being able to continue to breastfeed her infant was such a priority for her she struggled with the dismissive attitudes of hospital staff. In the one case where a woman did manage to have her baby admitted to hospital with her, nurses refused to help her with the infant due to legal implications. Midwives were also criticised for failing to facilitate mothering, not recognising the importance of helping an ill woman to spend time with her critically ill child and not assisting with breastfeeding outside the sphere of the midwifery wards.

Several women felt openly judged by nursing staff who offered their opinions regarding the women’s mothering choices and ability. Already coping with illness or injury, for some women this compounded the distress they experienced and further eroded their confidence in their ability to effectively mother their children.
Script. Act II, Scene II: The heartbeat scene – Mothering from hospital

Setting

A woman is sitting in a hospital bed in a shared room. She has intravenous infusions going through a central line just under her collar bone. A nasogastric tube snakes out of her nostril into a bag hanging by the bed. There is grassy coloured liquid in the tube and bag. She is catheterised. A man is standing at the side of her bed, a baby crying in his arms. He is holding the hand of a little boy standing next to him who is looking at the lines warily. There is an elderly woman in the other bed.

Character

Dialogue and Stage Direction

(The baby leans from her father toward her mother, arms outstretched)

MOTHER Oh Sweetheart, Mummy can’t hold you, her tummy is too sore.

FATHER Here give Mummy a kiss.

(Leaning the baby toward the woman)

MOTHER Come here Honey, give me a kiss.

(Kisses the baby and gestures to the little boy to come to her. The little boy cowers against his father’s leg, shakes his head and puts his thumb in his mouth)

FATHER It’s okay hun, you know it’s just the lines and stuff.

MOTHER I know. But it still breaks my heart.

(Looking upset)

ELDERLY WOMAN Can’t you stop that baby crying? There’s sick people in here you know!

(The woman glares at the elderly woman, the man rocks and shushes the baby. The elderly woman rolls on her side away from them)

FATHER We can’t stay long anyway; I’ve got to get the kids’ stuff ready to take to Mum’s before I go to work. And she wants to know what you want to do about the birthday party. Do you want to cancel it till you get out?

MOTHER You’ll have to bath them first too, his hair is dirty.

FATHER Yeah, all right. I’ve been just a bit busy you know! What should I tell Mum about the party?

MOTHER It’s all booked and paid for. If we cancel I don’t think we’ll get our money back. And he was so excited about it, his first proper party. I don’t want him to miss out even if it’s one more thing I’ll miss stuck in here. Can you ask your Mum if she can run it?

FATHER Okay, I’ll ask her. I better push off if you want them bathed.

MOTHER You better get going then.

(As her family leaves, the woman leans from the bed, watching their progress up the hallway until she can’t see them anymore. Laying back she wipes tears from her eyes. Lights fade.)
ACT II, SCENE II: THE HEARTBREAK SCENE – MOTHERING FROM HOSPITAL.

While Scene I was primarily concerned with women attempting to keep their baby with them when they were admitted, this scene explores the experiences of women who were separated from their children by hospitalisation. Women in this study described being physically or emotionally separated from their children in visceral terms of heartbreak. As patients, the women were temporarily replaced as the primary caregiver, becoming someone that the children visited. Used to feeling primarily responsible for their children, the women were shocked and threatened when their families coped without them.

Confined to health care facilities, several women expressed feeling abandoned and isolated from the family unit. While they were glad to see their families visit, the separation was felt acutely each time they left. As Zeta said: It was hard seeing them both go. I felt left behind in the stupid hospital. Feeling terrible, with the nausea. Yeah, I did find that hard. When Bailey was diagnosed with dilated cardiomyopathy she was admitted for several months to a hospital that was distant from her home. Financial constraints and the price of petrol meant that her husband and children could not visit as often, or stay as long as she would have liked them to, which left her feeling abandoned and displaced.

Bailey: I was so sick; I had no choice and was stuck in hospital for months. It was a nightmare. I cried most nights, knowing my family were doing all the usual family things without me. I wondered if they were thinking about me or if they were just carrying on like nothing had happened? The not knowing what they were thinking was killing me more than my heart condition. And if
I rang and they weren’t home, my heart would break. I was lonely, bored, and scared.

Because they were generally still working full time, as well as filling in for an absent mother, it was sometimes difficult for husbands and partners to bring children to visit as much as the women would have liked. While the women in this study appreciated that it was difficult for their partners, this did not stop them yearning for their children or worrying about their welfare. Maggie was hospitalised for approximately six months after she had a stroke; during this time she only saw her children once a week.

Maggie:  Being in hospital, being on the receiving end of visits, it wasn’t enough. He didn’t bring them in; he didn’t have a lot of time because he was working as well. And he wanted them to have normal lives [...] So I felt like I would have liked to see them more. But he did what he could [...] He’d take them bushwalking then bring them into see me afterwards, normally on a Saturday afternoon. I remember saying to him, ‘You’re leaving it very late in the day’ and he got very angry, ‘I didn’t understand at all. All the stuff he’s got to do.’ Every time I ever say anything, still, I hear the litany of all the stuff he has to do.

Being hospitalised gave women time to worry about how their children were coping emotionally without them. The women worried whether their children were being cared for properly, as most of the women in this study felt irreplaceable to their children. Immediately following her diagnosis of viral myocarditis, Quin was very restricted in who could visit her. With four small children at home, and no familial support, her children’s welfare was a constant source of concern.
Quin: *I was not allowed any visitors except my husband and he didn't have much time. In my first few weeks I was not allowed any visitors or to see my children, my worst worries were for my son, his world was turned upside down [...] I was allowed to see my eldest daughter once before I was transferred to [another hospital], she looked scruffy and uncared for which worried me.*

While the majority of hospitalised women maintained some contact with their children or were only hospitalised for a short period of time, in Olivia’s case, being hospitalised for tuberculosis meant no physical contact with her son for eight months. Because her condition was contagious, she could only see him from afar and she was terrified that their relationship would be lost due to the length of time they were apart.

Olivia: *So occasionally they would bring him, and he would stand outside and look up at me at the window, the balcony window. I remember that window; I’ve got pictures of me standing there. I thought I don’t want this; I want to go down there and pick him up! And I said to one of the sisters [nurses], because I was in the hospital for eight months, ‘He won’t know me, he won’t remember who I am.’ He used to look up at me as if to say ‘Well whose that standing up there on the balcony?’ He wasn’t crying, he wasn’t smiling, and he was just there. And I felt... well I felt as though my heart was broken.*

For women who could have visits from their children, these visits could be problematic, because while they yearned to see them, the hospital environment and the illness sometimes changed the way their children related to them. In many cases women discussed experiencing rejection from their children, which was difficult for them to cope with, and compounded their feelings of loneliness and isolation. When Bailey’s
children were brought to visit her they were uncomfortable in the intensive care environment and avoided physical contact with her.

Bailey:  *The worst thing was when they came to visit, and I was stuck in the bed with all the medical equipment around or on me. My older son used to freak out, it was like he was too scared to come close to me in case he broke me. My daughter was older and she understood more, but she was a bit standoffish which broke my heart as all I wanted to do was hug them and tell them how much I loved them, and that it was going to be okay [...] My husband bought the baby in, but to see them leave was heart wrenching and as they walked off down the hallway I would be in tears. I couldn’t cuddle the baby much because it put too much pressure on my chest.*

The women were concerned that their children were upset by seeing them in pain or distressed and admitted to hospital. Thinking their children were upset was an added burden for the already ill women, and it contributed immensely to their feelings of guilt. Cate had Crohn’s disease for over twenty years and had been hospitalised multiple times, yet her children were still frightened with each new admission.

Cate:  *When I have been hospitalised, the hardest thing for the kids and myself is them visiting me and the goodbyes. To have to look into the eyes of your children when you know you look like you are at death’s door and seeing how scared and sad they are is heartbreaking. Their goodbyes were always like it would be the last time they saw me, which made me have to re-assure them that I would be well enough soon and be home again.*
For women whose children were very small, there was the added difficulty of not being able to explain the situation to them. This was confusing for babies who expected to be held and comforted by their mothers. Rachael was hospitalised several times for major operations on her bowel for ulcerative colitis. At the time of her first stoma formation her son was only twelve months old. Rachael said that she thought he felt abandoned by her and was frightened by the strange way she looked in the hospital bed.

Rachael:  *Meanwhile little man was scared and angry at me for going away [*...*] While I was in hospital the day after the first operation, he was so scared he wouldn't touch me, and wouldn't talk to me, not even a smile. I had tubes everywhere and it was heart breaking, but I had to be strong. I couldn't move and I couldn't hold him. A few days later he came back, he didn't take his eyes off of me, ran his hand down my face to make sure that the tubes had gone, but moved away really fast.*

As well as the hospital environment influencing how women and children related to each other, in some cases the illness or medications used to treat it also affected a woman’s ability to behave naturally with her children. Some of the women were unsure whether their children should visit at all given the distress it caused. Eliza was admitted into a private mental health facility, where she stayed for a month following her diagnosis of postnatal depression. During this time her husband cared for their two year old daughter, bringing her to visit Eliza on the hospital grounds. However, Eliza found it difficult to assume the mothering role, in these short snatches of time.

Eliza:  *She was a little bit standoffish with me. It was all a bit strange for her [*...*] and I wasn’t myself. I would get very nervous and agitated knowing that they*
were coming to visit, then very nervous and agitated and upset when they were going to leave. And I didn’t know what was best for her, to come and go, or not to come, or come once a week.

Having had her baby confused and upset by her condition during a previous hospitalisation, Isabella chose not to have her child visit. However, both mother and child were then distressed by the separation.

Isabella: The second time, when I had surgery, they didn’t bring him to see me, which was very hard for me, I missed him so much. But we thought it would be best for him not to see me like that. Because, I wouldn’t have been able to hold him, and I was drugged with pain meds so I wasn’t acting like myself anyway. I talked to him on the phone some, and he was very sad. Which, as you know, it hurts really badly when your baby is sad!

Further complicating visiting was the logistics of children in the hospital environment. Several of the women commented that they felt their children were either ignored or unwelcome. In the hospital, children’s noise and restless activity was frowned upon. This was an added stressor for ill women trying to maintain their relationship with their children. Alice, whose daughter had autism and behavioural issues, was acutely aware of the staff and other patients if her visiting children were disruptive, to the point where visits were cut short, or the children not permitted to visit at all.

Alice: To be honest some staff are good and understanding but others, especially older staff are very impatient. There have been times that I asked for the kids to be kept away so I did not have to apologise and stress out so much. [...] I understand the situation, but it upsets me that seeing my kids when I am sick
is so hard and inconvenient. It is hard when I am sharing a room with others when the kids come to visit. My kids are very noisy and I often get very stressed at what the other patients must be thinking. I hate apologising for my kids, especially when I am feeling ill or stressed.

CODA

The drama of mothering disrupted by illness was especially apparent in the heartbreak scene. Incompatible with the mothering script, the hospital setting restricted the normal rapport between actors, stifling the interplay. Being hospitalised changed the context of mothering which had short and long-term consequences for the mother-child bond. Women had difficulties maintaining a natural relationship with their children in the hospital environment. The women’s demeanour was sometimes affected by the illness and medications, and children found it hard to relate to their mother in a hospital bed surrounded by medical equipment. Children were frightened by their mother’s illness which further distressed and worried the women. Women found it difficult and were saddened that they were the source of their children’s distress and were unable to comfort them properly.

Adult relationships could also be strained by hospitalisation. Husbands and partners became time poor as they attempted to continue in their usual role, as well as taking over some of the mother’s normal responsibilities. This limited the time fathers had to bring the children to visit their mothers, leaving some of the women feeling abandoned by their families. Visiting could be further constrained by the environment. If small children were noisy or demanding, some women felt that they had to limit how often, or
how long the children could visit with them to avoid disturbing other patients or hospital staff.
Script. Act II, Scene III: Receiving good direction – Supportive health professionals

Setting

Inside a general practitioner’s office. The woman is sitting in a chair opposite a doctor. She has been crying and is holding a tissue. The doctor is writing a referral.

Character | Dialogue and Stage Direction
--- | ---
DOCTOR | I’m not surprised you’re depressed; it’s very common in people coping with chronic illness. And you’re just out of hospital and home alone with two small children while you’re so unwell.

(Putting down her pen and looking at the woman)

MOTHER | I just feel like I’m failing everyone. I feel sick all the time; I’m crying all over the place, I’m short tempered with the kids. I wait all day for my husband to get home then snap at him. The house is a mess.

DOCTOR | You need to cut yourself a bit of slack. It’s hard looking after little ones, especially if you’re feeling so awful all the time. You’re a good Mum, you love your children. But you need to look after yourself as well. What about putting the kids into day care a couple of days a week to give yourself a break? Or is there anyone that can take them for you on a regular basis or come and help you with the housework?

MOTHER | We’ve talked about putting my son into day care, although we were thinking about it more as a learning thing for him than as a break for me. And I suppose I could ask my sister if she could help me with the house. She’s offered before but the house and kids are my responsibility. I hate asking for help.

DOCTOR | I know, but you might be surprised how willing people are to help, if you reach out. And what about your mum, girlfriends? If you can just get a bit of help from several people. Here write down everyone that you can think of that might help and how they could.

(Passing the woman a pen and piece of paper. Lights fade)
ACT II, SCENE III: RECEIVING GOOD DIRECTION – SUPPORTIVE HEALTH PROFESSIONALS

Often health professionals had no role to play in the women’s productions of mothering in illness. However, in contrast to Scene I, where women experienced misunderstanding regarding their mothering in the acute and clinically focused hospital environment, several women being treated in the community or admitted to mental health facilities reported feeling supported and validated in their mothering by health professionals. This was especially apparent where women had been consistently cared for by the same health team or individual health provider over a period of time. When validation and support were evident from health professionals it was experienced as invaluable. Notably, it was women treated for psychiatric illness who discussed feeling supported in their mothering by health professionals. General Practitioners (GPs) were considered especially compassionate and helpful and were identified as an ongoing source of support.

Tanya was diagnosed with postnatal depression by her local GP. Later Tanya’s illness evolved into pre-menstrual psychosis for which she was treated by a psychologist and then a psychiatrist. The psychiatrist proved especially helpful by taking the time to explain the origins of her illness to her; however, specialist treatment was not financially viable in the long term. As Tanya was unable to access the psychiatrist, her illness was mostly managed by her GP. ‘Knowledge’ of her as a person and mother and not just a patient was highly appreciated by Tanya. Furthermore, she identified this GP as being readily available and compassionate.
Tanya: The person who I found most valuable was probably my doctor, because he knew who I was, he knew us [...] He just seemed to be a bit better. Both my doctors were great but it’s like I can go in now and if I cry, I cry. He’s always there. I felt like ringing him up yesterday and saying: I need to see you, but it’s just one of those things.

Whereas Tanya’s rapport with her health care provider allowed her to easily discuss her feelings with him, Eliza felt a lack of familiarity with the community nurse and the generic nature of the postnatal screening forms had a negative effect on her ability to disclose her feelings. Being interviewed by an unfamiliar nurse using generic forms may have contributed to her diagnosis of postnatal depression being delayed by two years.

Eliza: And someone that you don’t know really [community nurse] says to you “have you smiled today?” You’re going to say “yes, I think so.” Unless you’re sitting there crying. And it’s too much of a range, it’s kind of like, “have you cried in the last week?” “Yes, sometimes, very occasionally, never”. And you can kind of go “well umm I’m sort of mmm”. Like the question, “are you going to harm your baby?” “No... but I don’t like my baby.” Or “I don’t particularly want to be left five days a week alone with my baby. But I’m not going to hurt her.”

Being ‘known’ to health professionals also had other advantages for ill women. Unity (who had schizophrenia) and her newborn baby were admitted to a specialist mental health mother-baby unit for the first three months of her life as a mother. She explained that while the unit primarily catered for women with postnatal depression, because she was known to the facility they admitted her and her infant daughter. There Unity was
stabilised on her medication and her mothering skills developed and monitored. Unity had a pact with the staff, that if she did everything she had to do for the baby consistently for three months, she would be able to retain care of her. Unity was eventually deemed successful in the mothering role and was discharged with her baby.

Unity:  
I had to get up every three hours, every night and every day to feed her, upstairs, before she came downstairs, and I did it. I kept on doing it, and I kept on doing it until they said, okay, we think you’re okay, and I would suggest everybody has that chance, with any illness, especially mental illness [...] to be given a chance like that is a very, very, very, very blessed thing to have happened [...] It happened and I was bloody lucky. I was so lucky.

Once discharged into the community, as well as having help from family, Unity continued to be well supported by one particular doctor and a social worker who visited her at home weekly. While it could have served the dual role of child protection surveillance, Unity was grateful for the support and positive feedback they gave her as it increased her confidence in the mothering role.

Unity:  
When I had my baby he [the doctor] was pretty good. He used to come once a week and see how I was going, reiterate that I was a good mother - and so did the social worker. They both were really good, helping me feel that I was actually doing the job. I think, if you’ve got a psychiatric disorder, it’s really important that you feel that what you’re doing is worthwhile and amazing.

Being validated as a mother by a health professional meant a great deal to some of the women in this study; Lilly also discussed being reassured by her psychiatrist that despite her illness she had managed to mother her children effectively. Although it was
not instigated by the doctor, he spoke to Lilly’s children about her illness and treatment, which was appreciated by both Lilly and her daughters.

Lilly: *He spoke with them recently for the first time; he spent about three quarters of an hour. And he said ‘look they’re marvellous, you needn’t have any concerns.’ And that was reassuring. It was not something I had thought of [having the doctor speak to her children] [...] It was my elder daughter who bought it up. She said ‘people ask me what does the doctor say about your mother’ or ‘what happens when she’s in hospital?’ And she said ‘I don’t know.’ So I bought it up with the doctor and he said ‘Oh I’m happy to speak with the children.’ Well from what I gather he was marvellous with them.*

Lilly’s story contained several accounts of her mothering being supported by health professionals. Revisiting the time when her children were small and she had taken them on holidays to another state and became acutely unwell, she discussed how her psychiatrist’s knowledge of her illness meant he was able to effectively manage the situation from a distance. His knowledge of Lilly as a person and a patient meant that he felt he could treat her over the telephone. During a phone call when she was in crisis he recommended that she increase her medication.

Lilly: *With a lot of the suicidality it was always my plan to take them [her children] with me, rather than leave them with my husband. I think just touching base with someone who was familiar with me and my story, and the fact that he didn’t over react and say get on a plane and come home [...] My doctor walked a very fine line in terms of not making notification. I could have easily lost the children. I had two psychiatrists, which is a very complicated*
story. One of them wasn’t happy at all about me having the children, and the other one was prepared to sit and wait and hope that it [harming the children] wouldn’t happen.

Retrospectively Lilly felt that her psychiatrist made some risky decisions in regards to the safety of her children and the potential threat that she posed to them. However, being treated by somebody that knew her, understood her illness, and how important her children were to her, meant that she managed to retain care of them most of the time. The fact that Lilly did not harm her children and that they have continued to choose to reside with her into young adulthood is perhaps a testament to his care, clinical judgement and knowledge of Lilly as a mother.

In between hospitalisations, Karina also spent a lot of her mothering time in crisis, very ill and alone with her young children. When she was hospitalised when the children were young, they were cared for by her siblings. However, when she became extremely ill when the children were older, Karina’s psychologist offered practical advice on matters pertaining to her mothering.

Karina: My psychologist was very good and suggested to me that my youngest went to boarding school, because the other two were leaving to go to uni [...] And even though it was dreadful, and once again the guilt was overwhelming, it was all I could do at the time. She was safe, and she was with other kids whose mothers had similar problems. So she actually got a lot of peer support.
CODA

In the theatre, directors and producers are the ultimate authorities. In health care it is doctors whose opinions carry weight. The relationship that was built between the women in this study and their regular health care providers empowered the women in their mothering. Being told by health professionals that they were good mothers was valued and appreciated. Professional validation gave the women confidence in the role and reassured them that their children had not suffered lasting damage from being raised by an ill mother. GPs, in particular, were credited with being approachable, empathetic, compassionate and providing emotional support.

Familiarity with their patients allowed the doctors to tailor treatments so the women could continue to mother their children. Conversely, where a woman felt that she did not ‘know’ her community nurse well enough to be able to disclose her feelings, an opportunity to detect a diagnosis of postnatal depression was missed. This left the woman in question to manage the illness untreated for a further two years.

Women in this study were grateful for advice from their doctors regarding managing mothering with an illness, welcoming suggestions for alternative care when they were too ill to continue caring for children at home. A doctor speaking to one woman’s children about their mother’s illness was another helpful and appreciated gesture.
Supporting characters aren’t just thrown on the page to give our protagonist someone to talk to in this scene, or someone to kiss in that big scene on page 73. They are part of the story themselves

(Martell 2012)

INTRODUCTION

When discussing their experiences of mothering in illness, the women invariably raised the support they received or would have appreciated. While ill, the women in this study drew upon a wide range of people and services to assist them in their desire to continue to actively mother and care for their children. Where the women were partnered, their partners were often their primary support (and in some case their only support). However, the women in this study did not always agree with the ways that partners (or ex-partners) went about the business of parenting children when they were too unwell to care for them themselves. Issues regarding the women’s partners and ex-partners assuming the main carer role are explored in ‘Act III, Scene I: The imperfect understudy – Partners in the spotlight’.

If the women did not have partners, or their partners worked, it was often other female relatives or friends who assisted them to care for their children. The women’s mothers featured prominently in their stories as a form of support and had a profound influence on the way these women mothered their own children. Where female friends were available, they could be an excellent source of support, yet many of the women in this study discussed consciously pushing friends away. Feminine relationships are explored in ‘Act III, Scene II: Women in the wings – Friends and female relatives’.
‘Act III, Scene III: Behind the scenes – Helpful others’ depicts other people and organisations that women also acknowledged in their stories of disrupted mothering. Although sometimes assisting in indirect and non-purposeful ways, these others often emotionally supported the women’s children for which the women were grateful. These other people also validated the women as mothers and gave them confidence in themselves in the mothering role.
Script. Act III, Scene I: The imperfect understudy – Partners in the spotlight

Setting

A lounge room in a suburban house. A young woman reclines on the couch, her hands over her stomach. Enter stage right a man holding a baby. A little boy skips in after him singing.

Character   Dialogue and Stage Directions

MOTHER     Hey guys, how was the park?
            (Awkwardly sitting up)

LITTLE BOY I went down the big slide Mummy, and I was only scared a bit.

MOTHER     What’s all over your face?

LITTLE BOY We had ice cream AND doughnuts!

MOTHER     Oh you didn’t fill him full of junk so close to dinner did you?

FATHER     Oh come on, it was a special treat. What is for dinner?
            (He tries to pass the baby to the woman but the baby resists and clings to him)

MOTHER     I haven’t started it yet, I’ve been sick all afternoon.

FATHER     So what am I cooking?
            (Sounding put out, still trying to get the baby to let go of his shirt)

FATHER     Let go Bubby, I can’t cook with you clinging.
            (Spoken sharply, the baby lets go and bursts into tears. The man succeeds in handing the baby to the woman)

MOTHER     Oh don’t upset her.
            (Holds the baby to her making soothing noises and patting her back)

FATHER     Well I’ve only got so many hands, and I’ve still got stuff to do for work tomorrow as well. You gunna help me cook dinner Mate?
            (He puts his hand out to the little boy and they start to leave the stage)

LITTLE BOY Will you read me a book after dinner Daddy?

FATHER     We’ll see, Daddy’s got some work to do after dinner, as well as the washing and everything else. Maybe Mummy could read you a book?

LITTLE BOY I want you to read it Daddy.
            (As the sound of their speech fades, the woman looks sadly after them still patting the baby. Lights fade)
ACT III, SCENE I: THE IMPERFECT UNDERSTUDY – PARTNERS IN THE SPOTLIGHT

Developing the sub-theme (Scene) ‘The imperfect understudy – Partners in the spotlight’ was the original catalyst for applying the theatre as metaphor framework to all of the findings in this study. Despite their perpetual feelings of responsibility for their children, all of the women stated that at one time or another illness had severely disrupted their ability to fulfil the mothering role. Much as the understudy in a play steps up to replace the incapacitated lead, for the majority of the women it was their male partners who filled the parenting void created by their maternal illness. However, the partners’ success in fulfilling some or all of the mothers’ activities was varied. In some cases the women reported that the men struggled or did not appreciate the added responsibility. Other men were said to be possessive of the primary carer role and unwilling to relinquish it when the woman was able to resume full-time maternal caring.

Although the ‘understudy’ title goes a long way toward capturing the idea that the women’s partners assumed much of the mother’s role when the women could not, it should be acknowledged that in many cases partners actually extended the fathering role. Indeed, in many of the women’s stories partners were credited with being ‘great’ or ‘fantastic’ or ‘very supportive’ and were not discussed at length. When Nora was diagnosed with breast cancer, her first thoughts were for her daughter. However, the nature of the relationship Nora’s husband had with their child meant that she felt no need to be concerned for her daughter’s care or welfare.
Nora: My initial reaction especially when I was in hospital was did she have everything she needed? That now seems silly as my husband is extremely capable and a very hands on father and I had no need to worry [...] My husband and daughter were very close before I got ill. They do a lot together. So whilst I was away he tried to keep it normal, the way he behaved with her] rather than trying to be me.

Therefore, while partners may have assumed much of the domestic and physical care of the children, they did not replace the mother but rather brought their own interpretation to the main carer role. For some of the women, however, even excellent care from a father was no substitute for a mother. This idea was captured in Veronica’s story. Despite detailing her husband’s devotion to their children Veronica still implied that a mother’s love was unique.

Veronica: My husband is fantastic. Like, if I’m not going to be home, he really makes an extra effort to do something special with them [sons] [...] But it’s not the same. I guess because we’re different, even though he’s very loving and affectionate towards the boys and stuff like that. But I guess it’s different with your mum. I know just from my experience, even though my dad was very affectionate and whatever with me. It’s a different kind of affection that you get from your mum.

Twenty of the 27 women who participated in this study reported that their partners had been a valuable source of support. Husbands and partners were perceived to either increase their share of or assume full responsibility for childcare and domestic responsibilities to compensate for the woman’s inability due to illness. However, there
were difficulties and misunderstandings reported as the women and their partners transitioned between the primary carer role.

While most of the women’s partners did increase their involvement with caring for their children, they also had to continue working in their usual employment. This caused conflict for some of the women in this study who perceived that the care of the children may not have been the partner’s main concern in the same way it was for them as mothers. Feeling that she was emotionally and physically detached from her children, Alice was grateful to her husband for his increased involvement with them and acknowledged that he was a positive force in their lives. Nonetheless she also highlighted their differing priorities.

Alice: *I have lost the ability to enjoy and play with my kids. My husband does most of that now [...] He is a great Dad. I have always seen him as a much better parent than I am. I was very thankful for this; however his job seemed to always come first which drove me crazy.*

Yet even where their partners did commit to full-time caring, women could still be disappointed as they then felt displaced in their children’s affections. When her baby was only four months old, Bailey was hospitalised for cardiomyopathy. She believed that the time her husband spent alone caring for their son changed the nature of her relationship with her child. Although Bailey’s son was later diagnosed with autism, which helped to explain his unwillingness to engage in or accept physical affection from his mother, the child did allow affectionate contact from his father. Bailey took this as proof that being replaced as the primary caregiver during this early time in her baby’s life had had a detrimental and continuing effect on the maternal bonding process. This left her feeling rejected and replaced.
Bailey: My husband was awesome the whole way through it all as he took over the role that I played and the fathering role as well [...] Mum would come and visit, and sometimes my sister would take the older two kids, but never the baby. My poor husband pretty much did it on his own. By the time I was released the baby had bonded with my husband, which is hard to deal with as he [the baby] doesn’t let me do any of the things a mother should do for their babies.

If she was unwell at home or hospitalised for bipolar disorder, Lilly had to leave her children in the care of her ex-husband. According to Lilly, her ex-husband was bitter about their divorce, and her illness gave him license to take over the primary carer role. Lilly found it very difficult to leave her daughters in his care when she was hospitalised as she thought he was poorly equipped emotionally to care for young children and suspected that he was addicted to prescription drugs. Having to leave her children in what she believed was a less than ideal domestic situation compounded her maternal distress at being separated from them.

Lilly: When he couldn’t cope he’d develop terrible migraines and he’d get the GP in to give him pethidine [...] And that was happening more and more often when the kids were with him [...] He was very possessive and obsessive about being the main caregiver. The responsibility was too much for him seven days a week but he wouldn’t admit that. So I had a great deal of trauma leaving them in that environment. And it was for weeks at a time, on one occasion I was in hospital for ten weeks. So for me that created an enormous amount of anguish and anxiety and guilt.
While Lilly did say that he was a loving father, her ex-husband’s emotional issues were such that she would have preferred the children to be cared for by foster carers during the times she was hospitalised. However, illness made it difficult for her to negotiate other options for childcare:

Lilly:  
*And I have to tell you he adores the children, he loves the children to death. And before we broke up, I would say that he was an outstanding father. He is very good with children and loves the kids but he has anger problems and is very needy [...] One problem was there was no social worker, no one to help. I didn’t have anybody to raise my concerns with about their care. I needed someone who could take over in regards to contacting the department [Department of Community Services] and getting them to look into the care the kids were getting, and not on a superficial level, but making weekly visits. The department would have been more likely to listen to a social worker than a mental health patient.*

Other women also felt that their illness left them powerless in custody matters. Farrah stated that her ex-husband used her mental illness to his advantage when they were fighting for custody of their children in court. Once he was granted conditional custody, she said that he reneged on the terms and prevented her from mothering them.

Farrah:  
*During the court case he would always say that I was a nutcase. Anyway we agreed that the children would stay in the family home and I would go there between seven in the morning and seven at night and continue doing the motherly things. That lasted one day, then that evening he said “I don’t want you coming back here”. And I thought after all of the rigmarole we’d gone*
through. So I rang my solicitor and the solicitor said “well he can do that because it’s not your home”. It was ridiculous.

Farrah said that her ex-partner did not have formal custody of the two boys, yet he had led her to assume otherwise and kept them. The discord between Farrah and her ex-partner combined with agoraphobia affected Farrah’s ability to spend time with her children.

Farrah: *Then he started demanding that I walk them home, which was in bush land and dark and he knew I didn’t have transport and had to walk all the way back to the station by myself. And I had lots of problems getting the train so there were a lot of weekends I’d miss because I had problems getting out. I just knew I felt sick, that I’d have to sit there for hours thinking “how am I going to get out this front door without having a panic attack?” Then on the times I did get them, because they lived at [remote bushland suburb] and the trains only ran once an hour on that line, at night-time when I dropped them off I’d have to sit and wait for the train and I started having massive panic attacks.*

Illness was often isolating and demoralising for women. The separation from her children had serious repercussions for Farrah’s emotional equilibrium and health. Missing special events and celebrations with them was especially distressing and caused her to engage in negative coping strategies.

Farrah: *But for eight years I never had them on Christmas day, it was heartbreaking, I’d be home by myself. By myself with a bottle of scotch and just proceed to wipe myself out for the entire weekend or throughout the*
Believing that when they were in someone else’s care their children were unloved or at risk was frustrating and a source of great concern for several women in this study. What really worried Farrah was that she did not think her children were loved and valued by their father and that he had sought custody out of spite rather than through any true concern for their welfare. She told many stories describing the ways she thought they were ill-treated or neglected.

**Farrah:** *He had different women looking after them, it didn’t matter to him, and he didn’t care. They weren’t allowed to do things at home. He’d come home at nine o’clock sometimes and they’d be sitting there waiting for their dinner. They couldn’t even feed themselves because they weren’t allowed to touch things.*

Despite being ill, both Farrah and Lilly believed that their children were worse off in the care of their fathers, questioning the men’s fitness or motivation in assuming the full-time carer role. However, other women in the study had problems when their partners were not happy about assuming increased responsibility for the children and household. When Maggie was hospitalised for six months for a haemorrhagic stroke, caring for their children and maintaining the household fell to her husband. According to Maggie, the increased responsibility weighed heavily upon him.

**Maggie:** *Well my husband says ... ’Why does he have to be the one? He goes to work faithfully every day, brings home the money, does the shopping’... he was doing everything at one stage [...] And its true there is a lot more burden on*
him to do stuff than there was before [...] But he thought it was unfair that he was doing all of this stuff.

Illness can put a lot of pressure and strain upon relationships. Maggie described her husband becoming very stressed when she was hospitalised and he was working full time, running the household and caring for the children. She also said that he was resentful about the extended role and berated her endlessly for the increased workload he had to manage while she was hospitalised. Institutionalised and partially paralysed, Maggie felt victimised and powerless, associating the conflict between her husband and herself with aggravating the seizures she experienced. Although she states that her doctor was dismissive of the correlation, Maggie truly believed that the marital discord had consequences for her health.

Maggie: You wouldn’t have wanted to talk to me straight after because I would have been crying half the time [...] the doctors thought it was to do with the scarring from the operation. If I got too emotional I would fit, or if I pushed it beyond my physical limits I would fit. I tried to tell the doctor that I was fitting because of the things my husband said, but the doctor just didn’t want to hear that.

Maggie revealed that despite his rejection of the main carer role, her husband became methodical in his approach to housework, and was later resentful of her trying to reclaim some of her domestic territory when she was discharged from hospital.

Maggie: My husband’s a... He’s not anal about it [housework], but he was getting frustrated about it. Because if Mum’s not there saying how this has to be, well you have to do most of it yourself, kids don’t naturally do it [...] He said he had a very strict routine, where he would walk in the door, put the
washing on, sweep the floor etc. That was the only way he could stay on top of it. So that was a bit of an issue when I came back and I was trying to do some of my old routine, because it totally screwed his up. So he was cranky about that too.

CODA

When the leading ladies were indisposed, they had to witness the understudies taking their places. Invested in the leading role it was difficult to watch others in the part, and the leading ladies evaluated the understudies’ performances from the wings. In some cases the understudies excelled, bringing their own interpretation to the role and displacing the lead in the part. Others struggled in the role, causing the leading lady distress as she watched the sub-standard performance and mourned for the production that might have been. In some cases the leads felt displaced by those they considered bit-players who had always coveted the spotlight.

While the majority of the women’s partners were supportive and either increased the amount of time and energy they spent caring for children and the household, or assumed complete responsibility while the women were ill, they were not always seen as ideal substitutes by the women in this study. Pre-existing tensions in relationships could be exacerbated by maternal illness and the shifting of parental responsibility. Some of the women discussed their ex-partners having their own agendas and reasons for assuming custody that were not altruistic, but were perceived by the women as punitive and self-serving. This was distressing as they were aware that their children were not always being cared for to the standards the women felt they deserved, which led to them experiencing further guilt and distress. Even cases where the partners effectively cared for the children could be problematic, as it could impact upon the
maternal bond women had enjoyed with their children prior to the illness. Although they appreciated that their children were being well cared for, women could be distressed if they thought that they had been displaced in their children’s affections.
Script. Act III, Scene II: Women in the wings – Friends and female relatives

Setting

A lounge room in a suburban house. A young woman is sitting on a couch folding laundry, another woman is ironing. A baby is asleep on a child’s fold out couch on the floor. There are piles of folded clothes on the coffee table, and a basket piled high with clothes.

<table>
<thead>
<tr>
<th>Character</th>
<th>Dialogue and Stage Directions</th>
</tr>
</thead>
<tbody>
<tr>
<td>MOTHER</td>
<td>I can’t thank you enough for this. It’s just beyond me. I get the washing done but I can’t stand long enough to iron it. (She stops folding and looks at her sister)</td>
</tr>
<tr>
<td>SISTER</td>
<td>No worries. I should have come earlier. You’ve always bounced back before. I didn’t realise how much this latest operation knocked you about. It was only when you said you’d asked mum to take the little fella for a few hours that I realised.</td>
</tr>
<tr>
<td>MOTHER</td>
<td>Yeah, she’s been great. Just having that little bit of time has been a big help. I can try to get things done while the baby’s asleep. And I feel so guilty; he’s missing out on so much and it’s so boring here for him. We don’t get out often; I can only do so much. And hubby has to keep working, so there’s only so much he can do. But between mum and day care he’s having more fun.</td>
</tr>
<tr>
<td>SISTER</td>
<td>Aren’t any of your friends around, what about those women from playgroup you always used to go out with? Are your friends any help? (Puts the iron upright on the board and picks up her cup of coffee. As she finishes speaking she takes a sip)</td>
</tr>
<tr>
<td>MOTHER</td>
<td>I’ve made friends with one lady who has the same thing, and that’s helpful. She understands what it’s like. We met in the specialist’s waiting room. And compared to her I’m actually pretty lucky support wise. She only has her mother to help and they’ve got all sorts of history. But no, not many friends, it’s hard to keep in touch. I can’t get out, and it’s such an effort to make sure everything’s clean and tidy for visitors. (Shoulders slumping, she gestures to the untidy room)</td>
</tr>
<tr>
<td>MOTHER</td>
<td>And the questions! They’re always so curious, and it’s embarrassing. One even asked me if she could have a look. I said “sure, but only if you drop your pants too”? You should have seen the look on her face! (The sisters laugh together at this last statement. Lights fade)</td>
</tr>
</tbody>
</table>
Although the majority of women were partnered, female friends and relatives still figured prominently in their accounts. The frequent references to female relatives and friends highlighted how important such relationships were to the women. ‘Act III, Scene II: Women in the wings – Friends and female relatives’ highlights the way that caring for children and the ill is predominantly still undertaken by women.

Several of the women reported being isolated from their peers, stating that they had withdrawn from social circles as a consequence of their illness. However, when they were available, friends were a valuable form of support. These female peers were supportive in many ways; they reduced feelings of isolation, promoted a sense of belonging, gave the women a feeling of normalcy, and provided emotional support and practical help with childcare.

Some female relatives were staunch advocates, assisting the women in the hospital and home environment and helping them to care for their children. After husbands and partners, women’s own mothers were the most supportive people. However, where mothers were deemed supportive there was often scant detail of how they helped. As Zeta wrote: my husband and my family particularly my mother was supportive. Yet women in this study who had previously unresolved issues with their mothers spoke of them at length and in great detail. Several of the women shared stories of feeling that they themselves were inadequately mothered, and believed that this impacted upon the way they related to their own children.
Farrah:  *At 12, my mother took me to the police station and just said “we don’t want her anymore” so I was placed into a home [...] My childhood had a huge impact on me and my life has had a huge impact on them [her children].*

These women rejected the mothering example available to them, and were consciously nurturing and supportive of their own children in ways they had not experienced themselves. The stories told by these women dwelled extensively upon how they thought about and constructed mothering.

Where women had a good relationship with their female relatives, and shared child raising beliefs, these other women were invaluable in providing childcare and emotional support. Some women’s relatives made major changes to their own lives to help the women while they were ill. This provided some of the women in this study with the surety that no matter what they had to deal with in regards to their illness, their children would be consistently cared for. Having a third adult available to care for children also contributed to safeguarding the family’s livelihood, allowing the partners to continue in paid employment.

Cate:  *As I was becoming increasingly sick and trying new meds, we asked my mother if she would move into a flat at the back of our home. Having her here has helped whenever I have needed to be in hospital and when I’m generally unwell. My husband can keep working and I know that my children are being well looked after.*

As Tanya’s mother was unavailable due to distance, it was her mother-in-law who assumed the supportive role. While her mother-in-law framed taking her grandchildren out as a privilege, it was a helpful reprieve for Tanya who had a mental illness. Her
mother-in-law enjoying having the children allowed Tanya to call on her when she needed some time to herself without feeling guilty or beholden.

Tanya:  *Sometimes my husband’s mum comes over and says: I want to take the kids. I’ve never denied her taking them. I never say no, because it’s time for me as well [...] yesterday I rang my mother-in-law, and I said, ‘Can you come and pick the kids up,’ because I felt really crook [unwell]. She doesn’t mind that. She’s only like ten minutes away by car.*

Some of the women’s grandmothers also had a role to play. After Isabella had her colon removed as treatment for ulcerative colitis, her son stayed with her grandmother for the six weeks it took her to recover from surgery. This help was invaluable as it provided constancy and care for her child, and time for Isabella to heal from major surgery. Isabella was entirely comfortable with her choice of carer when she was physically unable to care for her child herself.

Isabella:  *My husband worked nights and an odd schedule and we thought it would be easier on my son to stay somewhere stable, instead of being here with me when my husband was home and then somewhere else when he wasn’t [...] of course I was sad that he wasn’t with me, but I was very happy with my grandma taking care of him [...] she had raised two children of her own, and helped with numerous other ones.*

While women’s female relatives were supportive in helping to care for their children, there was a chance that the maternal bond could be damaged by somebody else assuming the primary carer role. Veronica’s mother helped a lot with caring for her
older son while Veronica was very ill with Crohn’s disease or recovering from major surgery.

Veronica:  *I get a little bit envious that he’s got a really good relationship with my mum. I mean, he’s got a great relationship with me as well. He’s very loving and everything like that. He will come up to me just for no reason and just and give me a hug and say I love you mum or whatever. I don’t know. Just when we go to Mum’s or Mum comes here, his whole face just lights up. I think oh I wonder if I hadn’t been sick if I would get that sort of thing […] He spends a lot of time with her. But when I was sick, she moved in again, for a few weeks here and a few weeks there. Plus, if she wasn’t staying here, she would come up every day and take him to kindy*. She would pick him up and she would be getting dinner ready and stuff like that, because some days I couldn’t even get out of bed. She certainly took over the mothering role there, I guess.

For Eliza, sharing the care of her child with her own mother caused the mothering role to become blurred. Eliza had postnatal depression that was undiagnosed for two years, and became almost completely dependent upon her mother to care for her little girl. However, this had consequences for Eliza’s mother’s mental health as well, resulting in both women being admitted to mental health hospitals for treatment at the same time.

Eliza:  *At the same time, my mother was diagnosed with anxiety and depression, and she went into [a different mental health] hospital for seven weeks. There was an enmeshed relationship between my mother, and I and my daughter.*

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6 ‘Kindy’ refers to kindergarten, a class for 4 ½ - 6 year olds that precedes grade school.
My mother didn’t know whether she was the grandmother, the mother. I didn’t know who the mother was. We had got all our boundaries confused, because we had spent so much time together, and because she was helping me look after my daughter, because I was obviously not coping too well, that caused her a lot of angst and anxiety so she was diagnosed at the same time.

While Eliza and her mother later resumed a healthier relationship, Samantha’s relationship with her mother was destroyed by conflict over the mothering role. When Samantha was hospitalised after being diagnosed with schizophrenia, her mother was granted full custody of Samantha’s two sons and took them to live with her in another state. Samantha expressed bitterness that she has been replaced in her sons’ lives by her own mother, whom she did not consider a suitable carer, based upon her own experiences in childhood.

Samantha: My mum did a lot of voluntary work and that type of thing. So while she was off volunteering and getting pissed with all her friends, I was at home, looking after her kids [Samantha’s siblings]. That is where a lot of it stems from. It is like, what, I can bring your kids up but you can’t even let me have access to mine?

Alice also had reservations about her mother helping with her children based upon their familial history. Several times in her story, Alice hinted at difficulties in her childhood, and a less than ideal relationship with her own mother, yet unfortunately Alice was dependent upon her mother to help care for her children.

Alice: I hated relying on my mother to help me look after the kids. We had a rather colourful past which I am trying to overcome. But I would give my life to
protect them from what I went through as a child. I no longer had control over being a mum to my kids [...] However, I have needed her to help look after them so it gets a little complicated and tricky sometimes. I just could not do it all.

Feeling that they themselves were not mothered at all, or were mothered in what they considered a dysfunctional way, also affected how some of the women in this study related to their own children during their periods of illness. Winter’s story reflected at length upon her mother. How her mother had coped with illness while Winter was still a child strongly influenced the way Winter responded to her own diagnosis of breast cancer as an adult.

Winter:  My mum had many physical illnesses and mental illnesses, and I vowed, as a child that I would not be like her. She used her illnesses as a weapon against people, so that she could manipulate them. When I was diagnosed, this was at the forefront of my mind, not to be a wimp, not to let it get to me, to roll up my sleeves and get on with it (whatever it was). So in my case, the way I handled the illness, was already decided before the diagnosis.

Women often attributed their own mothering style to their memories of being mothered. A traumatic childhood made it difficult for Unity to even think of herself as a mother. Unity stated that in the early days of being a mother she preferred to think of her own child as a younger sibling, as she associated the mother identity with violence and alcohol-fuelled rage.
Unity: Mum actually planned to knock us out- kill us, and bury us in the garden.
Yes, well - see why I wanted to be a good mother? I wanted to be the opposite [...] For the first couple of months, when I thought of myself as a mother, I felt absolutely horrible, so I pretended my little girl, was my little sister, and it worked. It worked. Even now, I will call her sometimes [sister’s name], rather than by her name, but she’s certainly my child now. I can accept the fact that I’m a mother and I like it. I worried about being a mother partly because I was ill, yes, and partly because of my own mother. Being Mum was scary and horrible. She was a horrid person, especially when she was drunk [...] So, what’s that’s got to do with anything? I suppose being a good mother. Well, anybody can do it, if you really, really want to be a good mother, and you love your child it doesn’t matter if you’re schizophrenic, it really doesn’t.

For Olivia, it was her lack of a mothering example to draw upon that concerned her. While Olivia was in a sanatorium as a young girl, her own mother (who also had tuberculosis) passed away. Losing her mother at a young age had a profound impact on Olivia, and subsequently affected the way she related to her own child. Her story dwelled often upon her feelings of loss regarding her mother, and how acutely her absence was felt. Olivia was particularly concerned that through losing her mother, she had also lost what she viewed as a primary source of mothering knowledge. And I know that this child was always so fearful to me, that I wasn’t doing it [mothering] right. And if I’m not doing it right, who’s going to tell me I’m not doing it right? Before she was admitted to the sanatorium for the second time as an adult, Olivia had to arrange care for her son, for an unknown but extended period of time. With no mother, aunts or close friends to call upon, Olivia admitted to feeling quite desperate. Although she did have a
much older sister from her mother’s first marriage, this sister had also had tuberculosis, had only one lung, was frail and had no experience with children. Olivia’s story highlighted the problems that could exist in a young woman’s life when lacking female relatives or friends able to assist with childcare in the face of severe maternal illness.

Olivia:  *So I got home, and I cried my eyes out, and I cried and I cried and I cried and I cried. And I had to think what I could do [...] And I thought, well at least I’ve got my sister there, she lives close to me, over the road [...] and she [sister] said, ‘Well, I can’t look after him all the time.’ And I said ‘What does all the time mean? A baby is all the time!’ And she said, ‘I can only have him some days.’ And then I thought of another lady I knew, because I thought it’s got to be somebody I can trust, somebody that would look after him, and care for him, like I would. Not just any old person would do. And she came through for me, and between this lady and my sister and my husband, when he was there; he [Olivia’s son] was cared for.*

While Olivia’s lack of a support network was circumstantial, other women discussed consciously withdrawing from their female peers due to their illness. The women in this study did desire female friends but were wary of being judged harshly by them, either for the limitations imposed upon them by their illness or their mothering skills. Occasionally the maintenance of friendships with resulting curiosity about their illness was more than they could cope with. The nature of Rachael’s illness (ulcerative colitis resulting in two separate stomas and a bowel re-connection) made her self-conscious around other people.
Rachael: *I did tell a few, and a few more found out, and I had problems with them, so I tried to turn away people. And I always thought I smelt a little so I tried to stay clear of people. I got told once, by a work mate towards the end of getting rid of it [having the stoma reversed] that I have good days and bad days smelling bad, but she didn't know about the stoma, she just knew that I had bowel problems. She was a nice lady, but I just didn't know what to say.*

This resulted in Rachael withdrawing from people she knew and consciously rejecting overtures of friendship. However, after her stoma was reversed she actively sought friendships but found it difficult to connect with people.

Rachael: *Now after pushing everyone away I am finding it hard to know what to say to anyone. As for friends I am trying but it is still not working. Everyone seems to be too busy. And I have become too depressed and given up on trusting anyone. I do have a friend that I have known for a long time though I've only seen her once in the last six months. I have lots of Facebook friends [...] There are old family friends, I am unsure if they know about the stoma, I am sure most of them do, as my father had to tell the world. So I pushed them away too and now people are pushing me away I think.*

Tanya explained how she was isolated from other women, and implied that this was by choice, repeatedly describing herself as shy and withdrawn. However, she also reported being chronically tired and unmotivated as a result of her illness and the medications required to treat it, and that this fatigue had consequences for her ability to maintain the family home. She also said that it was the state of her house that prevented her from receiving more visitors. So although Tanya blamed her shyness for isolating her from
other people, her story revealed that a fear of being judged an inadequate housekeeper might also have been a contributing factor to her solitude.

Tanya:  *I’m not a social mum. I don’t go for coffees. I do my own thing; I like to keep on my own but I think that’s a part of me, who I am [...] I don’t want to get too many people involved. I’ve got a few people that - well my friends - I call them my friends but we’re not close, close friends. There’s not much support [...] I always have a fear of what other people think [...] We don’t have a lot of visitors now because the house is always a mess [...] I’ve got washing to do, hang out and stuff after this. Every day is sort of a battle and I feel tired.*

Yet Tanya desperately desired to be able to talk with other mothers. Due to her isolation, she had raised her children in the absence of other mothers. Her fear of being judged by others reduced her opportunities to compare children’s behaviours and mothering experiences. This isolation left Tanya insecure about her mothering skills and unsure if her children’s behaviour and development was normal. However, Tanya knew that being able to share experiences of mothering and illness with other women would have been a source of reassurance.

Tanya:  *Just writing to you helps a little [...] Sometimes I feel as though I want to get all of the school mothers together for a tell all/ask all session, which you could talk about anything bothering you about your parenting [...] It would be nice to know if someone else has trouble with their kids like I do.*

Other mothers they met at their children’s schools were discussed by several women, not always in flattering terms. Unity explained that when she was quite unwell, she sometimes dressed strangely, wearing her clothing inside out, and a tea cosy as a hat.
This caused problems for her when she was collecting her daughter after school, as she felt judged by the other mothers. As well as the visible signs of her mental illness, Unity and her daughter lived in government housing, which further contributed to her feeling out of place among the private-school mothers.

Unity: *I thought I was the most stupid and ridiculous person in the world, and it didn’t help that when my daughter did go to school, my father and his partner, wanted her to go to a private school, which was all very nice and well, but I was not well and I dressed strangely, and I was very, very ostracized by the rest of the women [...] they were vicious, they were really vicious. But certainly I think it made it worse by being a private school. They lacked any compassion, any understanding.*

Similarly, Eliza had withdrawn from her friends as her illness had evolved; however, she made a concerted effort to reconnect with other women when her mental health improved. Like Tanya, Eliza recognised the value that being able to socialise with her peers held for herself and her daughter.

Eliza: *And then I started to go to a few playgroups and get back in touch with people that I should have been in touch with [...] I got to know some women, my age, with children roughly the same age, and it was good for my daughter because she got to interact with other kids, and it was good for me to talk to other mothers and that sort of thing.*

Where women had managed to retain relationships despite their illness, they gained support that was based on friendship, rather than the sense of duty that characterised some of the family support networks. This may have contributed to their sense of self-
esteem, as these women did not report feeling judged like those that had become isolated.

Veronica:  *I’ve got a few girlfriends who know about it [Crohn’s disease] and they are really good. So, like you know they know that sometimes I might have to cancel on them at the last minute and stuff like that. They’re really understanding about that which is really lucky for me.*

Of all the stories told by the women about female friends, Winter’s stood out, as it involved a friendship that developed between two mothers who had both been diagnosed with breast cancer and underwent treatment at the same time. The friendship provided the two women with mutual support and understanding on multiple levels. As well as understanding what the other woman was going through regarding the disease and treatment, the difficulties of mothering in illness were fully appreciated. Being able to discuss maintaining lower standards of housekeeping and childcare was reassuring and validating for Winter. That their friendship benefitted their children was a further source of comfort.

Winter:  *We would talk and see each other every week, swap notes, compare treatment. It was helpful to both of us, because here was someone else who understood how we were feeling, without having to explain anything. It also helped our kids. Here was another mum, who they knew, who was going through the same thing, so it seemed to "normalise the cancer" for the kids, if her mum had it and was going to be OK so was my mum [...] We both discussed early on, that we would be OK, that we would get through it, so we were both positive. We also found that to cope we had to let some of our*
standards slip. So the garden got a few more weeds. So the floor was not as clean. So our hair was falling out. So the kids were spending a bit more time at friend’s places [...] We were there to support each other [...] We are now friends for life.

CODA

The performance of disrupted mothering was made easier when the cast included women working together in the wings to support the leads. For the women in this study, mothering in illness was made easier when they had friends and female relatives to help them. Other women provided childcare and emotional support, normalised mothering in illness, and allowed women to compare parenting experiences and practices. For women with few friends or female relatives to draw upon, their absence was keenly felt. Yet often new friendships were not encouraged during the acute stages of illness as the women sought to reduce the opportunities that other women had to judge them, or to make them feel inadequate. If they had isolated themselves it was sometimes difficult to make friends when they were ready to re-engage.

Women’s own mothers were discussed frequently in their stories and were notable for the profound impact that they had on the way the women constructed their own childrearing practices. Where women’s mothers were supportive, they were a positive influence in their daughters’ lives and made mothering in illness easier. If the women’s mothers were a negative influence, this was a source of sorrow and affected many aspects of their lives. Women in this study were sometimes noted to be highly critical of their own mother’s parenting practices. However, it appeared to have positive connotations for the way these women approached mothering their own children as they
consciously rejected the mothering example provided to them by their own mothers and constructed their own mothering ideology.
Script. Act III, Scene III: Behind the scenes – Helpful others

Setting

The backyard of a children’s day care centre. Two women are standing together looking toward a young boy playing in the sandpit. Around them about twenty other children are engaged in various types of play.

Character | Dialogue and Stage Direction
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MOTHER | If you could just keep an eye on him, I’d appreciate it. He knows I’m going into the clinic for the day, and he tends to get upset. He might play up a bit. I think it’s how he copes.
TEACHER | No worries, I’ll look out for him. I’ll get him to help me with the morning teas and setting up the art. Keep him a bit distracted.
MOTHER | That would be great thank you. He’s actually a pretty good helper for a little tyke. Probably from helping me at home. I’ve always got him fetching something for me.
TEACHER | He is a good helper. I’m surprised that you think he might be naughty. He’s always so well behaved, and he’s lovely and gentle with the littler kids. And he’s very bright! Such an advanced reader for his age.
MOTHER | Yes, well we spend a lot of time reading and drawing and doing art and stuff. I’m not much good for outside play lately.
TEACHER | Well it’s certainly not hurting him. He is going to excel when he goes to kindergarten. If they’ve got the basics before they start they go ahead in leaps and bounds, and he will have you to thank for that!
MOTHER | That’s kind of you to say, I worry about what he’s missing out on, stuck inside with me all the time.
TEACHER | But he does all the outside stuff here, you keep doing what you’re doing and don’t worry. But it’s good you’ve told us what’s going on. I’ll keep an eye on him and we’ll get him to participate in as many outdoor activities as we can. We’ll wear him out for you!

(Laughs)

MOTHER | Thank you again. Mate come give me a kiss, Mummy’s going now.

(The little boy clambers out of the sandpit and approaches her. His eyes start to well and the corners of his mouth turn down)

MOTHER | Oh, Honey don’t cry. Mummy’s fine and I’ll be here to pick you up this afternoon.

TEACHER | Come on, give Mummy a kiss then I’ve got a surprise for you! You’re going to be my helper. Do you think you can help me set up the art room? We’re doing something special today! Come see, I’ve drawn giant dinosaurs and we’re going to glue their scales on.....

(The little boy kisses his mother and takes his teacher’s offered hand, distracted from his distress as he contemplates dinosaur scales. She leads him into the building. Looking back he calls to his mother)

LITTLE BOY | I’ll see you later Mummy, feel better but I’ve got to help Miss with the dinosaurs.

(Lights fade)
ACT III, SCENE III: BEHIND THE SCENES – HELPFUL OTHERS

A successful performance does not just depend upon the skilful rendition of the lead actress, but also the many theatre staff who ensure the production runs smoothly backstage. Although the previous two scenes discussed the primary sources of support (partners, mothers and other female relatives and friends), there were others who helped in more discreet ways that the women felt it imperative to acknowledge. ‘Scene III: Behind the scenes – Helpful others’ refers to the positive contributions these others made to the women’s experience of mothering their children in illness. Notable in the transcripts was the concern and worry that the women expressed for their children. Therefore the people who contributed to supporting and caring for their children were genuinely valued and appreciated by them. Knowing that their children were being provided for in practical and emotional ways lessened the stress and worry the women experienced.

As the women mostly saw themselves as central to the running of the household, they were threatened when their view of themselves as capable and useful mothers was damaged by illness. As a part of the process of re-establishing herself in the household, it was important to Maggie that her children were involved as little as possible in looking after her. Separating the needs of her illness from her role as a mother reinforced her independence and helped her to re-claim her former position in the family. This was where community-based support services were invaluable as they allowed Maggie some autonomy in who helped to bathe her.

Maggie:  *I tried to keep the kids away from the physical care of me; I think the physical care is a bit much [...] But we had a lovely lady who came from*
Quin was also fortunate in having access to domestic help during her long convalescence from viral myocarditis, as the local council provided the family with a housekeeper. Having help available facilitated Quin’s ability to mother her children as it meant she and the children were able to remain under the same roof. Quin believed having her children close aided her recovery.

Quin:  *My husband begged the local council for help so we could get the children home. We had no relatives in Australia to help us so the council designated a lady to our home from early morning when my husband went to work until he got home at dinner time, she was an angel. Got the children up and the older ones to school and looked after the younger ones like a mother until my husband got home. She cooked every meal [...] she was an angel!! It helped my recovery though to have the children [living with her], even though it was awful being in the same house and being useless.*

As highlighted in the women’s stories, mothering with an illness could be a lonely and isolating experience, as women sought to avoid the judgement of other perceivably more capable mothers. This meant that sources of support and encouragement were highly valued by the women when they were encountered. It was important that the difficulties they had mothering with an illness were acknowledged. However, they still

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7 Australian Home Care is a wholly-owned, not-for-profit subsidiary of the Multiple Sclerosis Society (MS) Limited. They help people across Victoria and New South Wales in Australia with a wide range of care requirements within their own homes.

8 Local Councils in Australia are a level of government that handle community needs like: waste collection, public recreation facilities and town planning.
treasured validation that they were doing a good job. Several women with a mental illness discussed how valuable some community-based consumer support groups were to their self-concept as capable loving mothers, and for providing friendship, and social opportunities.

In her interview, Unity was passionate when discussing a community based consumer support group named GROW⁹: *GROW is a self help group for people with psychiatric disorders. It is bloody brilliant. It is absolutely spectacular!* As well as providing Unity with self-help ideas and support for her mental illness, the group was invaluable in providing encouragement for her as an ill mother. Attending GROW put her into contact with other mothers. Wanting contact with other mothers was a desire of several women in this study.

Unity:  *I would go to GROW and I would bring up problems with my mothering, or what I was doing right, or what I was doing wrong, and there were other mothers there who were helpful. For instance, I was saying to somebody at GROW many years ago, when my daughter was younger. ‘I’m finding it very hard to do anything with my daughter but I do read to her’, and she said, ‘that’s good enough’. She said, ‘look, the fact that you’re bothering to do that is great’. And of course I could bring up with people from GROW, problems from my own family and their attitude towards me as a mother [...] I really needed that validation they gave me, and they did that for me, as a mother.*

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⁹ GROW is an educational/mental health organisation founded in Australia in the 1950s by people who were former psychiatric patients. There are now more than 800 GROW groups worldwide. Despite the capitalisation GROW is not an acronym (Corrigan et al. 2005).
GROW also provided Unity and her daughter with opportunities to socialise and go on holidays, which Unity might otherwise have been unable to afford as she was a single mother on illness benefits.

Unity: *We also have two holidays a year in GROW. When my daughter was at her last school [...] she said to her friends, ‘I’m going away for a weekend’. They said, ‘where to?’ She said, ‘oh it’s a special group my mother knows called GROW’, and it was so cute [...] GROW holidays in the past, my daughter had more freedom there than she’s ever had anywhere else, when she was young, because I know the people and I trust them [...] We’d have a group of kids and they’d just go off on their own.*

Lilly also found encouragement regarding her mothering in a support group called CHAMPS10 (Children And Mentally ill ParentS). While Lilly did not attend the program herself as it was designed to support children rather than their parents, it provided Lilly with respite from her children and the feedback she received regarding their attitude regarding her mental illness was very comforting to her. The women in this study almost unanimously expressed concern that their children may have suffered as a result of growing up with an ill mother. If the women were assured that their children were coping with their illness and were happy and well-adjusted, it relieved them of a great deal of worry and guilt.

Lilly: *When they were younger they used to go to a group near our home that was called CHAMPS. Their [CHAMPS staff] feedback to me was that out of all*

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10 CHAMPS “is a strengths-based peer support pilot intervention focused upon building resilience factors such as coping, connectedness and self-esteem in children of parents with a mental illness” (Goodyear et al. 2009, pp. 296-7).
the kids they took away on camp, mine were the most aware of what was going on, had the most knowledge and showed the most hope. So that was good feedback. That was out of an ad in the local paper; it was only five minutes away.

Children’s teachers also often provided women with a source of support. It was comforting for the women in this study to know that their children were able to obtain support outside of the family.

Dee: One day I went to the high school annual parent teacher interviews and during a chat with my daughter’s home group teacher he confided in me how worried my daughter had been about me and how it was affecting her at school. It broke my heart but I was happy he was such a great teacher and was there for her as well.

For Samantha, who was separated from her sons, the boys’ school principal was supportive in that he supplied her with information about her children’s academic progress, and always deferred to her as their mother despite her non-custodial situation. This was Samantha’s only insight into her children’s academic progress which she reported was withheld from her by her mother who was the children’s legal guardian. Several years ago, one of Samantha’s sons had an accident, which resulted in him requiring an intensive care admission and being ventilated for a period of time. That there was a residual hypoxic injury to his brain was a source of concern for Samantha. The opportunity to speak with his principal provided Samantha both with information and the comfort that her child was improving academically.
Samantha:  *Well, their principal at their school was my Grade 5 teacher, so he knows me and understands my situation. But he still always treats me well even though the boys don’t live with me. It’s not always like that when people find out they’re not with me. So I have talked to him a couple of times and he reckons that my older son is doing better this year than he was last year. They reckon he is a bit slow in reading. But I just reckon it is because of what has happened to him.*

Where women were in and out of hospital for treatment, childcarers and teachers could provide a familiar routine and emotional comfort for their children. This was reassuring for the women in this study who while having their own health concerns to deal with were also frequently worried about the effect of their illness on their children’s emotional equilibrium. Veronica’s eldest son did not cope well with her illness and treatments, and this was reflected in his behaviour at school.

Veronica:  *Usually, on a day where I’m going into hospital or whatever, he will usually have a bad day at school and he might end up getting in trouble or something. I don’t think - he can’t quite handle it. I don’t think he fully knows how to verbalise it and express the emotions […] I worry too when I have to go in. There’s been a few times where he’s come home from school after I’ve been to the doctors or into day treatment and he’ll just cry - I was really worried about you today. So, it’s a lot for him to have to handle. He’s really emotional. I think sometimes he thinks I’m not coming home. I don’t know. It’s hard sometimes.*
However, having child carers and teachers aware of her situation meant that her son could be emotionally supported and his behaviour understood and put into context. This was reassuring for Veronica who continued to be frequently admitted to hospital.

Veronica:  *When I first went into hospital he was going to childcare at that time. They were fantastic, they were really good [...] If mum or my husband were to drop him off, they would just say look he’s a bit unhappy today because of this. They would always give him lots of kisses and cuddles and things like that and make him feel sort of special. They would go out of their way to make him feel better. Even the schools that he’s been going to, he’s at a new school this year, but his teachers knew that I wasn’t well. They would be really good. I would just send them a note and say look I have to go in and have such and such done today. Can you just keep an eye on him because he’s really, he doesn’t cope well. They would be really good too.*

For Karina, it was other children rather than the teachers at her daughter’s school who were supportive. On recommendation from her psychologist, Karina enrolled her youngest child in boarding school when she became too ill with depression to care for herself, and her older two children had left the family home for study. Karina drew much comfort from the fact that her daughter was well supported and had made friends with other girls who coincidently also had mothers with mental illness. This helped to assuage some of the overwhelming guilt that Karina said she experienced when she could not continue to care for her children herself. Having friends with ill mothers also contributed to normalising maternal illness for her daughter.
Karina:  *The school were very supportive, but it was actually her friends who had mothers with a mental illness as well that could support each other. And it’s funny one of her friends said to her “At least your mothers got all her teeth.” The poor kid, you know how some people just can’t afford the dentist, or the medications rot your teeth. She said to her “At least your mothers got all her teeth.” I thought that was gorgeous.*

Prior to sending her daughter to boarding school, Karina’s siblings cared for her children when she was hospitalised. Karina was grateful that they provided her children with ‘normal’ activities and a family environment when it was beyond her capability to do so herself.

Karina:  *They came and took the kids, they took them to the museum, they took them swimming, and they took them out to dinner, and never made me feel like they were doing me a favour. That’s where I’m blessed because a lot of people haven’t got that, and it was a saving grace really. If they had, had to go into foster care, the guilt would have been even more horrendous.*

Help from a sibling was also evident in Unity’s story, as following her discharge from a mother and baby mental health unit; it was her brother’s willingness to live with her that allowed her to retain custody of her child. Although Unity reported her brother had a drinking problem that made him difficult to live with, she was grateful that his presence enabled her to keep her child. When she was very ill, she was also grateful that he motivated her through what she called ‘tough love’ to continue to function and care for her child.
Unity: *He was very vindictive and nasty to me. But I was told before everybody realised what it was [an undiagnosed thyroid condition], that if he didn’t stay with me, I would lose my child. So I was in a real genuine catch 22, because he was drinking every night and very vicious when he drank. When he was not, he was a beautiful lovely guy [...] but what he did is, tough love, get up, you’ve got to feed the baby, get up. So I would, and eventually it became part of me. I imbibed some of his ideas into my own self image. I think that tough love, in certain situations; with schizophrenia it’s extremely good. When people are over any sort of psychotic episode and they’re beginning to feel bad about themselves and what they did, and all that sort of stuff, that’s when it is a really good idea to get people to do things for themselves.*

Later Unity also benefitted from having her father move in with them as well. Although Unity had discussed having a difficult childhood, she found her father much easier to live with as an adult and with her mother gone. Providing housing for her father also contributed to Unity’s feeling of self-worth as she was able to provide for yet another person. It was also beneficial for her as a mother as she gained parenting advice that had been previously unavailable to her.

Unity: *I was kind enough to let him live here, and he would continually say, you put a roof over my head. And I found that very beneficial, being a single mother, because Dad would know things because he had been a parent of four children, that I actually don’t think I would have learnt otherwise, even in your normal nuclear family setup. There were things I learnt that I would never have guessed, and I have come to the conclusion that extended*
families are probably a better idea. Especially when you’ve got mental illness.

CODA

In addition to the actors, there are many cast members responsible for a successful production. Although hidden in the backstage shadows, the collaborative efforts of these others contribute to a play being successful in a myriad of ways. From the set designer to the props coordinator, all offer their own expertise, supporting the lead and the rest of the cast. The success of the performance may depend upon the contributions of all of these backstage members.

Obtaining professional help with domestic chores and physical care was invaluable for some of the women in this study. In one case it allowed a woman to ensure that the physical requirements of her care did not fall to her husband and children. This helped her to maintain the boundaries between herself as a mother and a patient in the eyes of her family. For another woman, gaining a housekeeper meant that her family could be reunited under one roof. Although she mourned her usual role as homemaker, she believed having her children close contributed to her recovery.

Community-based consumer support groups allowed the women and their children opportunities to socialise in a non-judgmental environment. These groups also provided some of the women in this study with a chance to compare their own situation and children’s coping skills with other mothers and children in similar situations. This provided the women with the assurance that despite their illness, they were doing an effective job raising their children.
While the outcomes for children are not the focus of this study, they were especially relevant and important to the women. Women in this study were comforted if their children were well supported and had other caring, empathetic people in their lives. One notable form of support for children existed in their teachers and childcare workers. If teaching staff or childcare workers were aware of the women’s situation, they were often more sensitive to the children’s needs. Knowing that their children were emotionally supported in this way reduced the stress and worry that women experienced regarding their children’s welfare.

Family members provided support in practical ways. Siblings assimilated children into their own families when women were unable to care for them themselves and provided children with everyday familial experiences. Family members could also provide support through the provision of parenting advice. For one woman it was only because extended family was willing to support her that she was able retain custody of her child.
ACT IV – REVIEWING THE PERFORMANCE

We must display ourselves to others, and we must understand something of their response to this display if we would be ourselves

(Wilshire 1982, p. 244)

INTRODUCTION

It is the critics who declare a play a success or failure. Aware that illness had disrupted the script of their maternal lives, the women were therefore sensitive to any critique. Reflecting on the quality of the relationships with their children was one of the ways the women measured the effect of their illness. The outcomes for women’s relationships with their children are examined in Act IV, Scene I: ‘Plot resolution - The consequences for mother/child relationships.’

For many of the women in this study, disrupted mothering raised issues of guilt and culpability, as they discussed how their illnesses had limited what they could do for and with their children, and how feeling ill could influence how they interacted with their children. The women also reported that their mothering was perceived to be evaluated by others. Friends, family and even women’s children were said to cast judgement upon the women’s mothering. The evaluation of their mothering is discussed in Act IV, Scene II: ‘A performance with poor reviews - Critics, guilt and blame.’

Despite sometimes difficult outcomes for maternal relationships, and feelings of guilt regarding their mothering, in their stories the women still sought to establish that their children were adequately mothered. They attempted to establish credibility as ‘good’ mothers by highlighting their children’s personal qualities and ending their stories of disrupted mothering on a positive note. This re-framing of the experience of mothering
in illness is explored in Act IV, Scene III: ‘Re-writing the script - The mostly happy ending.’
Script. Act IV, Scene I: Plot resolution – The consequences for mother-child relationships

Setting

It is twenty years in the future. In a restaurant at dinner time. There are several other diners in groups of twos and threes. Two middle aged women are sitting at a corner table. They have glasses of wine and water and menus in front of them.

Character      Dialogue and Stage Direction

MOTHER         So I just don’t know what to do with him anymore. He’s so hostile. I often wonder if it’s because I was so sick when he was little. But I tried hard to make it up to him.

FRIEND         How’s your relationship with your daughter?

(Puts down her glass and leans toward her friend)

MOTHER         That’s just it! She is wonderful to me, adores me. I might have had a bit more time to spend with her, because I was hospitalised a lot less after she was born and he was at playgroup and then school. But I’ve always treated them the same. He will swear black and blue that she’s my favourite though.

FRIEND         Hopefully he gets over it, perhaps when he has kids of his own.

MOTHER         I hope so. He can be downright nasty to his sister, but she idolises him anyway.

FRIEND         Look mine fought like cats and dogs until they were in their early twenties. Now they get on really well. They move past all that sibling rivalry eventually.

MOTHER         Sometimes I hope that’s all it is, but there’s a hurt in him. And I always feel like it was the illness. All the separations. When he was little, he was really clingy. He would get so upset when I had to go into hospital. I always felt like I abandoned him over and over again.

FRIEND         It’s not like you wanted to leave him. You were sick, you didn’t have any choice. And he was well looked after by family.

(Takes one her friend’s hands and pats it briefly)

MOTHER         I know, but it doesn’t help how I feel. He is really close to his Dad, and his Grandmother. Because they did take such good care of him. It’s just me he’s not fussed on. It makes me sad. But my daughter is the opposite. We’re so close. Knowing what I’ve been through, it’s like she appreciates me more.

(A waitress approaches carrying a notepad and pen)

WAITRESS      Are you ready to order now?

MOTHER         Yes thank you. I’ll have the.....

(Lights fade)
ACT IV, SCENE I: PLOT RESOLUTION – THE CONSEQUENCES FOR MOTHER-CHILD RELATIONSHIPS

The quality of the relationship women had with their children at the time of the interview gave insight into how disrupted mothering may have impacted upon the maternal bond. For the women whose children were now adults, the stories were retrospective and the status of their relationships fairly static and defined. At the time of this study, three of the women with adult children had little or no contact with some of their offspring. While they admitted that difficulties in their relationship could be reflective of the varied relationships experienced by all parents and their children, they still always referred back to the time mothering was disrupted by maternal illness. Earlier disruption to mothering lingered in the minds of these women as a potential cause of later difficulties.

In contrast, the majority of the women enjoyed close and loving relationships with their now adult children. These women also believed that their illness had in some way contributed to shaping the nature of their maternal relationship, albeit in a more positive fashion. For women whose children were still dependent, mothering and the associated tasks were ongoing. Participating in this study provided an opportunity for these women to reflect upon the perceived effect (if any) having an illness had on their mothering and their relationships with their children.

In many cases, women were aware of changes in the relationship with their children while they were acutely ill or incapacitated, and being ill for any portion of their children’s childhood altered the way the women subsequently mothered them. Where their health allowed, women sought to overcome these changes by being more
physically and emotionally available when able, as Yasmin wrote: *And I guess when you couldn't do things you tried to make up for it in other ways.*

However, it appeared that sometimes mother-child relationships were strengthened by sharing a difficult time. For Nora, the experience of breast cancer and its treatment intensified what was an already strong bond between a mother and her only child. The threats to Nora’s health and life contributed to their appreciation of each other:

Nora: *Throughout it all my daughter and I stayed very close. We are still close if not more than before. She is very protective of me in every way. We tell each other we love each other several times a day and she often says ‘I know you love me mum’.*

Separation altered the way women subsequently mothered their children as they attempted to overcome any resulting emotional distance that resulted: *And it changed how I behaved with my son for the rest of my life [...] If something has happened with your mothering that you think isn’t right, you try to compensate or make up for it* (Olivia).

Olivia had successfully mended any perceived breach in her relationship with her son following their separation and this was evident in the almost mystical belief she had in the strength of their bond:

Olivia: *When there’s something wrong with my son, and he hasn’t even rung me, I know it. I don’t know what it is, but it’s like an inner instinct... I mean some other mothers have said to me ‘Well I don’t have that.’ Perhaps it’s just something about the way you’ve mothered your child when he was young.*
Maternal illness was frequently considered a mitigating factor in the quality (either negative or positive) of relationships women had with their children. While Olivia was not certain it was the disruption to her mothering that contributed to her close relationship with her son, she raised it as a possibility.

Olivia:  
I know my feelings for my son are greater, bigger, more. I don’t know there is deepness, an emotional effect that it has had on me. I haven’t seen it in friends with their sons and daughters [...] we have a very, very, very, strong bond my son and me. Not to silliness. But he would do anything for me I know. I would only have to ask. Even though he’s got his own family and his own life. There is something super special. Now whether it was compensating for the time I felt I hadn’t given him the care and attention because I couldn’t, may have increased that.

Due to her illness Unity was subject to a high level of professional intervention and support during her pregnancy and early mothering years. She had been required to attend a court hearing to assess her fitness to become a mother, spent three months as an inpatient in a mother and baby mental health unit, and agreed to weekly visits from social workers and doctors. Yet she managed to continue to retain custody of her daughter despite having schizophrenia and a thyroid condition that was undiagnosed for a long period of time.

Notwithstanding the challenges her illnesses represented, Unity was determined to be loving and kind to her daughter, rejecting the example of mothering she herself had grown up with. Feeling that she had been successful was a source of wonder to her, yet the affectionate and loving relationship she enjoyed with her daughter was demonstrated repeatedly in her story.
Unity:  *My daughter, she is beautiful. She’s got big green eyes, and she’s just absolutely beautiful. She’s a lovely young lady. I’m so proud of her. I didn’t love my mother and I thought of course, my child wouldn’t love me. I used to think, well why does she love me? Why should she? She would say, because Mummy, you’re always nice to me. She just said this morning, Mummy when I’ve been to other people’s places their mother often shouts at them, but you always speak softly to me. So, yes, it’s a blessed thing. My daughter - she validates me every day of my life. Being a mother, it’s the most important thing to me.*

While Nora, Olivia, and Unity were sure of the loving nature of the relationship with their children, other women felt that illness had created a rift between them. Xanthia was very unwell with an undiagnosed parathyroid condition for the early years of her daughters’ lives. Mourning what she believed was a failure to bond, as she recovered Xanthia prioritised mothering over all other aspects of her life in an attempt to reconnect with her children.

Xanthia:  *To look back now I missed out on so, so much of my two girls’ lives from when they were born to when the second one was at least 4 years old. They bonded better with their father and that really hurts now. I am making up for this time and refuse to accept higher positions within the workforce while my two girls are still so young. It is more important to me to bond and be happy with my family [...] If it takes ten years, then it will have to take the ten years. Who knows? My family is everything to me.*

Eliza had postnatal depression for the first two years of her daughter’s life. Although Eliza did not think her depression adversely affected her child, it changed how she
subsequently mothered her. Being ill during her daughter’s formative years caused
Eliza to develop a heightened awareness of how she related to her child, and a deep-
seated sense of justice in how she dealt with her. Because both Eliza and her own
mother had experienced mental illness, Eliza became much more sensitive to her
daughter’s emotional state.

Eliza:  
*I think I do still feel very aware of my relationship with my daughter. If I do get
too cranky, or cross, I become quite apologetic. Because I just don’t want to feel like I’ve let her down. When I first came out I was worried for her, about what had happened and whether in the long term that was going to be a problem. But I don’t think she has any memory of it [...] I think I have to be very aware, well we, both my husband and I, are aware, we talk about emotions and we talk about feelings, and we talk about why you might feel like that, or why somebody said that to you, and how that made you feel.*

Farrah did not believe that her mental illness is any way compromised her ability to be a
good and loving mother; however, her ex-partner was granted custody of their two sons.
While Farrah had a good relationship with five of her six children, the relationship with
her youngest son was fraught with difficulty. Farrah believed that some of the problems
in their relationship stemmed from the sudden disruption to mothering when her ex-
partner assumed full custody when he was two years old.

Farrah:  
*I was breastfeeding him in the beginning, when all of this was going on and he was suddenly taken off the breast and taken to his dad’s and so there was a lot of animosity between his dad and myself. There is still to this day but yeah my youngest son was badly affected by it.*

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Farrah never believed that her ex-partner provided a stable or loving home for her sons, and held him largely responsible for the poor state of her relationship with her youngest child. In Farrah’s story, her son was physically and emotionally abused yet was continually returned to his father by the authorities.

Farrah: *There’d been reports about him [father] hitting him [son], punching him like a grown man. He was 14 at the time. DOCS rang me and said would I take him for a weekend and I said of course I would. Then on the Monday he’d gone off to school and that afternoon he didn’t come home and I thought I wonder where he is. So I rang up DOCS and the guy said ‘oh yes we’ve sent him back to his dad’. And I thought why? So then he ran away from home, rang me from the fruit shop, and his sister went and picked him up. About two hours later the police knocked on the door wanting to take him back home. He was standing there saying ‘I don’t want to go home’. They said he had to, so home he went, really unhappy about it.*

After years of separation, Farrah had her son returned to her. However, by then their relationship was severely damaged. While she was still in regular contact with her son at the time of the interview, who was now an adult and a father himself, they shared a tenuous and delicate bond.

Farrah: *So I had to nurture a very angry young man and unbeknownst to me their father had said I’d abandoned them which I think is one of the worst things you can ever tell a child [...] I’d called the police myself a couple of times on him [son] because he was being physical with me and I just said “I’m not going to give up on you” which I never did [...] But he and I have had a very strained relationship, more like a love-hate relationship which makes me sad.*
So that’s where I am in my life today. Still trying to have a proper relationship with my youngest boy and it’s still not there.

Quin was unsure if her years of illness when her son was young contributed to the later breakdown in their relationship. In Quin’s story, when she was very ill her children were left with people who were only casual acquaintances as her family had recently moved to the town and had no support network. While she was very ill with viral myocarditis it was her youngest child that she was the most concerned about, as he was very young to be left with strangers. It was this son that she was estranged from at the time of the interview.

Quin: My youngest child suffered the most from my absence, saying Sorry does not help […] He now lives in another state and I have very little contact. He will not reply to letters or e-mails, I rely on his partner for any news, I have no idea what we did wrong, he was wanted and loved and now wants nothing to do with me so whether it is the past, or my husband or me I have no idea. After my recovery when he was about three, I made an extra effort to spend so much time with him. I have no idea if it stems from his early years or not.

Women were often concerned about their youngest children during times of maternal illness, thinking that the children were too young to understand and might suffer emotionally. In the quote above, Quin stated that she made an extra effort to spend time with her youngest son when she was no longer acutely ill. Despite this their relationship still suffered. Karina also had relationship difficulties with her middle daughter following maternal illness, largely related to the perception that extra attention was being devoted to the youngest child.
Karina:  *But my middle daughter felt that after that, after I got home, that I was so guilty that I hadn’t been there for the baby, that I favoured the baby. Now I didn’t deliberately favour the baby. But in her eyes that’s what happened [...] I believe my middle daughter has been most affected and because she’s inherited the illness, and when she’s unwell, she is very sensitive. I virtually can’t mention her sister’s name and I have to be very careful. So, we’ve worked out the best thing for me to do when she’s ill is for me not be there [...] She lives far away, so I’m not with her a lot, but when we are with each other we really rub each other the wrong way. And we both try so hard not to do that, but for some reason that’s what happens.*

While Lilly also had some relationship problems with one of her two daughters, she was fairly pragmatic, attributing some of the difficulties she had in her relationship with her older daughter as normal teenage angst.

Lilly:  *My relationship with my older daughter has suffered to a degree [...] I mean she’s warm, and we get on well and communicate well, but she is very critical of me about little things [...] I think at this age it’s blame the mother [...] So it’s sort of the mother bashing stage.*

**CODA**

The portrayal of relationships complicated by the event of illness is what defines this play as a domestic drama. In order to resolve the plot it was necessary to discover the outcomes of the character’s responses to illness and the effect upon interpersonal relationships. The first scene in this act therefore explored the consequences disrupted mothering had for the women’s relationships with their children. As the children were
recipients of the women’s mothering, the quality of their relationships at the time of the study was one way of reviewing the mothering performance.

The women in this study described a range of different relationship outcomes with their offspring. While some of the women had no contact at all with their children, others described their relationships as more special, or deeper than that experienced by other mothers. Nearly all of the women believed that their illness had contributed to the shaping of their relationships with their children, whether this was in a negative or positive way. Where the women in this study had recovered from illness, they were keenly aware of the ways in which their mothering may have been compromised and sought to make amends to their children for perceived deficiencies. However, despite their efforts to compensate their children, some relationships were irreparably damaged.
Script. Act IV, Scene II: A performance with poor reviews – Critics, guilt, and blame

Setting

*In a restaurant at dinner time. There are several other diners in groups of twos and threes. Two middle aged women are sitting at a corner table. They have glasses of wine and water and finished meals in front of them.*

<table>
<thead>
<tr>
<th>Character</th>
<th>Dialogue and Stage Direction</th>
</tr>
</thead>
<tbody>
<tr>
<td>MOTHER</td>
<td>He blames me for being ill you know. He said to my ex-husband once that he thought I played on it for sympathy. And of course since the divorce his father agrees. If anything it was the opposite. So many times I felt so horrible, so sick, so depressed, but I still tried so hard to be there for them. Don’t get me wrong I’m not a saint. There were times when I didn’t cope, and I’d lose it and cry and yell. But that always made me feel worse, I think my entire mothering experience has been characterised by guilt and shame. I was never good enough.</td>
</tr>
</tbody>
</table>
| FRIEND   | None of us are saints darling! The times I cracked it at my kids. You know you come home from work, and there’s dinner to cook, and washing to organise, and school notes, and homework, and they’re all at you for something. I think sometimes they just saw me as the maid slash chauffeur slash ATM.  
*(Lifts the bottle and divides the last of the wine between the two glasses)* |
| MOTHER    | Mmm at least you had money to give them, and could drive them around. At least you were useful to them. We were always so broke when I was ill, because I couldn’t work. It still affects us now. I won’t have much to pass onto them when I die...  
*(Avoids eye contact as she twirls the wine in her glass)* |
| MOTHER    | I used to think about that. About dying, about suicide. I thought for a while during the worst of the depression that they’d be better off without me. That I was a burden, sucking the happiness out of the house and creating work for everyone. |
| FRIEND   | Oh no! How could you have thought of such a thing. They love you and need you. |
| MOTHER    | I remember one day, I could barely get off the couch, and he was meant to go to a friend’s party, and I had to cancel, and he was so upset. And I’ve never felt so guilty in my life. And I thought maybe if I was dead, their father could marry again and they could have a normal mother. One that plays ball and all that... Sorry I’ve gotten all maudlin on you. Cheers, here’s to a rare night out.  
*(Takes up her wine glass, toasts and sips)* |
| FRIEND   | That’s what I’m here for, but you’re right. Let’s lift the mood. Where’s that waitress, I think we definitely need dessert.  
*(Looks around the room for the waitress, beckoning to her when she catches her eye. Lights fade)* |
ACT IV, SCENE II: A PERFORMANCE WITH POOR REVIEWS – CRITICS, GUILT, AND BLAME

Just as every theatrical performance and actor is critiqued and evaluated, the women in this study were subject to their own and to others’ criticism regarding their ability to mother their children whilst ill. In Act I Scene I, women reported feeling guilty or judged by others regarding their ability or choice to breastfeed, and Act II Scene I had many examples of women feeling judged by nursing staff. This implies that for many of the women, maternal guilt was an intrinsic factor of disrupted mothering. The issue of maternal guilt is woven inextricably through almost every scene, which made it difficult to isolate. Although sections of transcripts containing expressions of guilt have been included in other scenes as the subject matter overlapped, such a pervasive issue called out to be addressed independently. Therefore, this scene explores the concept of maternal guilt and blame as it emerged from the women’s stories.

While only eleven out of the twenty-seven women actually said they felt guilty, many others implied that they felt culpable or accountable for perceived shortcomings in how they mothered, and invariably it was their illness that they held responsible. The women in this study had high expectations of themselves as mothers, and believed that by not fulfilling these expectations, they had failed their children. Women often evaluated their own mothering by comparing it to mothering performed by women they knew or saw in public places: When I see other mothers with their children, if they’re a good parent, I feel TERRIBLE, guilty, ashamed, if they’re a bad parent, proud - it could be worse! (Heather).

The women frequently discussed being distressed if they could not respond to the needs of their children, and this had negative consequences for their self esteem. Even when
women were physically present they could struggle to be emotionally present for their
children. Xanthia’s illness (hyperparathyroidism) left her chronically fatigued and
emotionally unstable. Despite barely being able to care for herself, she labelled herself a
flawed mother when she found it difficult to care for her children and home:

Xanthia:  I had no energy, my mood swings jumped around. To walk and eat was
becoming an effort [...] Many a day, my husband found me in my
bedroom, hiding from them, crying inconsolably, for not being able to be
a proper mother who should love and enjoy her children, and for
not having any energy or effort to be able to complete anything [...] My
greatest concern as a mother was the feeling of hopelessness. Have I lost
my marbles? What if it’s just me? I failed as a mother of newborns.

Tanya, too, judged her performance as a mother harshly, offering the unkempt state of
her home and her children’s behaviour as evidence that she had failed to be a ‘good’
mother. Yet repeatedly in her story she expressed the desire to have the kind of
relationship with her children that she had always imagined other women enjoyed.

Tanya:  I wanted to be able to have a bond with our children that other people would
yearn for, except it is me yearning for it instead [...] I want to be a good
mum, but I know I’m not a good mum because, well, look at the house. The
kids argue, they fight, and they shout at me, my son swears at me [...] there
are a lot of emotions tied up in depression. How I wish my life was free of it.

Chronic pain and fatigue lowered some of the women’s tolerance for children’s noise
and activity, making the women more prone to emotional outbursts, which they
reported they were later very remorseful about. As Xanthia wrote: Many a time I
shouted at them (something I totally regret, big time). Ginger, too, who had severe
chronic pain and fatigue from Lyme disease, discussed having difficulty controlling her temper. She had sought counselling to help her deal with her feelings regarding her illness and its impact upon her family.

Ginger:  *Due to my illness I do not feel like I am the mother I could be if I had been healthy. I am now disabled, and spend a lot of time in bed. I have a lot of guilt. I do go to psychotherapy, and it helps, but doesn’t make up for not being here emotionally for my kids all the time. I hurt so much that even hugs from my children hurt. Now that must be confusing to a kid! I also get really irritable when my pain is high. I tend to blow up and yell for dumb reasons. The things that bother me most are how this whole illness and process affects my children. I feel sad.*

Regret also existed in lost opportunities. Being ill affected the majority of the women’s ability to engage in paid employment, which in turn impacted upon their families’ financial security. This caused some women to feel that their children were at a further disadvantage as a result of their mothers’ illness.

Dee:  *I also feel badly for them as I feel sometimes like they missed out on a lot as well cause we also struggled financially as I haven't been able to work full time, so we never had the nice family holidays or were able to buy a home, we did try and struggled on one income so we had to sell. I do feel like my illness has robbed us of great family memories.*

Another source of remorse existed for women who required assistance from their children with physical tasks. While the women in this study did not like asking their children for assistance, some things were physically beyond them. Needing help from
their children, however, threatened the usual order that exists in mother-child relationships, or as Maggie said: *I think parenting is often seen as a capacity thing. Parents are more capable.* Maggie, who was temporarily blind for a time, was very reliant on her eldest child and felt that this had consequences for their relationship.

Maggie: *I was really glad when I got my eyesight back. It was so frustrating [...] not being able to see was horrible. That put a lot of strain on my relationship with my son. Because in order to do anything, I had to get him to do it or help me.*

After her sight returned, though, she only needed help with things that required two hands due to her hemiplegia: *My daughter will help me with my bra and that. My son ties my shoelaces [...] I usually manage one way or another* (Maggie).

Although being disabled changed the dynamics of her relationship with her children, it must be noted that Maggie was one of the few women who did not express guilt about what she described as her ‘diminished capacity.’ Instead Maggie viewed the need for her children to be more independent and responsible in the house as beneficial: *So mothering isn’t the same. But it’s a bit of an ego trip to think that you’re so important. Kids have got to grow up anyway* (Maggie). However, for Yasmin, seeking physical assistance from her young daughter was such a source of anguish that it made her question her legitimacy as a mother.

Yasmin: *As she got older I would get her to help me with the groceries as I couldn't push the trolley or bend to get things out. Was I turning her into my carer at times? What kind of mother does that?*
Guilt about their capacity as a mother affected some of the women so severely that they considered suicide. Several of the women discussed their death possibly benefitting their children. Tanya spoke of entertaining thoughts of suicide and making half-hearted attempts but not being able to go through with it. Frequently when telling her story, Farrah discussed being distressed because her sons were in their father’s care and she thought that they were desperately unhappy, and poorly cared for there. Thinking about her children being unhappy and at risk left Farrah feeling very desperate and she had attempted suicide several times.

Farrah:  *They would often say “oh wish we could come and live with you mum.” But it wasn’t an option because I assumed he had full custody. To hear them say they weren’t happy there made me feel so guilty and I took it all onboard. I tried to kill myself a few times because of the whole scenario. I thought I’d be better off out of their lives and they could get on with their own lives because it was like... they were stuck as well at the time.*

While some of Farrah’s inclination to commit suicide may have been caused by her mental illness as well as maternal guilt, Maggie, whose illnesses were physical, stated that thoughts of suicide are to be expected when a woman feels that her illness is negatively affecting her family.

Maggie:  *Thoughts of suicide are so normal; the main thing with me was I didn’t want to be a nuisance. Killing yourself is such an obvious thing to do [...] it becomes a moral duty [...] I think you can almost guarantee, that people who have been in this position will think about whether it’s better to keep going or not. Do you struggle to keep going, or you think, would it have*
been better if I’d died in hospital? [...] Death becomes an obligation [...] I thought about it seriously. I had the necessary pills available, they’re still there actually [...] And it seems as though someone will give you medals if you free your family of the burden that is your sick self.

Lilly thought that because her children were well adjusted despite her illness that perhaps they did not need her. This added to the grief and guilt she was already experiencing while she was separated from them in hospital, and compounded the symptoms of her mental illness.

Lilly: Over the time I had made six suicide attempts, and after one of the occasions, the kids were here and they seemed so happy, and I said to the staff, it didn’t seem to matter [...] When they came to visit me emotionally they were okay. They weren’t clingy and there were no tears at separation. I was dreadful, but guilt was the major problem, terrible, terrible guilt. Because of the depression my self esteem was so low anyway. So I would feel very useless and hopeless and a bad mother.

At the time of the interview Lilly stated that her mental health was much improved. She said: I have much more insight now and certainly a lot more strength, a lot more capacity to reach out for help. I’m well controlled with medication now. So not finding myself in emotional states where I’m prone to impulsiveness. Yet the repercussions of the earlier years of mothering in illness were still felt acutely. As her daughters grew, Lilly felt she had to defend herself to them regarding decisions she made while ill and vulnerable, as well as some situations over which she had no control. Lilly never wanted to leave her children with her ex-husband while she was ill or hospitalised, yet she said her eldest daughter still blamed her.
Lilly: The psychiatrist [Lilly’s daughter’s doctor] described it as an abusive and neglectful situation, which did not help me. I couldn’t do anything, but my daughter says to me “Why didn’t you get the Department of Community Services in?” I said to her “Had the Department gone in, they would have found two children who had had breakfast at the table, and were ready for school, who were getting fed, and didn’t miss a day of school”, I said “There would have been no indication for you to be taken away unless there were overt signs of abuse, they don’t take into consideration emotional abuse, unless there has been a complaint from the school or somebody else.”

Veronica also found herself having to answer to her eldest child. Her son was aware that his mother had been more available for his younger brother as her health had improved. This compounded the guilt that Veronica had as she was also aware of the difference, having been very ill when her eldest son was younger and more dependent.

Veronica: I feel really guilty because I wasn’t able to give my older son the attention that I was able to give my younger one. It’s a bit unfair and he sometimes will say to me “I’d just like to be able to spend time with you without anybody else.” He thinks I love the younger one more than him. Because I seem to do more things and I’ve just explained to him that it’s only because he’s little that he needs more attention. That’s why dad does a lot of things with you that I can’t do. But it doesn’t mean that I don’t love him any less.

For Karina, having a mental illness was made worse by not being able to pinpoint an instigating factor. The first of her family to be diagnosed, she said she was poorly
judged by them. It was only later when multiple members of her family also developed mental health issues that the genetic element of her illness became apparent.

Karina: *It was bad enough to be ill. It was bad enough that people didn’t think I was ill, but the guilt from not being there... [...] for me the worst thing about trying to mother with an illness was not being believed. Not just fighting the illness, but fighting everyone around me [...] fortunately in our family there’s no horrific child abuse or incest or anything like that. And that was another thing that made me feel guilty, that I didn’t have anything to blame [for having a mental illness]. It wasn’t until I realised that it was genetic that I let up on myself.*

With no previous experience of mental illness, Karina’s family and friends struggled to understand, and she was pronounced lazy, self-absorbed, and prone to hysteria. This had consequences for the support she received when not hospitalised. Karina also pointed out that had she been diagnosed with cancer she thought she would have been inundated with sympathy, but being diagnosed with a mental illness she was doubted and not assisted.

Karina: *I mean it was also my own family because nothing like this had ever happened before, but it was very much in-laws and some friends. So I got no support. I mean I got support in that if I was in hospital my family took my children, but nobody believed me. So when I came home, no-one ever bought me a meal. No-one ever bought me a meal because I should be doing that myself. I should be big and strong enough. I’ve got a husband, a house, and car and why can’t I cope?*
As well as from her own family, Karina said she was subject to judgement from her ex-husband, who she said shared his views regarding her illness with their children. Having others disbelieve that she was truly unwell added to the guilt Karina was already experiencing being separated from her children during the periods of hospitalisation.

Karina:  *Because I began to think that I must be lazy and useless and of weak character, as my ex-husband used to say to the kids when they were teenagers. That I had a weak character and that’s why I was like I was. It was very cruel [...] and the guilt, I was riddled with guilt. And everybody played into that. My ex-husband told me I was a bad mother and I wasn’t a bad mother, I was an absent mother, because I was sick. I was an absent mother because rather than be a bad mother; I chose to go to hospital. That was the choice I made, rather than to neglect my children [...] the separation from the kids, for me it was excruciating.*

Women who did not live with their children actively resisted exposing themselves to judgement by choosing not to reveal that they were non-custodial mothers. Samantha, whose children lived with her mother in another state, misinformed potential employers in order to avoid feeling censured.

Samantha:  *I have been going for job interviews and I tell them that I have got two kids. I just say that they are in school now and my husband is just around the corner so he can take care of it.*

Farrah also misled colleagues about her custodial state when she was working, rather than subject herself to their curiosity. Her story implied that she had previously experienced negative reactions from others regarding not living with her children. The
women in this study who did not live with their children were well aware that they were contravening societal expectations of mothering and sought to reduce the opportunity other people had to offer negative comments.

Farrah:  *Other people can be very critical. When I was working for the bank, I never told people at work I even had the two youngest boys because then would come the questions and the criticism and I didn’t want to go through that. It was bad enough not having them without having people at my job give me a hard time as well. But in the end I had to leave work, I was just filled with so much sadness that I couldn’t function properly.*

**CODA**

As the lead actors, the women felt pressure to carry the play that the production of mothering depended upon them. When the women faltered in the role, the cast held them responsible and the critics were swift to condemn their performance. Having let the production down, the leading actors experienced shame. Constrained by the script of illness, they detested the need to be carried by other cast members.

At some point in time the majority of women had experienced feelings of guilt regarding their illness. The women reported that due to their illness, they were short-tempered with their children, were at times poor housekeepers, and that their children had missed out on opportunities. They felt inadequate when they required physical assistance from their children, feeling that this altered the status quo of normal parent-child interactions. Feeling guilty had consequences for their feelings of self-worth about being a mother that culminated in several women considering or attempting suicide.
As well as harshly evaluating their own mothering, women discussed being judged poorly by others. Ex-husbands, extended family and friends, and the women’s own children were all said to have questioned the women regarding their capacity to mother, or choices they made while mothering. This judgement was despite women often not being in a position to make choices, disabled as they were by illness. Work colleagues were also a source of concern, with women describing withholding information about custody for fear of being judged poorly as mothers.
Setting

In a restaurant at dinner time. There are several other diners in groups of twos and threes. Two middle aged women are sitting at a corner table. They have coffee in tall glass mugs and plates of half-eaten cake in front of them.

Character Dialogue and Stage Direction

FRIEND I’m stuffed, that was wonderful. So how’s your daughter getting on at uni?

(Puts her spoon down and leans back in her chair)

MOTHER She is doing so well. I’m so proud of her. She is getting top marks in every class. I think she’s really suited to the course because it’s about helping people. She’s always been such a sweet compassionate child. Very mature for her years. I met one of her lecturers the other day, and she went on and on about what a good student she is. It’s always nice to hear good things about your kids from other people.

FRIEND I wonder how much of that stems from growing up with an ill mother?

MOTHER You know, I’ve thought that myself. It might have been a bit rough for her at times but I think being around illness and hospitals when she was little has made her more aware. Even now she’s sensitive if I’m having a bad day. And she’ll defend me against her brother.

FRIEND And how is he getting on in his new job?

MOTHER He loves it and they love him! They think he has so much potential; they’ve started grooming him for a management position in one of their overseas offices. Mind you his resume is excellent. He breezed through all of his studies. He also worked summer jobs so I think that’s put him ahead of the pack too. I’m very proud of him. He’s driven to succeed and live the life!

FRIEND So they’re both turning into fine young people! You must have done something right, they don’t raise themselves.

(Laughs)

MOTHER I know, I know. I’ll take some credit. I think all the early reading and stuff we did set their feet firmly on a road to success. They’ve always excelled at school, it became second nature. And I survived those early years. The illness, the depression...they must have inherited some of my tenacity. But enough about me and mine. How are your three going?

(Lights fade. Curtain closes)
ACT IV, SCENE III: REWRITING THE SCRIPT – THE MOSTLY HAPPY ENDING

Despite expressing feelings of guilt and culpability, the women in this study generally ended their stories of disrupted mothering on a positive note. Unhappy in the role of the patient, the women took advantage of participating in this study to re-write the script of their lives, casting themselves instead into the role of the ‘good’ mother.

Revealing a re-captured joy and commitment to the mothering role, many of the women discussed looking ahead to better times. Sifting through their experiences during the storytelling, most women found positive outcomes for their children in the form of personal, academic and professional success. One predominant thought was that their children were more compassionate people due to being exposed to their mother’s illness. Lilly stressed how charitably her daughters accepted the demands of her illness and sought to put her mind at ease regarding their welfare when she felt she was becoming unwell.

Lilly: The older one well, recently I said to her “Cross your fingers and toes, because I’m worried that I might have to go into hospital,” and she said “that’s all right Mum, you go. If you have to go, you go. We’ll be all right.” The younger one is the same, very generous, they don’t think “Oh my God, and how is this going to affect me?” Very caring.

Although Karina’s relationship with one of her daughters was strained, she was still very proud of all her children. Like many women, Karina felt that being exposed to her illness had increased her children’s awareness and empathy, and that despite being ill she must have mothered them effectively for them to have turned out so well.
Karina:  Such amazing, compassionate human beings. They don’t hold it against me. They don’t judge me [...] they are just remarkable human beings. I am so proud of them. What we have all been through together has contributed to that very much. Their insight into people with a mental illness is just amazing. And they are so non-judgemental [...] My son, if I listen to him talking to his patients, I just about cry. He is so respectful, so understanding, and the same with my middle daughter [...] you know you don’t see that respect from young people anymore. I think to myself, well, I wasn’t there some of the time, but some of my skills or whatever has passed onto them [...] they are beautiful, stable, all have good jobs.

However, Karina was especially moved by her youngest daughter. Despite sibling rivalry, Karina stated that this daughter looked after her older sister when she was unwell with mental illness, displaying compassion that disregarded any difficulties in their relationship.

Karina:  My youngest daughter is the most gorgeous child. She’s so tolerant. When her sister is sick, she goes down, she cooks for her, she loves her as much as she can, she supports her, she buys clothes for her. And she still has no animosity in her, she has no jealousy. She is the quintessential child who did miss out, but who has learnt from it.

Even Farrah, who mourned the difficult relationship she had with her youngest son, felt that despite growing up with a mentally ill mother, he had found success in suitable employment and a stable relationship. Throughout her story Farrah provided many examples of the animosity her son displayed to her, yet was still able to find positive things to say about him when concluding her story.
Farrah:  The youngest is now a corrective services guard which I think is the right vocation. He can be angry with them. I just tried different things that I’d learnt through my study and encouraged him to do things that would make his life better and he always had good jobs, well paid jobs and now he’s settled into corrective services and he loves his job and has three beautiful kids.

Most of the women described their children in glowing terms, which is perhaps indicative of a greater appreciation for their children, and a legacy of times when they were prevented from mothering them in the way they felt they should. The women in this study had children who they felt were ‘smart’, ‘happy’, and ‘beautiful’. Rachael wondered if her son’s experiences of having an ill mother made him more inquisitive. *He is one smart little boy very, interested in what is happening, I don't know if he has become more like that because of all of this.*

By seeking the positives that were gained from their experiences of disrupted mothering, women were able to frame the experience in a more positive light. Isabella thought the time she spent at home ill with her son had contributed to his intelligence and his ability to interact with adults.

Isabella:  *He is extremely intelligent, and I think that’s from spending so much time with adults, and since I haven’t worked the whole time [...] He is like a little man, that’s what everyone has always said about him. I can have an actual conversation with him, just like he is a grownup; it’s kind of cute.*
Like Isabella, Veronica found her son delightful, stressing that other people agreed. Women in this study cited outsiders’ positive comments about their children and this highlighted the value of external validation for maternal self-esteem.

Veronica:  *He’s always been a really smiley sort of kid. He just has thing charisma that when he meets people, they just think he’s fantastic. Probably because he’s really friendly, which is good; he’s always smiling even now. He’s just very charming. We were always getting comments when he was younger and still do now that he’s just such a wonderful person to talk to and stuff like that.*

For Adelaide, whose baby had passed away, confirmation from others regarding the uniqueness of her child was especially appreciated given the brief time she had to mother her. Acknowledging the beauty of her child contributed to maintaining her personhood, and verifying her existence.

Adelaide:  *And everyone said, there’s just something special about this kid. I don’t know there was something amazing, it was like she glowed, it was really weird. And it might sound stupid if it was just coming from me, but it wasn’t it was everybody that saw her. They’d say Oh my God, she is so beautiful. People used to say that she was just too beautiful, you know that verse...? Too precious for this earth, that one [...] Lots of people forget that, that one was your baby too.*

The extent to which children were affected by maternal illness was significant to the women as they felt responsible. Maternal guilt and worry were mitigated and the
women were comforted if their children were socially well adjusted, affectionate and able to engage well with others.

Jane:  *Looking back, I don't think that my being sick affected him like I was worried it would. He's either ahead or on track with all of the developmental milestones, and is an extremely happy, loving toddler.*

No matter the outcome of maternal illness, women attempted to find positives. While Dee had many regrets about how her illness had influenced her children, she prided herself that by not yielding to her illness she had been the best possible mother, and that her children had learned valuable lessons from her.

Dee:  *There have been times where I would struggle to get out of bed but knew I had to for my girls. They are the lights of my life and I am so proud of them all, but wish they didn't have to endure watching me go through chronic illness [...] I don't mean to blow my own trumpet but I do believe that one aspect of my daughters being so well grounded and compassionate is from what they saw me go through and how strong I always was (although I'm not so strong anymore), the years have taken their toll.*

After stating that her family made her feel lazy and self-indulgent in the earlier years of her illness, Karina later felt vindicated. Gaining control of her illness symptoms, and finding a vocation as a consumer consultant, Karina not only had an opportunity to help change health care practices for other people with a mental illness but she also felt she set a good example for her children and proved herself a hardworking woman of value.

Karina:  *This has been the best thing I ever did. And you might think that that’s not to do with mothering but it is. Because now my children see me as someone*
who isn’t weak, and isn’t lazy, and who has a lot of good qualities, and who can actually earn her own living and do what I do. So for my children, that example is that you can almost survive anything. You can go through the most horrific situations and be a survivor.

Farrah, too, felt that she had provided a positive role model for her children when she graduated from university. As well as studying she was politically active on campus. Farrah stated that this was an empowering time for her, considering she found it difficult to leave her own home due to her overwhelming agoraphobia and anxiety.

Farrah:  When I graduated from university I just was on such a high and then I encouraged the others so my daughter is now studying. My elder son and I graduated the same week so I waited and had photos taken with him [...] yes, so I am proud of all of them because they’re all achieving and following the things they really wanted to do. I sort of led the way for them and they’ve thought well if Mum can do it we can.

Cate’s legacy to her children was a desire to get on with life which included a staunch work ethic.

Cate:   My being sick has also shown my children how to tough things out as things could be worse. For example when I was diagnosed nearly four years ago with ankylosing spondylitis they saw me scream in agony getting out of bed, and saw my husband dress me, and me hobbling to the car to get to work. They all know that they have to be pretty sick to not do something [...] I think that my being ill has made them want to achieve in life. I think they realise that an illness can strike at anytime and make life that much shorter.
The women in this study believed that the role modelling they had provided, as well as the children’s increased awareness of the possibility of illness, had contributed to their children pursuing goals and achieving in life. Nearly all of the women who had adult children catalogued the children’s academic or professional successes, providing evidence that their children had turned out well.

Dee:  *I have three successful daughters my eldest has an advanced diploma and has been married for five years with two beautiful children of her own. My middle daughter has bachelor degree [...] has been working for three years in her profession and is engaged to be married. My youngest daughter has a certificate and she is currently trying to find work in that field but for now working in a shop.*

For Maggie, academic or professional success for her children was a secondary consideration. Her priority was to raise well-adjusted secure people who knew their own mind and pursued what made them happy. She believed that the skills her children had learned taking on more responsibility at a younger age stood them in good stead in their future. By considering the outcome for her children in this way, Maggie was also able to find the positives in disrupted mothering.

Maggie:  *But I think it is more important that children feel loved. So if my illness is interfering with that, with them feeling loved and appreciated then that’s a real problem. It hasn’t hurt my son. Because he had to do the cooking for me, and he was willing to do it, he’s sort of been foisted into a commercial cookery course. He’s really enjoying it.*
With the exception of Alice, whose prognosis was uncertain, the majority of women had either come to terms with the limitations placed upon them by their illness, or had recovered to a certain degree and were looking forward to the future. There was a sense of carpe diem (seize the day) as they found a new joy in their children and mothering that had been absent during the more acute periods of illness. Xanthia in particular was resolute in her quest to compensate her children for their earlier years when she was ill and physically and emotionally unavailable.

Xanthia: *My life after this operation has been fulfilling, rewarding and everyday I do not forget where I was at and where I am now. I pray my blessings [...] I have the love of my family and the girls turn to me when they are unwell. I look at my life now and know that we are on the right road. God Blessing. We are stronger now than we ever were.*

Eliza, who had given birth to her second child and not experienced a recurrence of postnatal depression, expressed gratitude that she had contracted the illness and been successfully treated as it had resolved issues she had with her own mother and childhood. Having experienced disrupted mothering, she had a new appreciation for what mothering entailed, and developed a more relaxed approach to raising her children.

Eliza: *But when my son came, I was a different mother anyway. And the breastfeeding was a lot easier, and you knew the nappies didn’t have to be changed every single minute of the day, and they [babies] don’t have to be washed every day. A lot more cruisy which was a good change that had come about [...] I think I’m just a ‘normal’ mother now. I’ve learnt that we have good and bad days, and I’ve learnt ... I think it’s very ... to do with the*
moon or something… Sometimes we’re totally together and in sync and in love, and then the moon moves over to this side and we kind of become… just that slight bit more distant for a week or so, not so needing each other.
So I’ve learnt that, it kind of goes round in a circle.

Recovering from her illness left Isabella with a profound sense of joy in everyday mothering activities. Her story ended upon a note of freedom, reveling in her ability to engage in ‘normal’ mothering activities. She credited her experience of disrupted mothering with making her a more relaxed and ‘fun’ mum, in her own way claiming the identity of the ‘good’ mother for herself.

Isabella:  *All the kids always want to come over here because I let them paint and play with playdoh inside! [...] I always, say, eh, it will wash! [...] I really appreciate stupid little things now, because I couldn’t do them for so long. Like getting up and getting him dressed and heading out the door whenever we want to go wherever we want. And I think that a lot of people take that for granted. I don’t think they realize what it’s like to be chained to your house because of illness. And what it’s like to miss out on things with your family because of that. I don’t know that anything is different between us and other mothers and kids. Just he is the most important thing to me in the world, and while it was hard to be away from him during the surgery and the recovery time, it was worth it to be able to sit in car line at preschool, and to go on field trips.*

Winter explained why some of the women in this study may have developed a different outlook on life following disrupted mothering in illness.
Winter: I think it puts things into perspective. You appreciate what you HAVE got, not what you will lose. You also shift your thinking from tomorrow, next week, next year, next 20 years, to now, the next second. So this has a profound effect on a person and their family and in my case the way you parent.

For Karina, who repeatedly described being guilt-stricken over her perceived failings as a mother when her children were young, the story of disrupted mothering came full circle. In her later years, in control of her illness, she found a new joy in mothering her adult children that had been absent in earlier years.

Karina: So my greatest achievement in life is being a mother. It’s having the kids that kept me going. At that point in time when my husband was away, who was going to feed them if I didn’t? Who was going to bath them and wash their hair? Even my daughter as an adult, when she was very sick, I visited her and she was mute on the floor, I bathed her as an adult and I washed her hair. And it was the most beautiful thing. She couldn’t do it. I remembered when I was sick and I bathed them and washed their hair. And they have the most beautiful long hair. But I did it with no feeling. So that second time when she was sick, all the beautiful mothering juices were there.

CODA

Cast into the patient role, the women did not write the script of mothering disrupted by illness, but nonetheless had to perform it. As they assumed the role of the ill mother they found elements of the script distasteful, portraying them as inadequate artists. Subtly they altered the script with each new performance, uplifting the ending and
leaving the audience with hope. Recognising their contributions to the performance of mothering imbued the production with a sense of accomplishment. The women rewrote the script, and re-framed themselves as heroines triumphing over adversity.

Although relationships were sometimes damaged, most of the women still had positive things to say about their children and their outcomes and the children’s academic and professional successes were offered as evidence that they were adequately mothered. Where they were too young to have achieved academic success (or in one case the child had passed away), these children too were described in terms of being special.

In several stories women spoke of being a positive role model for their children by teaching them about adversity and mortality, which encouraged the children to live their lives to the fullest while they were able to do so. Living with their mother’s illness also contributed to the children’s increased maturity, empathy and understanding.
EXEGESIS

What do we want from each other
after we have told our stories do we want
to be healed do we want
mossy quiet stealing over our scars
do we want

(Lorde 1986, p. 61)

INTRODUCTION

The women’s stories were unique reflections of their own lives and circumstances and, as such, not generalisable. However, there were similarities in their experiences as mothers that allowed the construction of Acts and Scenes, and a script that amalgamated their experiences into a chronological narrative. Henceforth the Acts and Scenes in their totality will be referred to as ‘the play’. This section of the thesis subjects the play to a scholarly examination in light of the extant literature.

The play contained several plots including the difficulties women faced when mothering was disrupted by illness, their experiences of treatment and health care, the social support they received and the outcomes for their relationships with their children. Pervasive in their accounts were: a preoccupation with the ‘type’ of mother they had been; how the quality of their mothering was judged by themselves and others; and, experiences of guilt and shame. These plots have been elaborated on under three main headings: ‘Disrupted Mothers: Flawed, Ambivalent and Guilty’; ‘The Morality of Early Mothering: Treatment and Threat’; and ‘Social Support: A Multifaceted Phenomenon.‘

Similar to the way in which the women’s experiences were distilled into the scripts that preceded each Scene, within this Exegesis scripts have been written for each plot. In Exegesis the scripts follow the text, offering an alternative performance to that dictated
by the original play. The title of the new performance overwrites the script heading of the original plot.

**DISRUPTED MOTHERS: FLAWED, AMBIVALENT AND GUILTY**

The recruitment advertisements for this study called for participants who identified they were disrupted in their mothering by illness. By responding the women recognised that the course of their maternal lives had been disrupted. Women in this study perceived that illness had caused them to transgress the standards of ‘good’ motherhood and that their culturally defined obligations to their children were unfulfilled. Obligation and responsibility for children is a recurrent theme in studies of ill mothers. In her research with women with HIV, Wilson (2007) initially avoided questioning the women about their mothering as she thought it was too sensitive a topic for inquiry. However, the narratives she collected were saturated with accounts of motherhood. Women in this study were ardent in their need to establish their identity as ‘good’ mothers, locating the discussion of their illness and treatment in the context of its effect on their ability to mother, and their view of themselves as mothers. Although women were threatened bodily by the disease, it was the threat to their capacity to mother their children that mostly concerned them.

Many studies that have examined mothering during illness have found participants distressed by the times their illness, hospitalisation or fatigue prevented them from mothering to their usual standards (Backman et al. 2007a; Elmberger, Bolund & Lützén 2000, 2005; Elmberger, Bolund, Magnusson, Lutzén, et al. 2008; McKay 2004; Savvidou et al. 2003). Exactly what compromises mothering, though, is complex, and the ‘work’ of mothering is largely hidden, misunderstood, and undervalued (Boyd 2002; Ruddick 1980). Francis-Connolly (2000, p. 285) comments that the “enfolded
aspects of mothering work” is the reason that the complexity of mothering is misconstrued. Its very ordinariness masks its intricacy (Francis-Connolly 2000). One aspect of mothering work that is rarely taken into account is that it often occurs in tandem with other activities. While a woman is involved in either tasks or leisure, more often than not the children are present. This means that even while she is not directly engaged in labour for the child she is still actively engaged in mothering (Forssén & Carlstedt 2008).

The tasks of mothering discussed by the women in this study included cooking, cleaning, minding, transporting, entertaining, playing, hygiene, educating and expressing love and affection for children. These descriptions of mothering reflect aspects of the mothering role defined in the literature as “physical, emotional, social, and nurturing” (Esdaile, Farrell & Olson 2004; Francis-Connolly 2000; Poole, Willer & Mendelson 2009, p. 214). Invariably the women felt that they had failed to satisfy one or more of these activities at some point in their mothering history.

Notable in the stories was the enduring concept of maternal responsibility. Even when they did not have custody, and despite sometimes severe and debilitating illness, the women in this study still felt primarily responsible for their children. Being unable to fulfil their perceived obligations to their children resulted in feelings of guilt and shame. To help counter this guilt and shame the women framed their stories in such a way that the outcome of their mothering, that is, their children, were displayed in the most positive light possible. The issues of unsatisfied obligations, maternal absence and framing motherhood will be discussed under the following headings, ‘Flawed and Faulty’, ‘Ambivalence and Absence’, ‘The Inevitable Guilt’ and ‘The Measure of a Mother’. 
The mothers in this study described themselves as flawed in numerous ways. For some women, their bodies represented imperfect vessels from which to bear their children. For others, the illness affected their ability to breastfeed or their breast milk was tainted and impure due to medications. For many of the women, their inability to be emotionally present and ‘there for’ their children was what made them feel inadequate. Being unable to engage in some of the more physical aspects of mothering was raised repeatedly by participants as a distressing element of disrupted mothering.

As women often evaluate themselves in terms of their ability to care for others (Kayser & Sormanti 2002), being unable to participate in physical activities can severely impact upon women’s views of themselves as mothers (Mitton et al. 2007). Yet mothering can be an intensely physical endeavour, especially with younger children, infants and babies, who require and desire to be held, rocked, lifted, carried and comforted (Griffin 2004). Echoed throughout the literature on maternal illness are women’s concerns that they are failing their children by being physically incapacitated. Women in a study of mothering with chronic inflammatory arthritis described their performance of mothering tasks as “sometimes I can, sometimes I can’t” (Backman et al. 2007a, p. 383), illustrating the unpredictability of their lives and their fluctuating physical state. The women in Backman et al’s (2007a) study had renegotiated their idea of themselves as mothers in order to accommodate their physical restrictions, lowering their expectations of what they could accomplish for their children. While some women expressed sadness, feeling that their illness restricted their children’s activities, others were more pragmatic, accepting their limitations.
In a recent study of mothers with scleroderma, participants reported that they had difficulty transferring, lifting and carrying younger children, which was frustrating, dangerous and frightening (Poole, Willer & Mendelson 2009). Not being able to engage in physical play with their children was another aspect of mothering that was worrying for those participants.

High levels of fatigue can be particularly debilitating and also affect women’s engagement with their children (Poole, Willer & Mendelson 2009). Other researchers have also reported women’s concerns at being unable to participate in sports with their children, and concerns about being able to provide children with transport to sporting events (Evans & de Souza 2008; Mazur 2006; Murphy, Roberts & Herbeck 2011; Poole, Willer & Mendelson 2009).

Pervasive in some of the women’s stories in the current study were descriptions of being unable to cook or clean to a standard they felt their children deserved. Although some do not consider that housework constitutes a mothering activity (Kittay 1999), the mothers in this study made no such distinction. In Swedish studies of women with cancer, participants also discussed their ability or inability to engage in housework in terms of their mothering capacity (Elmberger, Bolund, Magnusson, Lutzén, et al. 2008). In a New Zealand study of women coping with chronic pain, some participants believed that their children assumed a much larger share of household tasks than children whose mothers were not ill (Evans & de Souza 2008). Although these mothers thought that increased independence was a positive outcome of more responsibility, some of them felt guilty and thought that their children were sacrificing their childhoods. This idea was echoed in a study of Canadian mothers who had cancer (Fitch, Bunston & Elliot 1999). Other studies have emphasised that women disabled by illness may actually seek
to protect their children from engaging in more housework by overcompensating themselves (Cohen 1998; Mazur 2006; Prilleltensky 2004). Yet surveys of parents and children have found that children of ill women may in fact undertake similar amounts of housework as children whose mothers are not ill, and that how much domestic labour a child should undertake is constantly negotiated ground between most parents and children (Mazur 2006; McKeever et al. 2003). Many parents who are not ill struggle with balancing children and housework and this may be a salient observation for health professionals to impart to women experiencing illness or facing medical treatment to help mitigate some of their concerns.

Recognising the conflict inherent in being both a good parent and a good patient, Semple and McCance (2010a, p. 1287) recommend giving parents “permission or guidance to ‘let go’ of some of their parenting responsibilities during the acute phase of treatment”. Placing children into part-time childcare was another finding in the literature that could be of benefit to women physically incapacitated by illness (Farber 2004). Mothers who had disabilities were grateful for childcare workers who could pick up and carry children and engage in physical play with them. However, despite being grateful that their children could receive this type of attention, the women were envious that they could not provide it themselves (Farber 2004). Exposing the concerns mothers have when they are unable to cook and clean for their children and play with them extends understandings of women’s experiences of sickness and wellness. It is apparent from the current study and supported by the extant literature that mothers who are ill experience a sense of loss and consider themselves flawed when they cannot fulfil the more physical aspects of mothering.
**Ambivalence and Absence**

Illness can also impact negatively upon mothering by diminishing women’s emotional engagement with their children, even when they can still undertake the more physical aspects of the role. Dealing with the symptoms of their illnesses and their perceived inadequacies as mothers, several of the women in the current study reported experiencing a lack of joy in mothering. Although they attempted to satisfy the needs of their children, they derived no pleasure from it. Despite being physically present, they were emotionally absent. Participants in a study of mothers who had bipolar disorder also described going through the motions of mothering, performing the everyday activities such as cooking, cleaning, and making sure children were fed, clean and dressed but deriving no joy from the activities (Venkataraman & Ackerson 2008). Also supporting findings from this study, some of those participants stated they could be unjustly irritable with their children (Venkataraman & Ackerson 2008). Even though the ‘doing’ of motherhood without joy is well recognised in the mental health literature (Barr 2008; Montgomery et al. 2006; Venkataraman & Ackerson 2008), it is less evident in the articles that explore mothering with physical illnesses. However, in Grant’s (2001) study of women with arthritis, women also described feelings of being unable to enjoy their children despite feeling that finding pleasure in children and their accomplishments was an intrinsic part of mothering.

Many of the participants mourned for what might have been had they been well and able to mother to their full capacity, and their stories often revealed how they measured their own maternal worth in comparison to ‘other’ mothers. Their narratives assumed that mothers were normally sources of strength and succour for their children; however, illness threatened the usual order that exists in mother-child relationships. Discussing ‘other’ mothers, ‘proper’ mothers, and ‘types’ of mothers, the women engaged in
labelling, categorising, and defining mothers and rating themselves against them. Invariably they rated themselves poorly against an undefined ‘ideal’ mother who was presumably well and fully engaged with her children. These findings are strongly supported by other studies that report women comparing themselves to other mothers (Aston 2002; Frizelle & Kell 2010; Staneva & Wittkowski 2012).

Evaluating one’s own and other mothers’ performances of mothering can be undertaken by women as they attempt to align themselves to the culturally constructed ‘good’ mother (Frizelle & Kell 2010). Frizelle and Kell (2010), in a study of women in a postnatal group, found that the women engaged in scrutiny of the mothering practices of self and others. Feeling observed and judged as mothers had consequences for the information some of the women felt they could share in the group. Participants reported withholding negative feelings about mothering and remaining isolated and overwhelmed rather than risk being seen as inadequate in the role. However, comparing themselves to other mothers often resulted in feelings of failure and hopelessness (Frizelle & Kell 2010).

Staneva and Wittkowski (2012) concur with these findings. In their investigation of beliefs and expectations about mothering in a group of new mothers, young women reportedly observed other mothers to see how these other mothers coped. Although they took comfort in seeing that the majority of other mothers did cope with the role, some felt anxious about their ability to live up to the responsibility. Several of their participants also expressed the opinion that the reality of motherhood was not revealed until they experienced it themselves. Women reported feeling “cheated” by other women withholding information about negative aspects of the role (Staneva & Wittkowski 2012, p. 4). In contrast to Frizelle and Kell (2010), Aston (2002) viewed
mothers comparing themselves to each other as a process of normalisation. By engaging in normalisation the participants were thought to be actively engaged in constituting and evaluating the notion of normal thus challenging cultural ideologies of mothering. What was significant in these three studies was that they all portrayed women struggling to come to terms with their own worth as mothers compared to other women. Where they differ from the current study, however, is that they are composed of samples of presumably healthy women. If they were burdened with physical or mental illness it was not revealed by the authors. If samples of seemingly well women are engaged in contrasting and comparing themselves to other women in order to evaluate themselves and still feeling inadequate, it is conceivable that women additionally burdened by illness may find this process especially fraught.

The women in the current study discussed their shortcomings as mothers at length, yet often neglected to recognise their stoic efforts to continue to care for their children in the face of sometimes severely debilitating illness. Feeling inadequate as mothers distressed several participants so much that they considered taking their own lives. This demonstrates how much these women valued their identity as mothers and how detrimental perceived maternal failure could be to their wellbeing. Not having their experience of mothering meet their expectations can leave women feeling confused, inadequate (Mcquillan et al. 2008; Sevón 2007), and deviant as mothers (Arendell 1999). Women evaluating themselves so negatively as mothers gives credence to Aston’s (2002) call for health professionals to critique the concept of a ‘normal’ mother in order to empower women to feel secure about their individual mothering interpretations.
Several women in the current study revealed feeling emotionally unavailable, short tempered and frustrated as a consequence of feeling sick, in pain and fatigued. They described this as ‘not being there’ for their children. ‘Not being there’ for children is a term often used by mothers in studies of chronic illness (Evans & de Souza 2008), and ‘being there’ is frequently used by stay-at-home mothers to illustrate their dedication to the mothering role (Boyd 2002). The term ‘being there’ stems from the internalised belief that women are primarily both physically and emotionally responsible for children, and denotes a constant caring presence (Boyd 2002). As such ‘being there’ is a gendered notion that contributes to perpetuating guilt in mothers if they feel that they are anything less than totally available to their children. The concept of women imbibing the rhetoric of maternal responsibility is well illustrated in Elmberger et al.’s (2000, p. 491) study when a participant stated “my husband could manage practically to care for the children but not emotionally ... no man can be a substitute for a mother.”

Although in the current study a lack of joy was attributed to illness, many women who are not ill also experience ambivalence about mothering. Women feeling ambivalent in relation to motherhood is a sentiment echoed by many women writers including Chodorow (1978), Nicholson (1983), Rich (1986) and more recently Maushart (1997). In her seminal book on mothering Adrienne Rich (1986, p. 21) wrote:

My children cause me the most exquisite suffering of which I have any experience. It is the suffering of ambivalence; the murderous alternation between bitter resentment and raw-edged nerves, and blissful gratification and tenderness. Sometimes I seem to myself, in my feelings toward these tiny guiltless beings, a monster of selfish and intolerance. Their voices wear away at my nerves, their constant needs, above all their need for simplicity.
and patience, fill me with despair at my own failures, despair too at my fate, which is to serve a function for which I was not fitted.

Despite these scholars’ efforts to inform women that mothering is not always an enjoyable undertaking, the expectation persists that ‘good’ mothers are completely fulfilled by contentedly and unselfishly devoting themselves to the care of their children (Goodwin & Huppatz 2010b). The concept of maternal presence is frequently described in the literature as constitutive of motherhood (Boyd 2002; DiQuinzio 1999). A participant in Sands’ (1995) research into the parenting experience of women with serious mental disorders revealed that after regaining the care of her daughter from a foster carer she confined herself to the home even when her child was absent in order to ‘be there’ for her. Women with chronic illness in Thorne’s (1990) study were also concerned that they were less available emotionally or in their ability to do things for their children than other mothers, and that this resulted in their children becoming independent prematurely. This premature independence perhaps created the sense for Thorne’s (1990) participants that they were not needed in the same way as other children ‘need’ their mothers. The women were also worried that they themselves were dependent upon their children for physical and emotional support.

Women in a study of maternal breast cancer were frightened that an inability to ‘be there’ for their adolescent daughters during cancer treatment could have long lasting negative consequences (Stiffler et al. 2008). The women were concerned that the tumultuous nature of adolescence combined with the uncertainty of a maternal cancer diagnosis could jeopardise their daughters’ development into well-adjusted adults. The treatment and symptoms of the disease made it difficult for the women to be truly present for their daughters which resulted in expressions of deeply felt guilt and sadness.
Further complicating the mother/daughter relationship was the teenage girls’ response to their mothers’ illness. Some of the women in Stiffler et al.’s (2008) study reported that their daughters became hostile, withdrawn and angry as they struggled to cope with their mother’s potentially fatal illness. For some of the women, the mother-daughter relationships were damaged in the long term.

Although Maher (2004, p. 7) argues that the requirement for mothers to be perpetually ‘there’ for children constitutes “an impossible requirement for omnipresence,” Boyd (2002) argues that maternal presence can be more fluid and reconceived as a caring presence whether that means a physical or emotional presence. For mothers such as those in the current study, Boyd’s (2002) re-conceptionalisation of maternal presence could be employed to comfort women that any maternal love or care they can provide constitutes ‘being there’ to the best of their ability for their child.

**The Inevitable Guilt**

The experience of disrupted mothering with its accompanying physical, emotional and social difficulties culminated in feelings of guilt and shame for the majority of participants in the current study. Subscription to ideologies and cultural narratives aside, women generally love their children, feel connected to them, and are therefore committed to their happiness and wellbeing (Seagram & Daniluk 2002). Guilt for women in the current study may also be associated with a sense they are not physically and emotionally present in a sufficiently meaningful way for their children. Guilt related to feeling too tired to actively participate in mothering acts, being short tempered or emotionally absent when feeling unwell was also evident in the narratives of mothers in both Nelms’ (2005) study of HIV positive women and Grant’s (2001) study of mothers with arthritis. Women with cancer also reported feeling guilty because
they were often tired, and due to side effects of treatment, looked different than other children’s mothers (Elmberger, Bolund, Magnusson, Lützén, et al. 2008).

Guilt about mothering is problematic for many women (Barnes, Taylor-Brown & Wiener 1997) and is often considered to be an inevitable element of mothering in Western cultures (Mauthner 1999; Seagram & Daniluk 2002; Sutherland 2010). Shame and guilt arise in mothers when they perceive that they have transgressed the cultural and social mandates of ‘good mothering’ (Sutherland 2010). Maternal guilt stems from women’s feelings of primary responsibility for children; unrealistic standards of mothering; dedication to the mother-child bond; protective instincts; and feelings of inadequacy (Seagram & Daniluk 2002). As the role of mother can be so central to women’s self-identity, perceived failure is felt acutely (Tanner 2000). However, for women who are sick and unable to care for their children the guilt can become especially burdensome. This is particularly apparent in women with children younger than 18 years (Fitch, Bunston & Elliot 1999).

In the literature, women with breast cancer expressed guilt because they were sick; because cancer could be a genetic legacy from them to their children; because their children had to become more independent; and because they felt they could no longer fulfil the ‘good’ mother role (Elmberger, Bolund & Lützén 2005). In the current study, physical deficiencies were a particular source of regret. Having her young daughter help her with groceries caused Yasmin to feel flawed and question her legitimacy as a mother. This is in keeping with literature that states that depending upon children for help with physical things is a significant source of guilt for ill women (Opacich & Savage 2004).
For Veronica and Cate, guilt was felt regarding what they perceived as an unfair distribution of mothering attention among their children. Participants in Grant's (2001) study of women with arthritis similarly felt guilty about giving younger or older children different amounts of attention as their symptoms either worsened or improved. Children’s awareness of these differences and articulation of their displeasure to their mothers contributed further to feelings of guilt.

Several of the women were also keenly aware that their illnesses had affected their families financially, which left them feeling guilty that their children were economically and socially disadvantaged. This finding is echoed in a study of parents who had head and neck cancers, where participants discussed not being able to afford new clothes or toys for their children as a consequence of financial difficulty following illness and surgery (Semple & McCance 2010a).

In a study by Backman et al. (2007a), guilt was a variable issue for mothers with arthritis. While some of the women were disappointed regarding the effect their illness had on household routines and things they could do for and with their children, other participants felt that guilt over mothering was a normal phenomenon, and that struggling with a chronic illness was simply their lot (Backman et al. 2007a). The idea that guilt was normal for all mothers was also echoed by a participant in Nelms’ (2005) study of mothers who had HIV.

Although numerous examples and sources of maternal guilt and shame could be found in the literature, Sutherland (2010, p. 316) poses the question: “… who is NOT reporting guilt and shame in relation to perceived violations of good mothering ideologies? With the preponderance of cultural messages telling mothers how they should behave, it is a wonder that any escape without negative self-evaluations.” In the case of the current
study, the answer to Sutherland’s (2010) question is Maggie. Despite catastrophic health events in her life, and extreme physical limitations she maintained a view of herself as a good and loving mother by concentrating upon the emotional aspect of mothering. Maggie unknowingly enacted Boyd’s (2002) re-conceptualisation of maternal presence by focusing on the areas of mothering she did feel she fulfilled.

The Measure of a Mother

In this current study participants exposed the challenges of maintaining maternal self-esteem in the face of debilitating illness. While none of the participants directly claimed that they were ‘good’ mothers, they each found ways in their stories to mediate between their own experiences and the cultural narrative of mothering. The women in this study reframed their experiences of mothering, offering their children’s virtues of independence, compassion and empathy, respect, good manners, amicable personalities and educational or professional achievements as evidence of ‘effective’ mothering. As Chase (2001) noted, a woman’s success as a mother is contingent upon her children’s behaviour, their manners, independence and self-esteem. It appears little has changed in the past thirty years, as back in 1980 Ruddick wrote similarly, “... a mother typically takes as the criterion of her success the production of a young adult acceptable to her group” (Ruddick 1980, p. 349).

Evans and de Souza’s (2008) study of mothers with chronic pain also found that women considered their children more independent and caring than children whose mothers were not ill. However, independent children might be a bittersweet concept for women torn between wanting their children to cope and allowing them to be dependent and fully experience childhood.
The women in this study reflected extensively on the ways in which their illness had altered their performance of mothering, and how their children may have been affected. For nearly all of the women, disrupted mothering raised issues of guilt and culpability, as they discussed how their illnesses had limited what they could do for and with their children. Yet despite these expressions of guilt, the women sought to position themselves as adequate mothers by offering evidence that they had produced a socially acceptable child. As shown in other studies, children represent a tangible ‘product’ of mothering. In Malacrida’s (2009, p. 106) qualitative study of Canadian women with disabilities, participants discussed having to be even more competent than non-disabled women to be considered ‘good’ mothers. Women in Malacrida’s (2009) study focused on the visible signs of ‘good’ mothering such as fastidious grooming, fashionable clothing and entertaining children in public to make others aware of their mothering efforts.

Asian women living in Australia measured maternal accomplishment by their children’s academic success, manners, and respectful attitude in Liamputtong’s (2006) study. May (2008) found similarly in a sample of Finnish women’s written life stories, that women detailed the social skills and maturity of their children as evidence of effective mothering.

Participants in this current study generally compared themselves unfavourably to other women, yet they did not stray far from the idea of the ‘good’ mother, constructing their stories in ways that could still accommodate the ideal. Despite being incompatible with the realities of present-day mothering, the Western cultural narrative of motherhood is persistent, defining motherhood and the actions of mothers (Austin & Carpenter 2008). This cultural narrative can cause women to seek to present a positive image of
themselves when sharing stories of mothering (Miller 2005). Dillaway (2006, p. 51) notes that “once women are mothers, they are always mothers, and they are always impacted by mothering ideology.” She interviewed menopausal women to find that the women still put children first and suppressed their own needs (Dillaway 2006). Even though their children were often grown with families of their own, the women still expressed guilt if they put their own needs ahead of those of their children and grandchildren.

In Kruger’s (2003) study of motherhood, participants’ narratives were framed in reference to the dominant mothering ideology. Kruger (2003, p. 203) argues that by situating their stories in deference to this ideology, “they were therefore denying the possibility that motherhood, womanhood and even personhood can mean different things for different women at different times.” Like the current study, Kruger’s work (2003) illustrated the extent to which women’s personal motherhood narratives are unconsciously influenced by the dominant ideology. This dominant ideology does a disservice to women who mother (Andrews 2002). Women need to understand that any compromises they make regarding their ability to mother need not affect their view of themselves as mothers. By still subscribing to the myth of the ‘good’ mother they are further contributing to the perpetuation of the myth.

When life is disrupted from its expected course it can be difficult to construct stories that are congruent with the limited cultural and socially acceptable narratives that exist (Miller 2005; Somers 1994). The women in this study shared ‘situated stories’, that is, stories created for a particular purpose, in this case in order to participate in the research study (McLean, Pasupathi & Pals 2007). McLean et al. (2007) propose that situated stories are a vehicle people use to both create and maintain a sense of self. Perhaps the
women unconsciously saw participation in the study as an opportunity to repair damage to their identity as mothers. As such, sharing stories of illness can represent a reclaiming of a favoured identity (Frank 1995). By telling their stories they were creating new memories of the experience (Frank 1995). Giving women the space and opportunity to speak or write of mothering disrupted by illness may have contributed to the experience being reconstructed in a “more promising relational form” (Gergen & Gergen 2004, p. 43).

Some of the women in the current study felt that they were role models for their children, and that the way that they had either dealt with or overcome their illness set a good example to follow. Elaborating upon how the experience of having an ill mother may have benefitted their children could be considered as constructing consoling plots. Consoling plots are constructed in order to make experiences bearable, as they focus upon the positives of a situation (Kermode 1967). Similarly, in a study of substance-using mothers, Reid, Greaves and Poole (2008) found that some of their participants emphasised how despite their perceived failing as mothers on one level, they compensated in other ways. For instance they were aware of the need to protect the health of their children and did not smoke or allow others to smoke near them. Heltsley and Calhoun (2003) found women who entered their daughters in beauty pageants also engaged in the construction of consoling plots. In order to resist vilification and the suggestion that they were deviant mothers engaging in the sexualisation of children, the women emphasised the positive aspects of appearing in pageants for their daughters such as increased self-esteem and confidence.

The findings of this study suggest that the women needed to find ways in which to reconcile the demands of their illness with their perception of themselves as mothers.
Reconciliation was partially accomplished by reframing the illness as being of benefit to their children and thus, as Baxter (1990) would suggest, transforming meaning and reducing the contradictions in their stories. In Elmberger et al’s (2008) study of women with cancer, accepting limitations in some areas of mothering and concentrating on others assisted some participants to reformulate their identities as ‘good’ mothers. These scholars recommend that women need opportunities to redefine themselves as mothers and come to terms with their limitations in order to retain self-esteem (Elmberger, Bolund, Magnusson, Lützén, et al. 2008). These recommendations mirror those by Sutherland (2010, p. 317), who stated that “child centred rhetoric appears to be the main ingredient for reducing guilt and shame.”

When providing examples of their children’s qualities, the women in this study often offered external validation to support their claims. Significant in several of the women’s stories was how much they appreciated validation of their mothering skills, especially from health professionals. Notably, validation from doctors was discussed by many participants, in contrast to reported conflict and hostility from nurses. Women’s self esteem can be intrinsically linked to how well they feel they fulfil the mothering role (Forssén & Carlstedt 2008; Jackson 2000; Jackson & Mannix 2003). Validation of mothering from health professionals can therefore be particularly affirming for women, as health professionals are seen as authorities (Lathrop & VandeVusse 2011). As May (2008, p. 480) noted, positive feedback from health professionals is “perhaps the highest and most authoritative form of praise.” Conversely, the negative emotions that result from feeling invalidated by health professionals can be intense and recollected years after the event (Lathrop & VandeVusse 2011).
Women can be very invested in their identities as mothers, which makes it important for health care professionals to acknowledge that a patient is also a mother (Davies & Allen 2007). Yet often in the literature, where health care professionals are discussed, they are portrayed as unhelpful in facilitating women’s mothering whilst ill. In the Elmberger et al. (2005) study, health care professionals failed to ask how women were managing their mothering roles, resulting in them feeling unable to broach the subject (Elmberger, Bolund & Lützén 2005).

In a recent Australian survey, participants welcomed respect, reassurance and support from child health nurses regarding their parenting ability (Eronen, Pincombe & Calabretto 2010). However, the women did not appreciate unsolicited advice or feeling pressured by nurses to assume the nurses’ preferred methods for some aspects of infant care (Eronen, Pincombe & Calabretto 2010). It is therefore recommended that nurses find a balance between providing expert advice and assisting parents to make autonomous decisions based on an array of options (Eronen, Pincombe & Calabretto 2010). There is a need for all health professionals to exercise non-judgemental practice and foster respect for the mothers that they care for (Eronen, Pincombe & Calabretto 2010).
Setting

In a consultation room. A pregnant woman is sitting in a plastic chair. A health professional is sitting facing her. A young girl of about 4 years old is lying on the floor looking at a picture book.

Character Dialogue and Stage Direction

HEALTH PROFESSIONAL So tell me how are you coping with everything? You have a lot on your plate with the kids, the pregnancy and your illness. How is this all impacting on your mothering?

MOTHER Some days are really difficult; I’m so tired all the time. I’m crap on so many levels. My little girl fetches and carries stuff for me all of the time. My eldest does so much stuff around the house. He does it but I can tell he’s not happy about it. I’m sure they wish they had a better mother sometimes. Some days it’s all I can do to get out of bed. We have pyjama days on those days and we read on the couch and stuff.

LITTLE GIRL Look Mummy, Lazy Lions, loun, loun... in the library

(Showing her mother the book)

MOTHER Lazy lions lounging in the local library hun

HEALTH PROFESSIONAL Wow you’re really clever aren’t you! And you’re a great helper for Mummy. What a good girl you are. Well it doesn’t look like reading on the couch is harming her, she reads really well for such a little person.

MOTHER I know it was good for my son too; he’s top of his class at school. He won an award yesterday and he’s written a speech to run for school captain, it’s really well written. Every time I see his teacher she tells me what a good kid I’ve got. I’ve been really lucky actually.

HEALTH PROFESSIONAL Maybe instead of being a lucky mother you are simply a good mother?

MOTHER I don’t know. I see other mothers down the park and they’re so much more active. I’m flat out getting them there then I just sit on the bench and watch. And it’s up to my son to carry the supplies.

HEALTH PROFESSIONAL I think it’s fabulous that you take them to the park. You need to consciously try not to compare yourself to other mothers, they might look like they’ve got it all together but most mothers feel inadequate in some way. I bet there are other mothers that wish they could spend as much time with their kids as you do. And try not to worry too much about your son helping. Better he is a kid that helps than one that has everything done for him anyway. He’ll grow up much more independent and capable. I’ve seen it happen a lot. Kids that have ill parents are often said to be more compassionate than kids that grow up without any real hardship as well. What are some of the good things you can tell me about your mothering?

MOTHER Well I let my son have his friends over a lot. The house isn’t always neat enough for visitors but kids don’t seem to mind that sort of stuff too much. I think it’s good he’s got some company; I can struggle sometimes to really spend quality time with them. I’m so tired all the time. But I think it’s important to let their friends come over. I was never allowed to have anyone over when I was a kid.

HEALTH PROFESSIONAL I’m sure that you are doing everything you can. How about you tell me a bit more about your own childhood first...

(Lights fade)
THE MORALITY OF EARLY MOTHERING: TREATMENT AND THREAT

Although there were specific clinical issues raised through the women’s stories, such as the importance of pre-conception counselling for women with a pre-existing illness; medication adherence during conception, pregnancy and breastfeeding; and the teratogenic risks of medications or untreated illness, these subjects are addressed at length within the extant literature (e.g. Blackford, Richardson & Grieve 2000; Dragoman, Davis & Banks 2010; Einarson 2007; Frieder 2010; Henry & Crowther 2000; Keely & Barbour 2008; Keely & Rosene-Montella 2008; McCauley-Elsom, Cross & Kulkarni 2009; Nielsen et al. 2010; Sanz, Gómez-López & Martínez-Quintas 2001). However, returning to the idea of flawed mothers, a uniting concept running through these issues is the moral risk inherent in conceiving, gestating and breastfeeding a child from a body compromised by illness.

It is important to be seen as a moral being in order to be accepted as a member of society (Goffman 1959; May 2008). Mothering is viewed as a moral undertaking when it is conceptualised within the expectations of social and cultural constructs. Conceiving mothering as a morally coherent practice, Leonard (1996) envisaged the care of a child not as a socio-cultural responsibility but rather as a self-affirming means of defining self-identity and worth. Therefore, the inability to fulfil valued social roles such as the mother role can be existentially threatening and pose a risk to personal identities (Townsend, Wyke & Hunt 2006).

For middle-class Western mothers to appear moral, it is necessary to privilege children’s needs above their own (Fisher & O’Connor 2012; Hays 1996; May 2008; Vincent 2010). Therefore, attending to their own treatment needs can make women feel self-indulgent (Opacich & Savage 2004). This was a pervasive concept in the stories
told by the mothers in this study. In their study of people with multiple chronic illnesses, Townsend, Wyke and Hunt (2006) also found that women privileged the mothering role over their own health. The women in their study drew upon traditional family roles to explain why they risked their own health deteriorating to continue to assist their children, explaining “it’s a mum thing, a mother thing, a woman thing” (Townsend, Wyke & Hunt 2006, p. 191). These researchers attribute the privileging of social roles over illness to people wishing to maintain a coherent and positive identity. Health professionals should be aware that fulfilling the mothering role can take precedence over women’s self-health care. Yet in the current study, nurses added to the burden of disrupted mothering by forming moral judgements of the women they were caring for. These moral issues will be discussed under the headings ‘Perilous Pregnancies’, The Morals of Milk’ and ‘Nurses Contravening the Code.’

Perilous Pregnancies

For women who are ill, the morality of early mothering may be even more critical due to the symbiotic nature of pregnancy and breastfeeding (Ogle, Tyner & Schofield-Tomschin 2011). Many studies have been conducted that explore conception and pregnancy in the context of specific disease processes, including inflammatory bowel disease (Mountifield et al. 2009; Nielsen et al. 2010), mental illness (Coverdale, McCullough & Chervenak 2010; Frieder 2010; Galbally et al. 2010), multiple sclerosis (Payne & McPherson 2010; Prunty et al. 2008), epilepsy (Davis et al. 2008; Pennell 2004; Thompson et al. 2008) and HIV (Barnes 2009; Craft et al. 2007; Nelms 2005). However, research that explores the subjective reproductive and treatment decisions of women who have a pre-existing illness is limited in the available literature (Ogle, Tyner & Schofield-Tomschin 2011; Payne & McPherson 2010; Thomas 2003; Thompson et al. 2008).
Although mothers are generally subject to hegemonic social control, moral standards are heightened during the visible months of pregnancy (Bell, McNaughton & Salmon 2009; Lyerly et al. 2009; Ogle, Tyner & Schofield-Tomschin 2011). Women seeking to conceive and give birth may experience judgement and criticism if they are thought to present any potential risk to the unborn child (Lyerly et al. 2009; Ogle, Tyner & Schofield-Tomschin 2011; Thompson et al. 2008). To ensure the optimal conception and growth of the child, women are expected to engage in healthy behaviours, and can be labelled careless or deviant if they contravene these standards of behaviour (Bell, McNaughton & Salmon 2009; Thompson et al. 2008). The fear of being judged can lead to women concealing behaviours that are perceived to be risky and responding to inquiries about their lifestyles with answers that are influenced by a social desirability bias (Ogle, Tyner & Schofield-Tomschin 2011).

There are generally held societal assumptions about how women should behave when considering motherhood (Bell, McNaughton & Salmon 2009; Lyerly et al. 2009). Described as the moral work of mothering (Thompson et al. 2008), women are expected to plan pregnancies and ensure that their bodies are as healthy as possible before conception in order to provide an optimum environment for the developing foetus. Thus a woman’s body and womb has been viewed as a vessel for the developing child and subject to romanticized ideas of purity (Lyerly et al. 2009). The medicalisation of the pregnant body that results in disembodiment, disempowerment and objectification of women has been discussed at length by feminists (Hayter 2005; Stenhouse & Letherby 2011). During gestation there is the expectation that women do not jeopardise the health of the unborn baby in any way. This is well illustrated in the literature that examines the use of alcohol and drugs during pregnancy (Bell, McNaughton & Salmon 2009). However, for women with pre-existing illness such as those in the current study, it can
be difficult to avoid threats during the pregnancy, and childbearing can be complicated by medical treatments, prescribed medications, and the woman’s own health status and functional ability.

Thomas (2003) reported women with a pre-existing illness being subject to widely varying responses from health professionals regarding their pregnancies, ranging from dismissal to outrage. This researcher stated that health professionals made moral judgements regarding the desirability of pregnancy for these women. “The role of medicine, however, in judging the advisability of the pregnancy, in the sanctioning of (moral) failure to observe advice and treatment, and in proclaiming the nature and implications of medically complicated pregnancy, is clearly pre- eminent” (Thomas 2003, p. 405). There is also often a focus on potential harm to the unborn child to the detriment of the woman’s health or comfort (Lyerly et al. 2009; Thomas 2003).

Risking impairment to a developing baby as a consequence of pre-existing illness or condition has been also viewed as irresponsible by women themselves (Thomas 2003). Women will hold themselves responsible even for threats outside of their control. This was evident in Yasmin’s story when she feared for her unborn child’s health following an extended period of maternal hypotension, or in Alice’s story, when she discussed her developing baby being unknowingly exposed in utero to many drugs and treatments before she was aware that she was pregnant.

For women who are ill, reproductive decisions can be complicated and fraught with potential threat. Women with a pre-existing illness who conceive have “already acquired the status of patienthood before the status of pregnant woman” (Thomas 2003, p. 404). For these women, pregnancy can be highly medicalised as they and their health care providers seek to optimise their health and reduce the threat to the unborn child.
Reconciling illness with pregnancy was raised recently in the literature by Ogle, Tyner and Schofield-Tomschin (2011) as an area requiring more investigation. These scholars discussed the duty to be well to satisfy the cultural expectations of motherhood in a group of healthy expecting women and their partners. Also mentioned in their discussion was how difficult it would be to comply in the face of concomitant illness.

Recently Thompson et al. (2008) also drew attention to the moral work of women with epilepsy as they planned and birthed their children. Resonating with the current study, their participants shared concerns regarding medication use in pregnancy and the potential for maternal culpability if harm were to befall the unborn child. Evident in their article was the conflict between being a good mother by protecting the child and being a good patient and protecting self. Continuing to take medication to control seizures was the general professional consensus; however, this was at odds with the women’s preconceived ideas of what ‘good’ mothers did during pregnancy (Thompson et al. 2008).

*The Morals of Milk*

Breastfeeding was another area of significant moral distress for the women in this study. The women felt inadequate if they could not breastfeed due to illness or there were concerns about medications filtering into the breast milk. Breastfeeding has come to be understood as what a ‘good mother’ does for her child. Rather than viewing breastfeeding as a single element of mothering, for some women failure to breastfeed can be construed as moral failure as a mother. In order to be able to consider themselves ‘good’ mothers, women will continue to attempt to breastfeed their children even in the face of enormous difficulties (Sweet 2008b). Another tenet of ‘good’ mothering is the generally held belief that good mothers are always available to their children (Goodwin
& Huppatz 2010b; Krane & Davies 2007). The centrality of the concept of maternal availability is well illustrated in breastfeeding as routinely it is only biological mothers who can breastfeed children. Separation and disruption to breastfeeding due to hospitalisation therefore represented a significant moral risk for participants.

After giving birth, there is evidence that some women feel pressured by health professionals to breastfeed (Hall & Hauck 2007; Lamontagne, Hamelin & St-Pierre 2008; Mantha et al. 2008; Marshall, Godfrey & Renfrew 2007). Yet this pressure by one set of health professionals is at odds with my participants’ experiences of being actively discouraged from retaining the care of their infant so that they could continue to breastfeed. Sweet (2008a), too, raises the question of who is actually responsible for promoting breastfeeding beyond the postpartum period when mothers and babies are integrated into the general health system. The lack of commitment to sustaining the breastfeeding dyad experienced by participants in this study implies that once women and babies are outside of the maternity wards, the importance of breastfeeding is all but disregarded within some hospital environments. Yet it is in the interest of public health to support the initiation and continuation of breastfeeding (Sweet & Power 2009). Therefore health professionals need to find ways to facilitate contact and breastfeeding for mothers and their infants when the mothers are ill. Although there are obvious difficulties, and the appropriateness of the admission would have to be judged upon an individual basis, women and their breastfed infants need to be viewed as inseparable except in the direst of circumstances.

The experience of mothers in this study highlights the importance of viewing breastfeeding as part of a symbiotic relationship, not just as a means of providing nutrition for a child. This concept has been acknowledged repeatedly in studies that
investigated mothering in neonatal intensive care units (Flacking 2009; Lupton & Fenwick 2001; Sweet 2008b), and studies of mothers who share custody of infants (Sweet 2010; Sweet & Power 2009). Sweet (2010, p. 384), who has investigated breastfeeding in several different contexts, noted that breast milk has been “considered only as nutrition, without recognition of its immunological and cognitive benefits and the security and comfort it provides.” Flacking (2009), in Sweden, as well as Lupton and Fenwick (2001) and Sweet (2008b, 2010), in Australia, have all advocated that providing breast milk should be recognised for the uniquely maternal, connecting, nurturing, comforting mothering act that it represents.

Studies report a number of reasons why hospitals do not provide adequate support for breastfeeding, which include inadequate resources and staffing levels (Hall & Hauck 2007; Taylor et al. 2010), and staff who lack competence, time, or interest (Kynoch, Paxton & Chang 2010; McInnes & Chambers 2008). Individual attributes such as subjective breastfeeding experiences, investment in keeping up with current discourse, personal beliefs regarding infant formula, and degree of advocacy or belief in new mothers’ right to choose the source of infants’ nutrition, all affect individual nurses’ promotion and support of breastfeeding (Martucci 2012; Nelson 2007). Furthermore, if health professionals feel unprepared to support breastfeeding mothers this may manifest as unhelpful behaviours (Dykes 2006; McInnes & Chambers 2008; Smale et al. 2006).

A lack of nursing support for breastfeeding is also attributed to deficient nursing knowledge regarding best practice and is considered amenable to education (Dykes 2006; Mantha et al. 2008; McInnes & Chambers 2008; Taylor et al. 2010). Education is seen as intrinsic to changing health professionals’ attitudes and empowering them to support women and advocate for breastfeeding (Schmied, Sheehan & Barclay 2001;
Taylor et al. 2010). It is recommended that all health professionals be educated on “… lactation physiology, exclusive and continued breastfeeding … and feeding in difficult circumstances” (Labbok 2006, p. 284). In Taylor et al.’s (2011) study, the availability of lactation consultants was seen as a powerful force for increasing breastfeeding rates in the neonatal intensive care unit. In Kynoch, Paxton and Chang’s (2011) study of ICU nurses, lactation consultants were also viewed as a primary resource when caring for postnatal patients. Dykes (2006) therefore advocates for the provision of breastfeeding specialists to assist patients and educate staff.

With the exception of studies of postnatal patients in intensive care units (Elmir et al. 2012; Kynoch, Paxton & Chang 2011; Pollock, Rose & Dennis 2010), there is little discussion in the literature of health professionals who work outside of maternity focused areas in relation to breastfeeding. Further research on non-maternity focused wards would be illuminating to discern nurses’ attitudes to admitting breastfed babies as boarders with their mothers, their confidence to care for a mother-baby dyad and their awareness of the policies and directives regarding facilitating breastfeeding.

The choice to breastfeed is considered to be a mother’s inalienable right (Bar-Yam 2003; Kent 2004; Labbok 2006; Sweet & Power 2009). The dominant discourses surrounding breastfeeding also correlate it with being a ‘good’ and responsible mother (Sweet 2008b). Yet health services often separate mothers and infants (World Health Organization & UNICEF 2009). This is despite the existence of Australian health policies and recommendations for practice regarding both the facilitation of breastfeeding and admitting a lactating mother with her child where possible (see for example: Sydney South West Area Health Service 2008). Commitment to sustaining breastfeeding mothers is also evident in health policy directives that call for the
implementation of the Baby Friendly Health Initiative [BFHI] (Department of Health NSW 2006). These directives make supporting breastfeeding the obligation of all health workers caring for lactating women, and also advocate for mother-baby hospital admission and recommend access to lactation consultants (Department of Health NSW 2006). However, the experiences of the women in this study suggest that these policies may not be widely implemented in practice: a case of rhetoric not being matched in practice. Recognising the moral imperative to breastfeed in Government policy and health promotion, it should be acknowledged that although policies and protocols exist, they must be enforced in order to bridge the gap between directives and practice (Hong, Callister & Schwartz 2003). In institutions where clear written policies exist and are well communicated to staff, breastfeeding outcomes are improved (Rosenberg et al. 2008). Although breastfeeding is promoted in public policy, the lack of resources available to support it in actual health care situations needs to be remedied through the provision of education and funding (McInnes & Chambers 2008).

It was noteworthy that in the current study it was physicians advocating on behalf of the women’s rights to keep their children with them and continue to breastfeed, given the nursing profession’s claim of being patient advocates. This was well illustrated in Pearl’s story where the nursing staff expressed overt disapproval regarding her continuing to breastfeed while taking antibiotics despite her specialist’s advice to do so. The disapproval of nursing staff implied her breast milk was tainted, adding to the burden of being a breastfeeding mother caring for an infant in what was perceived as hostile environment while very ill. Similarly, breastfeeding for a participant with epilepsy in another study was complicated by nursing staff disagreeing with her specialist about the safety of her breast milk (Thompson et al. 2008). The tensions between being a ‘good’ mother and a ‘good’ patient can make women feel that they are
in a no-win situation. In attempting to satisfy the moral work of being a ‘good’ mother by continuing to breastfeed their infants, women are in danger of contravening nursing opinion which puts them in danger of being labelled irresponsible mothers (Thompson et al. 2008). The purest food of all is rendered impure and tainted through the moral judgement of authoritative strangers. What is of great concern is that it was nurses’ subjective opinions that influenced their treatment of participants, rather than knowledge based on empirical research. The tensions between women as mothers and nurses will be further explored in the next section.

_Nurses Contravening the Code_

In Australia, Registered Nurses are held to standards of ethics, competencies and codes of conduct. Within the code is the imperative to “promote and protect the interests of people receiving treatment and care” (Australian Nursing and Midwifery Council 2008, p. 4). This includes taking appropriate action to ensure that “the safety and quality of care is not compromised because of harmful, prejudicial attitudes” (Australian Nursing and Midwifery Council 2008, p. 4). This conduct statement is reinforced by the competency standards which discuss nurses not imposing personal values in order to develop therapeutic relationships with their patients (Australian Nursing and Midwifery Council 2006). However, despite these codes and standards of practice, several participants in the current study reported that they were subject to moral judgement from nursing staff. Already coping with illness and their own feelings of inadequacy, the women in this study were highly sensitive to any criticism of their mothering.

Moral judgement of patients by health professionals is an understudied area in the literature, despite being present in everyday clinical encounters (Hill 2010). The caring ideology that governs nursing discourages forthright examination of what nurses really
think of their patients (Hill 2010; Nelson & Gordon 2006). Much of the research regarding moral reasoning in health care examines decision making in the face of ethical dilemmas (Dierckx de Casterlé et al. 2008), attitudes to stigmatised conditions, and difficult clinical relationships (Hill 2010). Many examinations of morality in nursing research focus upon the clinical moral dilemmas of nurses and fail to acknowledge that subjectively nurses may be less than entirely altruistic and patient focused. Yet even within the nursing profession it is recognised that some nursing work is “controlling, hierachial and task focused, being more concerned with the performance of tasks and procedures ... rather than people” (Awty, Welch & Kuhn 2010, p. 109).

A survey of Dutch nurses found that when considering moral problems in practice, many nurses considered them objectively and not in relation to their own actions (van der Arend & Remmers-van den Hurk 1999). Yet nurses are human and susceptible to being influenced by personal, cultural, and social beliefs when interacting with patients in the already pressured health care environment (Brennan 1998; Carse 1996; Hill 2010). Furthermore, nurses have a history of oppression and subordination in the hospital hierarchy, and may find themselves caught between facilitating their patients’ desire to be ‘good’ mothers and meeting the demands of the institution (Martucci 2012).

Nurses care intimately for patients, spend extended amounts of time with them and their families and thus become familiar with their stories. This familiarity with patients can result in harsh moral evaluation by nurses (Cassell 2004). Negative moral judgements being made by health professionals also increase in the face of time and resource restraints (Hill 2010). Patients at increased risk of being negatively labelled are those “who fail to validate the clinicians’ sense of themselves as effective professionals, who threaten their control, and/or who create fruitless work” (Hill 2010, p. 2). However,
with more informed patients, the expertise and power of nurses as professionals is increasingly being challenged (Tschudin 2003). Without interviewing nurses, nurses’ motivations for commenting on women’s mothering and treatment choices can only be speculated upon. Perhaps commenting upon breastfeeding choices and citing infant safety allowed nurses to display hostility with a sense of legitimacy. Alternatively, it could be implied that by taking their babies to hospital with them, the women were threatening the nurses’ control of the hospital environment. Having an ill patient caring for a baby could have also represented the creation of extra work for the nurses. Nursing morale is bound to decrease in the face of chronic heavy workloads and scarce resources (Tschudin 2003). Perhaps the nurses resented the extra labour or paperwork a woman admitted with a dependent infant may have represented.

If a nurse is opposed to a particular aspect of practice they can elect to not work in that area of nursing (Huntington 2002). The nurses discussed by the mothers in this study worked in non-maternity-focused adult wards such as day surgery and gastroenterological wards. This preference of practice could explain in part their reticence to care for women accompanied by breastfed infants. They were not equipped professionally to care for these women, and this may have affected their interactions with them.

From a feminist perspective, it should also be considered that as a group primarily consisting of women, nurses are believed to be oppressed. Oppressed characteristics of nursing behaviour relevant to the current study include “horizontal violence ... lack of self-esteem and disdain for other women” (Wittmann-Price 2004, p. 441). However, the nature of the judgement that was occurring was on a personal level, as the nurses reportedly judged the women as mothers. Reflecting on the gendered nature of the
caring professions, Jackson and Mannix (2004) discussed an expectation that as women and mothers themselves, health workers may be less inclined to pass unfair judgement upon women patients. However, women often felt judged as mothers by nurses (Jackson & Mannix 2004). Gender has been reported to be a powerful influence on female nurse and patient interactions especially regarding the feminine experiences of birth and breastfeeding (Martucci 2012). It should also be recognised that the majority of nurses are women and mothers themselves, and not immune to the hegemonic nature of Western mothering ideology.

Seagram and Daniluk (2002) recommend that health professionals examine how they themselves are affected by the prevalent cultural beliefs about mothers and mothering. As health professionals are in a position of power it is important to avoid imposing and perpetuating unrealistic standards of mothering that further contribute to women feeling guilty and inadequate as mothers (Seagram & Daniluk 2002). Jackson and Mannix (2004) also recommend health professionals reflect upon their feelings and attitudes regarding mothering and acknowledge where deficits might exist in interactions with women. These scholars further suggest that health professionals develop communication strategies such as active listening in order to foster a supportive and non-judgemental practice (Jackson & Mannix 2004). Other nursing research concluded that nurses should develop strategies to conceal judgement (Lipp 2010). To overcome moral indignation nurses should take active measures to put aside their personal opinions and live up to the professional standards of their profession (Cassell 2004).

Tschudin (2003) maintained that getting to know a patient better could assist in nurses developing liking for that patient. However, it could be argued that no nurse will ever ‘like’ all of their patients and that it is not necessary to ‘like’ a patient to care for them
in a nursing capacity. All nurses will at some time care for individuals that they find it difficult to relate to. Instead, nurses need to be encouraged to avoid expressing their own “biases, prejudices, affections and attachments” (Carse 1996, p. 104). Nursing codes of practice dictate that nurses will behave in a way that reflects well on the profession, respects the patient as an individual and maintains appropriate professional boundaries (Australian Nursing and Midwifery Council 2006, 2008; Tschudin 2003).

The findings of this study have implications for all nurses who care for mothers. Women can experience pregnancy, breastfeeding and caring for their children as a moral undertaking that has consequences for their self-perception and social standing. Therefore they may be extremely sensitive to perceived judgement of their mothering. Rather than criticising women for their mothering choices, nurses should seek to support and validate women in the role. The therapeutic relationship between patients and nurses may be threatened if women feel vulnerable, disempowered and judged as mothers. It is therefore important to ensure that patients feel respected and that their concerns as mothers are heard and taken seriously.
Alternative Script. The morality of early mothering: Nurses supporting mothers

Setting

In a single bedded hospital room a young woman sits in the bed holding an infant. The baby is approximately four months old. A nurse is standing at the bedside. In front of the bed is a recliner chair with extra linen, a blanket and a pillow on it.

Character | Dialogue and Stage Direction
---|---
NURSE | It’s great that your mother could stay to help you overnight. There are sheets and blankets there for her. I’m sorry I couldn’t get the trundle bed for her. They’re using them all in the kids ward. Asthma season you know. Those recliners are pretty comfortable though and she will be able to put the feet up and stretch right out. Lucky we had a single room spare too.
MOTHER | I’m sure it will be fine. I’m so grateful that you’re letting mum and the baby stay with me. My husband is fine with the other two kids. My son’s in school and my daughter goes to day-care. But he can’t work and look after the baby. And after all the trouble I had getting my milk to come in I don’t want to risk losing it now. As it is I worry that she’s getting enough.
NURSE | While you’re here would you like me to refer you to the lactation consultant? She works hospital wide and she can come and have a chat to you about increasing your milk supply. I’ve done some basic courses but she’s the expert. Sometimes the medications can affect your milk supply as well. Have you spoken to your specialist about it?
MOTHER | Yes, she’s been great all through the pregnancy and everything. She did a lot of research when she was prescribing for me, and she’s got me on the lowest dose she can. She is really supportive of me wanting to breastfeed. She said that it was better she get some of the meds rather than putting her on a bottle. I think she knew how much that would upset me. It would be good to see the lactation consultant though.
NURSE | It’s good we’ve got a lot more treatment options these days. I’ve just got to put these ID bands on the baby so she’s properly admitted as a baby boarder. Here I’ll pop it on her foot so she doesn’t suck it.
(Smiling, the nurse attaches an identity band to the infant’s foot, the baby gurgles and waves her hands at the nurse)
NURSE | Oh you are too cute. There you go baby you’re official now. Is there anything you need right now? I’ve just got to go and put you on the computer so you are included on the dinner run.
MOTHER | No, I think I’m right for the minute, those pain killers are kicking in, and mum will be back in a minute. She was just calling home to make sure everything is all right.
NURSE | Okay then. I’ll just go and do this admin stuff and chase your meds up from pharmacy. Let’s just put the back of your bed down a bit, and here’s your buzzer if you need me.
MOTHER | Thanks so much, for everything.
(Using the electronic controller the nurse reclines the bed. Handing the mother the buzzer she waves at the baby and leaves the room. Lights fade)
Social Support: A Multifaceted Phenomenon

Definitions of social support refer to a network of relationships within which an individual finds a sense of value and belonging, love, empathy, understanding, caring, and practical or physical assistance with life’s stress and strains (Arora et al. 2007; Beeber & Canuso 2005; Hough, Brumitt & Templin 1999; Johnston & Swanson 2004; Xu & Burleson 2001). The size and nature of people’s social networks impact upon their physical and mental health, health practices and mortality risk (Umberson & Montez 2010). Although social support can have negative elements (Umberson & Montez 2010), positive support (affirming and assisting) is correlated with brighter health outcomes (Gallant 2003) and adaptation to illness (Coty & Wallston 2010; Simmons et al. 2007). Even in adults already diagnosed with an illness, there is evidence that increased social ties reduce the risk of mortality and contribute to an individual’s ability to cope (Beeber & Canuso 2005; Umberson & Montez 2010).

A healthy social support network is reported to improve psychological adjustment (Johnston & Swanson 2004), self-management of disease (Gallant 2003), and quality and length of life (Umberson & Montez 2010), and to buffer the effects of stress (Beeber & Canuso 2005). Adults with cohesive and supportive social contacts are generally “healthier and live longer than their more isolated peers” (Umberson & Montez 2010, p. S54). In contrast, a lack of support or problematic support (non-supportive, critical, or unsolicited advice) is associated with a decrease in wellbeing and poorer health outcomes (Coty & Wallston 2010; Orth-Gomér et al. 2000; Umberson & Montez 2010). Francis-Connolly (2000) and Llewellyn and McConnell (2004) recognised that individuals in a woman’s network of relationships can either support or hinder her in the mothering role. For women who are challenged in their mothering, the
quality of their social networks may affect their mothering capacity (Llewellyn & McConnell 2004).

Despite the potential benefits, not all people are capable of taking advantage of available social support (Simmons et al. 2007). Accustomed to providing rather than receiving, women may be uncomfortable seeking and receiving care (Opacich & Savage 2004). In Fitch, Bunston and Elliot’s (1999) study, women with cancer expressed a reluctance to ask for support, yet when they did seek assistance people were more than willing to help. Also, some women will attempt to conceal illness and reject overtures of help if they think it will influence how others perceive them as mothers (Davies & Allen 2007; Montgomery et al. 2006; Savvidou et al. 2003).

Illness can also contribute to the disruption of usual support systems (Opacich & Savage 2004). As women who are ill may not seek help, and family and friends may not know how to respond, emotional support can decrease at a time it is most needed (Vilhauer 2009). Furthermore, changing family demographics (divorce, more women working, geographic mobility) have made traditional sources of social support less available (Tummala-Narra 2009). Also, the overwhelming responsibility of mothering in illness may leave women very little time to cultivate a social network (Hough, Brumitt & Templin 1999). The relative youth of ill women of childbearing age may also be a factor, as although the elderly commonly receive familial assistance with managing their illnesses, this same support could be less forthcoming for younger people who may be considered more able (Gallant 2003). These issues are especially pertinent for single women who also have to provide financially for their children (Hough, Brumitt & Templin 1999).
Women in this study considered themselves irreplaceable to their children, believing that they brought something unique to parenting. Invariably, though, there were times when they were either too unwell to care for their children themselves or absent due to hospitalisation and they needed to draw on others for assistance. Drawing on others for support, however, was not without problems. In families there were sometimes pre-existing interpersonal difficulties. Partners, who were the most frequent form of support, commonly had work commitments and friendships had often suffered as a consequence of the women’s illnesses.

Apparent in the women’s stories was tension between the social support that was accessible to them and the social support that was acceptable to them. Findings from this study indicate that although mothers who are ill require support with their mothering, the support offered is not always satisfactory to them and may erode their autonomy as a mother. The women often had little choice in who was available and willing to help and some support was received reluctantly as there were few alternatives.

The majority of social support available to the women in this study was from those who were the closest emotionally and geographically; notably partners, ex-partners, and participants’ mothers. Even where social support was valued and appreciated by the women there could be negative consequences for the maternal bond by somebody else assuming the primary carer role. More often than not, changes in the relationship were transient; however, for some women there were longer-term ramifications. The support the women received will be discussed under the headings ‘Pressure on Partners’, ‘Mothers of Mothers’, ‘Women Need Women’ and ‘Online and Organisational Encouragement’.
Pressure on Partners

When they were present, partners were the most accessible source of support for the women who participated in this study. Other research has shown that regardless of age category, partners are the primary source of support in illness (Bracke, Christiaens & Wauterickx 2008). In the extant literature, support from a partner is reported to be the most useful form of social support and alternative forms are often perceived as inferior (Xu & Burleson 2001). These studies have connotations for single women and women with certain forms of illness. For instance, women with a serious mental illness are reported to often lack supportive partners, and are more likely to be single mothers with poor socioeconomic circumstances (Mowbray et al. 2005).

Although it is intuitive that a woman’s partner would be the primary source of support and would assume more of the care of their children as a natural extension of their co-parenting responsibility, in this study when partners were supportive their contribution was often only briefly mentioned by the women. This lack of acknowledgement supports the theory that partner assistance is expected and perhaps taken for granted. In a study of women with multiple sclerosis, the majority of women also discussed the essential support that they received from their partners. Partners were the most immediate and accessible help, assuming the care of the children when the women in that study were disabled by relapsing illness (Payne & McPherson 2010). Also resonating with the current study, the participants’ partners were mostly engaged in full-time employment. Full-time employment can impact upon how much practical support partners can provide, with partners in part-time work reportedly much more supportive (Bracke, Christiaens & Wauterickx 2008). Working full-time while attempting to care for an ill partner can also impact negatively on the relationship (Howell, Fitch & Deane 2003). Negative effects on relationships were also evident in
Howell, Fitch and Deane’s (2003) study of women with ovarian cancer, where partners with work commitments were the primary source of support.

The expectation that partners provide the bulk of social support for ill women, and the discussion surrounding the unique nature of partner support (Xu & Burleson 2001), draw attention to the physical and emotional burden that may be placed on the partners of ill women as they engage in full-time work, while simultaneously caring for the woman, their children and the household (Cowder & Knudson-Martin 2005). Furthermore, the caring role itself may cause discomfort in men. In a study of cancer patients that lived in remote areas, Clavarino et al. (2002) found that family functioning suffered significantly. The researchers attributed a large portion of the distress to “clashes between the constructs of masculinity associated with rural and remote lifestyles and those associated with the caring role” (Clavarino et al. 2002, p. 194).

Arora et al. (2007) hypothesise that over the long term, support for ill women may decrease in the face of caregiver burnout, and Payne and McPherson (2010) advocate for workplace support and flexibility for men caring for an ill wife and children. Supporting the caregivers would ideally contribute to the women continuing to receive the support they need. Furthermore, the value of being able to draw on others cannot be underestimated as balancing the support among several family members or friends may relieve the partner from being overburdened by the responsibility of work and the increased expectations of domestic and emotional labour for their children and wife.

Mothers of Mothers

The second most common form of support reported in the current study was female family and friends. Family members are well recognised as a valuable source of emotional and practical support, as they generally have an intimate understanding of the
person, their needs and limitations (Rosland & Piette 2010). Furthermore, women are likely to identify family members as people they are more comfortable seeking support from (Llewellyn & McConnell 2004). Significantly, other women are the most prevalent sources of care in society, with networks of support revolving around feminine relationships (Bracke, Christiaens & Wauterickx 2008).

An unexpected finding in the current study was the extent to which some participants dwelled upon their own mothers when telling their stories of disrupted mothering. Like their descriptions of supportive partners, where the women stated their mothers were helpful or supportive there was often little elaboration. However, if conflict had existed in the relationship, the woman perceived that her childhood had been dysfunctional, or their mother was unavailable, their stories were saturated with discussion of their mothers. Participants’ experiences of being mothered themselves also had profound connotations for how they mothered their own children. Even when women disagree with certain aspects of how they were raised, their mothering is influenced by the behaviours they intentionally reject (Golden 2001). Women seek to improve on the mothering they experienced as children (Hays 1996).

Although there is a large body of research that examines mother-daughter relationships during infancy, childhood and adolescence, and a burgeoning interest in adult daughters caring for their elderly mothers, little research has examined mother and adult daughter relationships between adolescence and old age (Bojczyk et al. 2011; Shrier, Tompsett & Shrier 2004). There is a particular paucity of research that examines tensions in mature maternal relationships (Fingerman 2001), and no studies were located that explored mother-daughter tensions when mothers are supporting adult daughters who are ill.
The mother-daughter relationship can be one of the most enduring, intense and ambivalent relationships experienced in women’s lives (Birditt et al. 2009; Shrier, Tompsett & Shrier 2004; Suitor & Pillemer 2006). As daughters age and have their own children, and their roles converge, they can develop a greater depth of empathy for their own mothers (Fingerman 2001). However, in the face of new challenges tensions can arise from the renewal of past problems (Fingerman 2001). As evidenced by several participants’ stories, some mother and adult daughter relationships in this study were so affected by their history that they remained unresolved and in several cases they were estranged. The intense preoccupation displayed by women regarding their mothers in this study, and the lack of researcher inquiry into mother-adult daughter conflict, makes this a topic worthy of further investigation.

In the main, though, and in common with other studies of ill women (Howell, Fitch & Deane 2003; Mowbray et al. 2005), many participants in the current study described their mothers as a primary source of support. Many of their mothers went to extreme lengths to support their ill daughters and were particularly valuable in filling in when partners were at work. Mothers being supportive is not surprising given the generally greater affectional ties, and shared values and attitudes reported between mothers and their daughters (Bracke, Christiaens & Wauterickx 2008; Suitor, Pillemer & Sechrist 2006).

Women are socialised to provide care for others, and indeed it is women who provide the bulk of informal care (Bracke, Christiaens & Wauterickx 2008; Fingerman 2001; Gonyea, Paris & de Saxe Zerden 2008). Not only do women provide the most care, they are also more likely to be recipients of care at some point in their lives (Bracke, Christiaens & Wauterickx 2008; Uphold, Lenz & Soeken 2000). Research into
women’s support of their adult children has found that women were more “likely to provide support to children who were female, younger, lived closer, and had experienced serious health problems as adults” (Suitor, Pillemer & Sechrist 2006, p. S15). Support was also more forthcoming for unmarried daughters as it was perceived they had less alternative forms of support available (Suitor, Pillemer & Sechrist 2006).

Although Fingerman (2000) hypothesised that as daughters become adults and less dependent the intensity of maternal nurturing normally decreases, other research conducted with American women and their adult daughters has shown that generally daughters remain dependent upon their mothers for emotional support, guidance and influence well into late adulthood (Bojczyk et al. 2011). Certainly in the current study, women were often dependent upon their mothers for childcare and emotional support. Bojczyk et al. (2011) concluded that continuing to mother daughters, even when they become adults, is an enduring feature of maternal relationships (Bojczyk et al. 2011).

An evident cause of conflict in the current study was women feeling replaced by their mothers as the primary carer. In the women’s stories this happened to various degrees. Although feeling replaced may have been inevitable for Samantha or Heather who had lost custody of their sons to their own mothers, it was an intriguing finding in the stories of the women who were not estranged from their mothers and reported them as being helpful and supportive. In a study of women who had been incarcerated, Butler (1994) noted that women sometimes had difficulty re-establishing a maternal relationship with their children following separation, and reported their children forming strong bonds with other adults (Butler 1994). Recommendations from Butler’s (1994) study included keeping the mothers and children together in prison so that the maternal bond was facilitated by proximity, and providing counselling for women distressed by the threats
to the maternal bond. This point is reinforced in Fitch, Bunston and Elliott’s (1999) study of women newly diagnosed with cancer. A woman was distressed by being separated from her child when her daughter was cared for in different family homes, as the family members sought to support the woman during treatment by sparing her childcare responsibilities (Fitch, Bunston & Elliott 1999). This highlights that although support may be available, it needs to be tailored to the woman’s needs if she is to experience the offered support as beneficial. Given the results of the current study, it may be especially important for women to articulate to potential carers their concerns regarding maintaining their maternal bond with their child. What this study adds is the knowledge that regardless of the disease process, even during illness women retain their sense of responsibility for their children and assess any support accordingly. Therefore, in order to support ill women it is necessary to ensure that their children are cared for by people in a manner and location that allows the woman to retain her identity as their mother.

It could be a useful strategy for ill mothers to negotiate with potential carers that their child be cared for in the mother’s home rather than in another dwelling. Verbalising their concerns would ensure that others caring for their children were aware and could include supporting the mother’s bond as a part of their caring efforts. Although families often desire to assist their ill family member they sometimes need guidance in specific actions they can perform (Howell, Fitch & Deane 2003; Rosland & Piette 2010).

**Women Need Women**

Several participants discussed having few female friends, despite craving the company not only of women but other mothers. Throughout history women have supported each other through life events such as sickness, birth and death (Knickmeyer, Sexton &
Nishimura 2002). However, it is a common occurrence that during illness social circles can diminish. In studies of social networks, depressive symptoms were found to be higher in groups of people with no friends compared to those without family (Fiori, Antonucci & Cortina 2006; Vassilev et al. 2011). Furthermore, women lacking friends are reportedly more prone to experiencing a range of psychological problems including loneliness and depression (Greif & Sharpe 2010).

Friends may withdraw, unsure of how to relate to the ill person, or the person experiencing illness may withdraw, finding it difficult to participate in work or leisure activities, or to summon the energy to maintain contact (Ahlström 2007). Yet social support in the form of friendship can give people a sense of belonging and encourage productive coping strategies (Brockopp et al. 2010; Knickmeyer, Sexton & Nishimura 2002). Friends can sometimes be less judgemental and easier to discuss illness with than family members (Gallant, Spitze & Prohaska 2007; Vassilev et al. 2011). In Evans and de Souza’s (2008) study of mothers coping with chronic pain, the women discussed their shrinking social circles. Some of the women were housebound because of disabling pain. Others were unwilling to engage in social activities for fear of exacerbating their symptoms or felt judged and stigmatised as their afflictions were not visible to others.

Essential to women forming close relationships with other women is the confidence to self-disclose and receive and provide emotional support (Greif & Sharpe 2010). This could be the basis of some research reporting that women value friendships with others who share their circumstances (Johnston & Swanson 2004). The value of shared experience was evident in the current study in Winter’s story when she discussed the importance of having a friend undergoing treatment at the same time. Although Winter
had a supportive husband, it was her friend and their similar experiences that she
discussed at length when reflecting on her key sources of social support. Although
family are often the most available and willing caregivers, social support from friends
has been found to be positively received and more appreciated by women (Samarel,
Tulman & Fawcett 2002). Speaking to others in the same situation can be a great source
of relief (Vilhauer 2009), and developing friendships with other women who have the
same illness or are undergoing similar treatments may facilitate women adapting to
illness (Samarel, Tulman & Fawcett 2002). Described as ‘universality’, being able to
share feelings and information with others who have had similar experiences lends itself
to people feeling understood, less alone, less anxious and more in control (Vilhauer
2009).

**Online and Organisational Encouragement**

Social support that was based upon friendship was empowering for participants as it
entailed a sense of mutuality and reciprocity, rather than the sense of duty that
characterised some of the family support networks. However, friendship can be difficult
to establish or maintain in the face of serious illness. Several of the women discussed
their desire to have people to talk to about both mothering and their illnesses. For
women struggling to maintain close friendships, peer support could be a valuable
resource, as belonging to a maternal community can assist women to feel less isolated
and more understood (Farber 2004).

Several participants discussed how valuable support groups were to both their self-
concept as capable, loving mothers, and in providing friendship, and social
opportunities. This idea is well illustrated by the support for her mothering that Unity (a
single mother) found in her mental health support group GROW. Support groups of this
type are deemed extremely successful in facilitating recovery, reducing hospital admissions and length of stay, and improving self-esteem and self-efficacy (Corrigan et al. 2002; Corrigan et al. 2005; Solomon 2004). Rather than existing in opposition to traditional psychiatric treatment, consumer-based support groups complement and encourage compliance to prescribed treatments and medications. Unlike health professionals who function on a medical model, these types of groups do not operate from a place of hierarchical power (Corrigan et al. 2002). Consumer-operated services provide social contact with others who have personal insight into the experience, which reduces stigma, normalises the illness and contributes to improved interpersonal skills (Corrigan et al. 2002; Corrigan et al. 2005; Solomon 2004).

Support from other people who have the same condition is reported to decrease pain, make illness more manageable and meaningful, improve quality of life, and provide perspective that others may be worse off (Sallinen, Kukkurainen & Peltokallio 2011). Due to shared experiences, other patients may have insight into a person’s circumstances that are superior to that of their close friends and family (Dennis 2003; Sallinen, Kukkurainen & Peltokallio 2011). Being able to discuss illness with others who have the same condition can be validating and assist to legitimise the experience of symptoms (Sallinen, Kukkurainen & Peltokallio 2011).

Benefits to participating in consumer-based mental health support groups are thought to be greater the longer a person is a member of such a group, as seeing others recover provides strategies for coping with the illness, contributes to trust in the system, and builds hope, optimism, and self-efficacy (Solomon 2004). As people recover and become more functional there are further benefits to be found in modelling recovery
themselves and helping others (Corrigan et al. 2002; Corrigan et al. 2005; Solomon 2004).

Although the success of consumer-based support groups is discussed at length in the literature, mostly in regards to mental illness, no articles could be found that discussed their value to women’s mothering outside of the postnatal period. Scholars do, however, note that it is difficult to conduct rigorous research with consumer-based self-help groups because professional involvement is generally antithetical to their philosophies (Solomon 2004). However, as much of the extant literature acknowledges the importance that the mothering identity holds for women with a mental illness (Alakus et al. 2007; David, Styron & Davidson 2011; Lagan et al. 2009), and given the value to mothering several women in the current study attributed to consumer-based support groups, this may represent an understudied area. There is also a significant lack of professional parenting programs for people with mental illness who have older children (David, Styron & Davidson 2011; Reupert et al. 2009). Given the apparent benefits, opportunities for women mothering in illness to participate in such groups should be encouraged and facilitated.

Several participants, including all of the American women, were recruited via illness support group websites on the internet. Support groups of this nature allow people to anonymously compare experiences, treatment and health outcomes with other people who have similar conditions (Solomon 2004; Vassilev et al. 2011). However, none of the women in the current study identified these internet groups as a salient source of mothering support. Although these websites have the potential for people to find support, there are risks that they can also be exposed to unpleasant realities and potential outcomes of their illness which some may find difficult and confronting to
deal with (Sandaunet 2007). Sandaunet (2007), in a study of attrition of members from an online breast cancer support group, found that reading the stories of others in whom the cancer had metastasized was too confronting and hope eroding for some women. Other women had left the group as they felt too well, and found that the experiences of others did not correlate with their own, or they did not find the anticipated emotional support for the fear and depression they were experiencing. Not wanting to allow the disease to occupy too much of their time and energy was another source of attrition for participants. Many women had originally joined the group looking for people with similar experiences, who had finished treatment and were leading ‘normal’ lives (Sandaunet 2007). Sandaunet (2007) postulated that the desire to overcome the disease led these women to seek others who had restitution narratives.

Unlike face-to-face support groups where the benefit is thought to increase over time, internet-based support groups tend to be more useful immediately following diagnosis and were not found to benefit long-term condition management (Meier et al. 2007; Vassilev et al. 2011). However, for women isolated, housebound, without natural support networks or perceivably stigmatised illnesses, online support groups may represent at least some contact with people who have had similar experiences (Meier et al. 2007).
Setting

A lounge room in a suburban house. The room is messy, littered with toys. A young woman is sitting on the couch talking on the telephone. A baby is asleep in a bouncer at her feet. Occasionally the woman rocks the baby gently with her foot.

Character | Dialogue and Stage Direction
---|---
MOTHER | I just wanted to thank you again. It was really good advice. My husband spoke to his boss and they’ve given him a few days carers leave and he can work the weekend and have days off during the week instead.

(Listens for a few moments)

MOTHER | Well that way my sister can cover weekends, so between the three of them I won’t be alone very much at all over the next few weeks and it will give him one day a week he can do whatever he wants without worrying about me. You were right, they wanted to help, they just didn’t know how. And it was hard, but I asked them about helping me here at home instead of taking the kids to their places. Once I explained that I was missing the kids and got upset that they weren’t here they understood.

(Listens for a few moments)

MOTHER | Yes, I rang them as well. A really nice lady rang me back. She was saying the next meeting is in a month. I just might be up to going by then. It would be nice to talk to other mothers with the same thing.

(Listens for a few moments)

MOTHER | Yeah, look he’s great, but sometimes you just want to talk to another mother, who isn’t your own mother.

(Laughs)

MOTHER | Yes. Each day I’m feeling a bit better, and knowing now that the kids will be looked after but still here with me has helped a lot.

(Listens for a few moments)

Yes I will make the effort to go. It will be nice. I’m a bit nervous but it will be nice to get out and meet some new people. I’ll let you know how I get on. Thanks again. I’m still in pain and still feeling crappy but at least some things are starting to go well.

(Lights fade)
CONCLUDING COMMENTS

Exegesis situates the findings of this study within the extant literature and offers alternative scripts for health professionals caring for women who have been disrupted in their mothering by illness. Although separation, loss, guilt and shame, social support problems and moral conflict have been recognised in other empirical research exploring maternal illness, these consequences are fragmented across studies. In the literature there is no previous recognition that they form an identifiable phenomenon, that of disrupted mothering. The current study has therefore extended understanding both into women’s experiences of mothering while ill, and proposed that disrupted mothering is a phenomenon with potential for further research in other contexts.

The ways women were influenced by the dominant Western cultural narratives of mothering were explored through examining how they shaped their stories to convey that their children had been effectively mothered. As other scholars have also found, the women predominantly sought to situate themselves as adequate mothers by offering the virtues of their children as evidence. Many offered examples of validation from others, particularly health professionals to support their claims. The value of validation from health professionals for women’s mothering has strong connotations for improving therapeutic relationships and facilitating mothering for women who are ill. This is particularly pertinent given the reports of conflict with nurses.

Disrupted mothering as a constellation of emotional and social consequences challenged women morally and created tension between their ideals of mothering and their own needs as patients. These tensions transferred into the clinical arena where it was found that despite being women and potentially mothers themselves, nurses failed to facilitate mothering for ill women and were perceived to be judgemental and critical.
That nurses are perceived to make moral judgements regarding women’s mothering and treatment choices is another area of nursing research that requires further investigation.

Although the literature supports the findings that women gain the most amount of support from their partners and female friends and relatives, a unique discovery of this study was the intense preoccupation women had with their relationships with their own mothers if they were perceived as inadequate or absent, and the consequences this had for the support available to the women. Another unexplored area of social support revealed by this study was the potential value that belonging to consumer groups represented for supporting women’s mothering. The issues raised in Exegesis have implications for clinical practice which will now be elaborated on.
EPILOGUE

The words are being spoken now, are being written down; the taboos are being broken, the masks of motherhood are cracking through.

(Rich 1986, pp. 24-25)

THE REVIEW

In ‘Disrupted mothering: A drama in four acts’ the mothering role which is often performed masked and rendered mute by cultural narratives was exposed for the complex, intricately layered rendition that it is. Illness and disruption represented primary elements of the script, with the story unfolding as an often sad yet uplifting tale of triumph over adversity. The core audience message being that disrupted mothering is often characterised by feelings of inadequacy, guilt and shame with regards to being a flawed or absent mother, whilst attempting to reframe self as an adequate mother. In the following text I summarise the study, present implications for health professionals and further research, limitations of the study and concluding remarks.

Although having and raising children could be considered an essentially private matter, the social constructions of mothering and the hegemonic ideologies they culminate in make it a political concern. The incursion of the political into the private prompted the use of social constructionist and feminist principles to underpin the research. As it was congruent with feminist and social construction principles, a storytelling methodology was employed to explore women’s experiences of mothering in illness. Some feminist scholars such as Banks-Wallace (1999) also consider storytelling a powerful means of regaining a sense of self worth for women through naming and articulating experiences.
Furthermore, having an opportunity to tell their stories of disrupted mothering may be validating for disempowered women.

Twenty-seven women participated, sharing their stories via their preferred medium of face-to-face meetings, the telephone or email exchanges. Findings were interpreted thematically. Inspired by the naming of one sub-theme and the idea of mothering as a performance, a theatre metaphor was explored and considered and the remaining themes revised to allow the theatre metaphor to extend throughout the entire thesis. This metaphor transformed the findings section into a play, with themes and sub-themes becoming Acts and Scenes. The findings and discussion sections were further distilled into scripts that concisely summarised the outcomes into coherent theatre format.

All of the women who participated in this study were deeply invested in being a good mother and routinely privileged motherhood over their own health needs. However, in many cases they considered themselves flawed mothers due to illness. Conception and pregnancy therefore often represented moral conflict as they attempted to keep their unborn children safe while dealing with the symptoms and treatment of their illness. For some women this meant omitting medication during the perinatal period in order to avoid the teratogenic effects it may have had. Avoiding medication, however, left them susceptible to the symptoms of the illness which, especially in the case of mental illness, could also prevent them from being seen as a ‘good’ and responsible mother. For others whose condition precluded stopping medication, pregnancy could be fraught with fear that their unborn child could be affected.

Breastfeeding was another area of moral concern. The cultural belief that ‘good’ mothers breastfeed their children had connotations for women who due to the nature of their illness or medications could not breastfeed. However, women who did continue to
breastfeed were still conflicted due to health professionals disagreeing about the safety of medications filtering into the breast milk. If they could not breastfeed, or they breastfed while taking medication, the women reported feeling negatively judged as mothers.

Nurses were reportedly insensitive to the distress women experienced trying to manage the conflicting roles of mother and patient, with several of the women perceiving that nurses had made negative judgments of them as mothers. Some of the women discussed attempting to take their breastfed infants to hospital with them, when they were being treated for acute conditions. Whether they were allowed to retain the care of their child or the baby was refused admission, the women experienced conflict with nursing staff and disempowerment. Breast milk was considered simply in terms of nutrition by the nurses, and the symbiotic, nurturing and emotional elements of breastfeeding were disregarded. These findings implied that facilitating breastfeeding and maintaining the mother-infant dyad was not considered a nursing priority outside of maternity-focused wards.

Positive experiences with health professionals correlated with knowing them and feeling known by them. Validation from health professionals that they were doing a good job of mothering, or that their children were coping, was a great source of comfort to the women. The women welcomed advice regarding their mothering from doctors and valued those who were approachable, empathetic and responsive. Hospital specialists, GPs and mental health professionals were considered especially supportive.

Social support emerged as a major consideration for the women as they needed assistance with caring for their children when they were acutely unwell or hospitalised. The most common and accessible source of support was partners. Some of the women
stated that fathers struggled with the extra responsibility, or did not prioritise the care of the children in the same way they did as mothers. In some cases, fathers assuming the primary carer role had negative connotations for the women’s relationships and feelings of closeness with their children. Some of the women also reported that their ex-husbands or partners became possessive of the carer role and were unwilling to relinquish the children when the women were more able to care for them themselves.

Where fathers were deemed to be helpful and supportive and not usurping the mother’s place in the child’s affections, there was very little discussion regarding the way that they helped. This was also true when the women were discussing support from their own mothers. However, if there had been conflict in their relationship, their mothers were absent, or if the mother had custody of the woman’s children, the women’s stories dwelled upon their mothers intensely. Relationships between women and their adult daughters during illness emerged as an intriguing and understudied area of research.

Female friends were a valued source of support; however, several of the women discussed difficulty maintaining friendships while they were ill. Lacking female friends resulted in several of the women feeling isolated and cut off from other mothers. Due to feeling self-conscious about their illnesses or lacking energy, some of the women had withdrawn from their female friends. Yet, recognising the value of being able to socialise with peers, these women expressed a desire to talk to other mothers, to compare children’s behaviours and development, and to provide a sympathetic ear to discuss the difficulties they were having mothering while ill.

Although it may not have benefitted the women personally, support for their children emerged as another issue that was important to them. Thus, children’s empathetic friends and compassionate teachers or child carers were greatly valued, as were support
groups that catered to children whose parents had a mental illness. Community-based consumer support groups were found to be of value to women with mental health issues not only because they helped them to cope with their illnesses, but also because attending these groups also allowed them to socialise with other mothers in a non-judgmental environment. Being with other mothers who had a similar illness was normalising, and allowed the women to compare themselves to women in a similar situation. This was an important finding given that the women in this study made frequent reference to how they were lacking as mothers compared to other presumably healthy women.

Regardless of expressing dedication to the mothering role, and detailing sometimes heroic efforts to care for their children despite their illness, the majority of women in this study considered themselves morally, emotionally, and physically flawed as mothers. The women felt guilty for the times that they perceived they had been physically or emotionally absent or deficient in caring for their children. Attempting to reconcile their mothering with the cultural narratives they had imbibed, the women’s stories invariably included the positive attributes of their children as evidence of effective mothering. Many of the women felt that the time they had spent with their children on more sedentary activities had contributed to them achieving academically. Another perceived benefit was that children were considered more compassionate and empathetic having been raised by an ill mother.

Whether they saw living with an ill mother as character building, increasing empathy, or contributing to academic success, the women attempted to reframe their illness as being of benefit to their children. Each of the women found something positive to say about their children’s attributes even when there were ongoing difficulties in the
relationship or they were estranged. The majority of the stories came full circle with the women either recovered or accepting the limitations of their illness and expressing a newfound joy in mothering.

**IMPLICATIONS FOR HEALTH CARE PROFESSIONALS**

There are many implications for health care professionals that can be derived from the current study and put into practice to mitigate the negative consequences illness can have for women’s mothering. The majority of these implications are not expensive, difficult or dependent on institutional resources. Rather, they rely on encouraging health professionals to reflect upon their beliefs and attitudes regarding mothering and foster a non-judgemental and problem-solving approach to practice.

*Validating Mothers, Practising Professionally and Banishing the Myth of the Perfect Mother*

Validation from health professionals that they were adequate mothers was both valued by the women and drawn upon in their stories to provide evidence that their children had been effectively mothered. As negative appraisal of their mothering by health professionals was experienced as deeply wounding and recollected bitterly by some of the women in this study, health professionals need to carefully consider how they interact with mothers who have an illness. Health professionals would be advised to reflect on their personal beliefs and how they might be subjectively influenced by cultural ideologies about mothering themselves, in order to consciously resist the temptation to morally judge women.

However, often women’s maternal responsibilities are not considered by health professionals unless they are a source of conflict or concern. Given the centrality of the mothering role to women’s self-esteem and sense of worth, this is an easily remedied
omission of practice. Women’s mothering responsibilities or plans for conception should be part of a routine assessment. Women who have children should be asked how they are coping and if they have any particular concerns. Acknowledging women’s maternal responsibilities and encouraging them to discuss challenges they face also offers an opportunity to identify problems that may be amenable to other interventions or referrals.

There are several interventions for women suffering guilt and shame regarding their perceived flaws as mothers. Firstly, it can be highlighted to them that the majority of women consider themselves as flawed mothers in some sense. It may be useful to assist women to identify what skills they bring to mothering rather than concentrating upon their supposed deficits. Understanding that no mother is perfect may allow women to judge themselves by kinder, more inclusive measures.

The women in this study instinctively drew upon their children’s positive personal attributes and successes as evidence when attempting to position themselves as adequate mothers. When discussing their children, the women drew attention to personal qualities such as compassion, empathy, independence and intelligence. Health professionals could capitalise upon this maternal inclination, and assist women to reframe their mothering experiences by encouraging them to articulate positive things about their children. For women concerned about being unable to engage in robust physical play, attention could be drawn to the academic advantages for children of engaging in sedentary activities such as reading. Furthermore, encouraging women to identify positive outcomes of their mothering provides an excellent opportunity to offer reassurance and professional validation of their mothering skills.
Health professionals can also draw women’s attention to the dominant ideologies of mothering and emphasise their unattainability. In this way women can be facilitated to resist the dominant discourses that identify the ‘correct’ ways to mother and instead gain understanding and acceptance of the best way they can mother. Through making women aware of the ideologies they may be unconsciously subject to, health professionals would be engaging in consciousness raising which will further contribute to challenging the hegemonic nature of Western mothering ideologies.

**Supporting Women’s Emotional and Physical Engagement with their Children**

Not ‘being there’ for their children was a particular concern for mothers in this study. For women distressed by separation through hospitalisation or custody issues, nurses can encourage maintaining contact in any way possible. Facilitating the daily enactment of mothering should be a priority through providing opportunities for women to maintain close contact with their children. This could occur through: child friendly spaces in hospitals being created to enable more natural visiting; the boarding of breastfed infants being standard care; and where visiting is inappropriate or impossible, helping women to stay in touch by telephone, mail and the internet.

Findings from this study showed that several women appreciated health professionals giving them constructive advice regarding mothering. This implies women may be amenable to a frank discussion regarding their physical and emotional limitations and how mothering might be tailored to accommodate their restrictions. Due to the conflict women can experience between being a good mother and a good patient, some women who are acutely ill may even benefit from ‘permission’ to relinquish some of their mothering responsibilities during the intense phases of treatment. Guidance of this type from a health professional may be seen as prescriptive and authoritative and could
contribute to alleviating some of the negative emotions women experience when mothering is disrupted.

As women frequently expressed guilt that younger children might be missing out on the more physical and robust activities of childhood, perhaps a compromise can be found by suggesting that women enrol children into preschool programs that can provide this type of physical stimulation. It could be stressed to women that their children could benefit from interacting with other children, give the children and women some respite from each other, and allow the women some time to rest. Having some time away from their children could also improve the women’s capacity to be more emotionally present when reunited.

Women who are struggling physically with caring for their children may benefit from referral to other health professionals such as occupational therapists who are qualified to assess and optimise environments within which the women are mothering. Given the emphasis women in this study placed on housework, it would also be beneficial to identify if they qualified for any form of government-subsidised home help. Assisting women to identify people in their social support networks that may be willing to assist them may be immediately helpful. This idea will be explored further in the next section that discusses social support.

Although women may be reluctant to seek help with activities they consider their domain as mothers, it could be useful to assist women to identify mothering activities they are not willing to relinquish and those activities that could conceivably be relegated to others. By focusing discussion on what they can and cannot accomplish for their children, the women’s own problem-solving skills could be fostered.
Women who are finding it difficult to be emotionally engaged with their children may appreciate being reassured that they are not the only mothers who feel that way. Empathy, understanding and a non-judgemental stance might encourage sharing and problem solving. Encouraging women to articulate their feelings can reassure them that these emotions are common and that at some point all women are dissatisfied with the mothering role. Discussing women’s own experiences of being mothered in a therapeutic context may provide insight into how mothering was represented to them as children and create opportunities for them to resolve any difficult thoughts or feelings. Unearthing their expectations of themselves as mothers might also foster occasions to encourage a more realistic ideal. However, if these negative emotions are unmanageable or severely impinging upon the women’s quality of life and they are not already being treated for mental illness, referral to mental health professionals could be appropriate. For women whose illness is psychiatric in nature a review may be warranted that takes into account existing treatments and stressors.

**Assessing and Recruiting Social Support**

When discussing social support it should be acknowledged that women in different contexts will have different support needs, and some may even be unwilling to seek support for fear of it making them vulnerable. However, findings from this study suggest that women might benefit from being encouraged to identify where they could draw support from existing relationships. Taking a proactive approach to recruiting and organising support people could assist in accessible support being perceived as more acceptable to them. Furthermore, identifying social support might make women feel that they have control over who helps them in caring for their children. Actively sourcing support might also contribute to reducing reliance upon too few people, thereby helping to avoid overburdening willing caregivers.
When identifying potential support people, it could be useful to classify what type of support people might be able to provide. Although families often desire to assist their ill family member they sometimes need guidance in specific actions they can perform. Encouraging women to speak with their support network and outline the types of support they would appreciate could facilitate having them met. Given the results of the current study, it may be especially important for women to be encouraged to articulate to potential carers their concerns regarding maintaining their maternal bond with their child. Verbalising their concerns could ensure that others caring for their children were aware, and could include supporting the mother’s bond as a part of their caring efforts.

It should also be stressed to women that allowing others to assist them may benefit their ability to continue to mother their children. Willingness to seek help should be framed as evidence of their desire to continue to actively mother, rather than as a reflection of deficit.

The value of being able to draw on others cannot be underestimated as sharing the support among several family members or friends may relieve women’s partners from being overburdened. Given the reports of marital tension and conflict arising from maternal illness reported by several women in this study, there may also be a case for inquiring if women and their partners are interested in relationship counselling.

The apparent isolation of several of the women in this study, their interest in developing and maintaining friendships with other mothers, and the value of friends for health and wellbeing discussed in the literature, represent a largely unexplored area of study. Women who mother while ill should be encouraged to maintain existing friendships. If their health allows, participation in social events should be promoted. For those struggling with fatigue or the symptoms of their illness, staying in touch with friends
via telephone, email or social media could assist them to feel connected to the wider maternal community.

As support groups appeared to be such a valued source of support for several of the women in this study, health professionals could assist women to find groups in their local area or direct them to online organisations. As some psychosocial needs may be outside of the scope of practice, referrals could also be made to social workers to assist in locating further support where existing networks are unavailable or inadequate. Social workers would also be valuable for assessing any government entitlements the women qualify for, thereby optimising financial and practical support from professional agencies.

*Maintaining the Breastfeeding Dyad*

This study revealed the difficulties that several women had reconciling their breastfeeding role as a mother with being a patient with an acute illness in hospital. Although there are policies and directives to support women to retain the care of their infant while in hospital, for these women the reality was conflict, disempowerment and distress. Promoting awareness of these policies, educating all health professionals about the benefits of breastfeeding and the need to maintain the mother-baby dyad, and improving access to lactation consultants or midwives outside of maternity wards could contribute significantly to the care of breastfeeding mothers admitted for treatment. Women and their breastfed infants should not be separated until every other alternative has been considered. All health professionals should be educated and aware that breastfeeding is not merely about nutrition and that there can be lasting and detrimental outcomes from separating a mother and her breastfed infant.
When women are admitted without their children, they should be given assistance with expressing breast milk, including access to lactation consultants or midwives in order to maintain their milk supply. The availability of a lactation consultant hospital-wide may have made participants in the current study feel more supported; facilitated the admission of mother and child together; allowed for educating non-maternity-based health professionals on the importance of facilitating the breastfeeding mother-baby dyad; and reduced the moral distress and disruption to mothering they experienced. Furthermore, there should be encouragement for carers of babies not admitted to hospital to bring them to visit as often as possible in order for the hospitalised mother to see the baby. On discharge, referral to breastfeeding support services would be appropriate as women overcome any potential difficulties re-establishing exclusive breastfeeding.

FURTHER RESEARCH

This study revealed that disrupted mothering can threaten women morally as mothers. Feeling that they are inadequate in the mothering role resulted in expressions of guilt and shame and efforts to articulate a positive outcome for their children. Further research would be illuminating to determine if disrupted mothering concepts were relevant to groups of mothers such as mothers who live in different countries from their children, non-custodial mothers, mothers who share care with ex-partners, incarcerated mothers, mothers who have experienced domestic violence, and mothers with substance dependence issues. Discovering how culture and socioeconomic status influence the subjective experience of disruption would also be revealing.

The intense preoccupation displayed by women regarding their mothers in this study, and the lack of researcher inquiry into mother-adult daughter conflict makes this a topic
worthy of further investigation. There is a particular paucity of research that examines tensions in mature maternal relationships, and no studies were located that explored mother-daughter tensions when mothers are supporting adult daughters who are ill.

The body of nursing knowledge would also benefit from further research into the expectation of support from caregivers, the type of support women desire compared to that which they actually receive, alternative sources of support such as peer support groups, how women learn about and are put into contact with such groups, and the perceived benefits of engaging. Given the detrimental effects of isolation from other mothers on some of the women in this study, and the perceived benefits to those who enjoyed close relationships with other women, investigation into friendships during illness is also long overdue.

LIMITATIONS AND EXPLANATIONS

Despite this study making an important and original contribution to nursing knowledge regarding mothering in illness, like all research it has its limitations. Although the findings of this study resonate with others in the literature, it draws its conclusions from the experiences of a small number of women. The inclusion criteria that specified women were fluent in English potentially limited the sample size. All of the women who responded were Western, White, heterosexual, and predominantly middle class. These participant characteristics located this study firmly within the Western ideologies of mothering, and therefore did not address other cultures, communities and socioeconomic constructions of mothering. The experiences of women from more diverse cultures and socioeconomic backgrounds could conceivably be quite different. However, participant characteristics in this study mirror the vast majority of nursing literature that explores mothering and may be reflective of White women’s increased
likelihood of participating in research. The women’s willingness to participate in research exploring mothering may have also been indicative of their desire to undertake narrative repair of their identities in response to perceiving that they had transgressed the ideologies of motherhood to which they were culturally aligned. This study has also not included the perspectives of women in same sex relationships who could otherwise also subscribe to the ideologies of Western mothering, as none volunteered to take part in the study.

CONCLUDING REMARKS

The women’s stories exposed the challenges of maintaining maternal self-esteem in the face of debilitating illness. Mothering in illness was further complicated by isolation from other mothers; inadequate, inappropriate or unappreciated social support; misunderstandings with health professionals regarding their investment in the mothering role; and conflicting medical advice concerning the safety and efficacy of prescription medications during pregnancy or breastfeeding.

Regardless of the disease process, during illness women retained their sense of responsibility for their children. This study has provided further insight into the ways that illness can morally and existentially threaten women as mothers by interfering with their ability to protect and care for their children. While interpreting the women’s stories, it became apparent that they were sensitive to the cultural expectations of motherhood and were keenly aware of the ways they may have transgressed the ideal, conceiving themselves as flawed mothers.

Accounts of inadequacy coloured their mothering experiences from conception through to mothering adult children. Detailing the ways they may have been physically or emotionally inadequate or absent, the women expressed feelings of shame, guilt, regret
and loss. Opportunities for health professionals to facilitate mothering therefore exist in assisting women to maintain contact with their children and employing strategies to help mitigate these negative emotions and feelings of culpability. This research contributes to the existing literature by sensitising health professionals and others to the conflict that women might face when they are both mothers and patients. Validation from health professionals regarding their mothering was experienced therapeutically by women, yet several women encountered judgement and disempowerment, which provides direction for improving the way that health professionals interact with patients who are mothers.

There are several unique insights resulting from this study that extend understanding of women’s experiences of mothering in illness. This research has recognised disrupted mothering as a phenomenon with potential for further research in other contexts of maternal disruption. Neglected in the extant literature is discussion of women who want to retain the care of their breastfed babies when they are admitted to hospital for non-maternity-related illness. Also unexamined is the resistance and conflict the women experienced with nursing staff regarding the babies being admitted as boarders onto medical-surgical wards. Additionally, how women are affected by the absence of their own mothers or previous conflict with their mothers, in the context of gaining familial support for childrearing, are new findings.

Although none of the women who participated in this study directly claimed that they were ‘good’ mothers, they each found ways in their stories to mediate between their own experiences and the cultural narrative of mothering. Reframing their experiences of mothering in illness, the women offered their children’s positive attributes as evidence of effective mothering. Thus through their stories the women sought to repair their
damaged maternal identities and establish themselves as adequate mothers who had produced socially acceptable children, therefore extending and challenging the notion of what it is to be a ‘good’ mother.

Nurses encounter women in all stages of the illness trajectory and need to recognise that women’s primary identities as mothers does not change in the face of illness. We might refer to these women as patients, yet to them and their families they remain mothers. Instead of thwarting women in their attempts to continue to mother despite illness, nurses should advocate for them and for services to ensure that women can continue to mother to the best of their abilities. As models of care develop that see an increased focus on seamless and community based care this is even more essential.

The scripts that classify women as ‘good’ or ‘bad’ mothers need to be exposed and disrupted. The spotlight on the lead, alone in centre stage, should be cast further so that she is illuminated in the context of the entire production. As critics we need to learn to be tolerant of alternative acting styles, and to recognise that the performance of mothering is adlibbed, fluid and individual. Some mothering is performed as a monologue, other performances are supported by a large cast, complete with understudies and stage hands. The performance is further bound by the range of the actress and access to props and budgets. Acclaim should be offered to all mothering performers that they have undertaken a difficult role, that they are fulfilling that role to the best of their ability, and that each performance is a unique and personal interpretation.
CURTAIN CALL


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APPENDIX 1: PRESS RELEASE

Mothers needed for research study

Researchers from the University of Western Sydney are looking to interview mothers who have experienced difficulties caring for their children as a result of illness, to find new ways of tailoring their care to better suit their personal situations.

PhD student Tamara Vallido, from the School of Nursing and Midwifery, says health care professionals rarely consider maternal responsibilities, but children are often a woman’s primary concern when they are sick.

Ms Vallido says the issue hasn’t been sufficiently examined, and as such the study will help raise awareness among health professionals into the varied needs of female patients.

“In Western countries the standard of mothering is almost impossibly high, so when mothers become ill they often feel extremely anxious about their children,” she says.

“It is well documented that hospitalised women want to be acknowledged as mothers and to have their maternal concerns addressed by health professionals, and this study will help bring the issue into the professional arena.”

Ms Vallido is interested in finding out if there are common patterns in the experiences of the mothers, and what steps can be taken to make mothering during illness easier.

“By sharing their personal stories, we can better understand how disruptions to the family affect the wellbeing of women over both the short and long term,” she says.

“The study will also help determine if their illness affected their relationships with their children, and how health care providers can adapt their treatments to mitigate this,

“Being a mother can be time consuming, challenging and extremely rewarding, and we want to make sure families are supported as much as possible.”

Ms Vallido says women interested in taking part can choose to be interviewed over the internet or phone, or take part in a face to face meeting.

“I’m more than happy to meet in person or to talk to them over the telephone, and this will take a little over an hour of their time,” she says.

“Otherwise women can email me their stories, and it would only take a few exchanges to fully record their experiences for the study.”

“All the information will be confidential, and this study has UWS ethics committee approval.”

Mothers over 18 who have had an illness that has interfered with their ability to take care of their child or children are encouraged to contact Tamara Vallido on 0435 044 715, or email t.vallido@uws.edu.au
APPENDIX 2: NEWSPAPER ADVERTISEMENTS

10/02/2010
Tammy’s project
Blacktown Advocate, 10/02/10, General News, Page 12

Tammy’s project
UNIVERSITY of Western Sydney
PHD student Tammy Valldio is studying how being sick affects
mothers and their children. If you are a mother and have been separated
from your children by illness and are willing to help the study, phone
0435 044 715 or email
t.valldio@uws.edu.au

Mums needed
Fairfield Advance, 10/02/10, General News, Page 26

Mums needed
UNIVERSITY of Western Sydney PHD student
Tammy Valldio is studying how being sick
affects mothers and their children. If you are a
mother and have been separated from your
children by illness and willing to help the
study, phone 0435 044 715 or email
t.valldio@uws.edu.au.
**III kids’ study**

Parramatta Advertiser, 10/02/10, General News, Page 8

UNIVERSITY of Western Sydney PHD student Tammy Vallido is studying how being sick affects mothers and their children. If you are a mother and have been separated from your children by illness and willing to help the study phone 04356044715 or email t.vallido@uws.edu.au.

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**09/02/2010**

**Separation study**

Macarthur Chronicle, 09/02/10, General News, Page 77

UNIVERSITY of Western Sydney PhD student Tammy Vallido is studying how being sick affects mothers and their children. If you are a mother and have been separated from your children by illness and willing to help the study phone 0435 044 715 or email t.vallido@uwa.edu.au.
Beginners computer class: Offered at Nasyong House, 64 Falmouth Road, Quakers Hill, from 10am, February 12, 9am to noon. One-off fee of $10. Free childcare available.

Sub-branch meeting: A special meeting will be held after the monthly meeting of the Seven Hills Toongabbie RSL Sub Branch on Sunday, February 21, from 10am, to elect a sub-branch committee and trustees to take office on March 22, after the amalgamation of Seven Hills Toongabbie and Wentworthville RSL sub-branches. Nominations will be called from the floor. The meeting will be at Seven Hills Toongabbie RSL Club, corner of Beat Road and William Street, Seven Hills.

Mothering study: Have you ever been ill and separated from your children? Tammy Valido is calling for interview subjects for a University of Western Sydney study about mothering. Call Tammy Valido on 0435 044 715 or email tamvalid@uow.edu.au.

Spanish classes: Intensive classes are open at The Hills Sports High for students interested in learning Spanish as a second language. Courses are offered for beginners, intermediate, and advanced for years 7 to 10 and years 11 and 12. Classes are held every Saturday from 9am to 11.15am at the school in Beat Road, Seven Hills. Call Ms Chavez on 0404 840 450, Mrs Garcia on 9623 8121 or Ms Moneya on 0404 724 878.

Free English classes: Run in Blacktown by Eda Amilien for people of non-English-speaking backgrounds. Will be held on Tuesdays and Fridays from 12.30pm to 2.30pm at 32 F loscombe Road, Blacktown. Call Peter on 0412 244 361 or 9614 0679.

Computer class: Free UFE class at Dean Park Community Development Project, 9 Yarramundi Drive, Dean Park. Call Karen on 9626 5128.

Children's art class: Blacktown Arts and Craft Group classes in drawing, watercolour, oil painting, acrylics, drawing, paint, pastels and craft on Tuesdays, 4pm-6pm, and Wednesdays, 4pm 6pm and 6pm 8pm. Call 9629 1144.

Parents Without Partners: Meets first Tuesday of each month at Blacktown Workers Sports Club. Ideal for those divorced, separated, widowed. Regularly arranged outings. Call Ullman on 9634 7592 (10am-8.30pm).

Buddhist meditation: One-hour classes every Saturday morning in school terms. 9am-10am. Call Deborah on 9837 7237 or 0413 327 750.

VIEW club: Meets for lunch on the third Wednesday of each month at Blacktown Workers Club. Open to women 18 and over. Guest speakers. Monthly outings. Call 9611 7065 or 9831 6055.

Toastmasters: Quakers Hill group meets at 7.30pm on the first and third Mondays of the month at Quakers Hill Neighbourhood Centre. Call Tony on 0400 202 514.

Activities: Downside Cottage at 2, Astor Drive offers a range of regular activities. Free community breakfast last Tuesday of the month, 9am-10am. Free first aid training. Learn techniques for managing child misbehaviour. Call Megan on 9621 2037.

Gambling support: Group for anyone with a gambling problem, including partners and family members. Runs 10am to noon Saturdays at Cessnock Blacktown, 51 Alannah Street. Entry via side door and parking available.

Writers: Blacktown regional group of the Fellowship of Australian Writers meets on the second and fourth Sunday of the month on the second floor of the Max Weber Library in Blacktown, 2pm-4pm. Call Stan on 9621 4292.

Probus club: Rolly Hill group meets on the third Wednesday of each month at 10.30am at Rolly Hill RSL. Call Genny Taylor on 9625 0175 or Iona Le Bletston on 0412 416 721.
Disrupted Mothering: Australian Women’s Stories

- Are you a mother?
- Are you over 18 years of age?
- Have you ever had an illness that interfered with your ability to mother your children?
- Do you speak English?
- Can you spare 1-2 hours of your time to tell your story, face-to-face, via the telephone or through an exchange of emails?

If you answered yes to all of the above questions, you are invited to participate in a research study. All information you provide will be dealt with in privacy and confidentiality. For more information, please contact Tamara Vallido (researcher) on 0435044715 or email t.vallido@uws.edu.au.

This study has been approved by the University of Western Sydney Human Research Ethics Committee.
The approval number is HREC/14/3

APPENDIX 3: RECRUITMENT POSTER
Human Research Ethics Committee

Office of Research Services

Participant Information Sheet

Project Title: Mothering in Illness: Australian Women’s Stories

Who is carrying out the study?

This study is being undertaken by Tamara Vallido and forms the research basis for the degree of Doctor of Philosophy (PhD) at the University of Western Sydney under the supervision of Professor Debra Jackson, Professor Lesley Wilkes and Professor Bernie Carter.

What is the study about?

The purpose is to investigate women's experiences of mothering their children while they (the mother) is ill. For the purpose of this study illness is defined as having an acute, chronic or life threatening disease. We seek to learn about the individual experiences of women disrupted in their mothering by illness, especially how they feel that it has impacted upon their health and wellbeing, their relationships with their children, and their experiences with health professionals. You do not need to be currently ill. You are welcome to share your story of previous illness, if you felt that it disturbed your ability to mother your children.

What does the study involve?

If you choose to be involved, and you live in Sydney or its surrounds, we would ask you to meet Tamara either on campus or at another mutually agreed, quiet private place and tell her your story of mothering disrupted by illness. If you are geographically distant, or do not wish to be interviewed in person you are also welcome to tell your story via an email letter exchange, or over the telephone.

How much time will the study take?

It is expected that the face to face or telephone conversations will take approximately one hour of your time. If you prefer to share your story via an e-mail exchange, it will take as long as it takes you to type your story, plus possibly two or three further e-mails to answer some clarifying questions.

Will the study benefit me?

It is not expected that you will personally benefit from participating, however sometimes participants find that they appreciate an opportunity to tell their story in full to an interested researcher.

Will the study involve any discomfort for me?

Sometimes discussing what may have been a difficult time in your life can be emotionally upsetting for participants.

How is this study being paid for?
This study forms part of a degree and is not funded.

**Will anyone else know the results? How will the results be disseminated?**

All aspects of the study, including results, will be confidential and only the researchers will have access to information on participants. All stories are de-identified. You will be referred to by a false name (a pseudonym) and any places or people you discuss will also be changed or blanked out. Your story, along with other women's stories, will be included in a doctoral thesis. Also, journal articles will be written and published in professional journals, and presented at professional conferences. If you wish, you may receive a summary of the study after it is complete (January 2012) and be alerted to any publications from the study, by contacting Tamara by phone or e-mail.

**Can I withdraw from the study?**

Participation is entirely voluntary: you are not obliged to be involved and if you do participate you can withdraw at any time without giving any reason and without any consequences.

**Can I tell other people about the study?**

Yes, you can tell other people about the study by providing them with the chief investigator’s contact details. They can contact the chief investigator to discuss their participation in the research project and obtain an information sheet.

**What if I require further information?**

When you have read this information, Tamara will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Tamara on 0435044715/0246203355 or her principal supervisor Professor Debra Jackson on 02 46203532. You may also contact Professor Jackson if you wish to confirm Tamara’s identity or express any concerns about her conduct when interviewing you.

**What if I have a complaint?**

This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is HREC7473. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel 02-4736 0883 Fax 02-4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome. If you agree to participate in this study, you may be asked to sign the Participant Consent Form.
APPENDIX 5: LIST OF FREE COUNSELLING SERVICES

**General support and counselling**
- Relationships Australia [http://www.relationships.com.au/]: 02 9418 8800 or 1300 364 277

**Parenting issues**
  24 hour parenting information and counselling
- Parent Line: 1300 1300 52
  Toll free, 24 hour telephone information, counselling and referral service for all NSW parents of children aged 0 - 18 years.
  Operates 7 days (including public holidays).
  24 hour information and counselling for parents or carers of children under five years
APPENDIX 6: EVOLUTION OF THEMES

Coding Stage 1

<table>
<thead>
<tr>
<th>Abandoned</th>
<th>Dedication</th>
<th>Loss</th>
<th>Private Health Cover</th>
<th>Time</th>
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<tbody>
<tr>
<td>Alternative Activities</td>
<td>Demands</td>
<td>Measuring Mothering</td>
<td>Professionals</td>
<td>Treatment Decisions</td>
</tr>
<tr>
<td>Alternative Carers</td>
<td>Different</td>
<td>Meds Treatments</td>
<td>Protecting</td>
<td>Visiting</td>
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<td>Ambivalent</td>
<td>Dissatisfaction</td>
<td>Money</td>
<td>Rape</td>
<td>What Helped</td>
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<td>Baby Boarding</td>
<td>Emotional neglect</td>
<td>Mother as Central</td>
<td>Regret</td>
<td>Women Need Women</td>
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<tr>
<td>Bad Mother</td>
<td>Fear</td>
<td>Motoring Tasks Affected</td>
<td>Relationship</td>
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<tr>
<td>Barriers</td>
<td>Good Mother</td>
<td>Motivation</td>
<td>Resistance</td>
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<td>Being Judged</td>
<td>Grandmother</td>
<td>Negatives for child</td>
<td>Responsibility</td>
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<td>Benefits for Mother</td>
<td>Guilt</td>
<td>Normal</td>
<td>Ra-Storying</td>
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<tr>
<td>Breaking Point</td>
<td>Heartbreak</td>
<td>Powerless</td>
<td>Separation</td>
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<td>Breast Feeding</td>
<td>Heroic</td>
<td>Own Mother</td>
<td>Suicide</td>
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<td>Carpe Diem</td>
<td>Ill Child</td>
<td>Partners</td>
<td>Support</td>
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<td>Custody</td>
<td>Isolation</td>
<td>Physical</td>
<td>Teachers</td>
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<td>Pregnancy</td>
<td>Tenacious</td>
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<td>Threat of Death</td>
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<td>Kids as Carers</td>
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<td>Kids Empathy</td>
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Coding Stage 2
Coding Stage 4
Coding Stage 5
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<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
<th>Explanatory Sentence</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Beginning: Cast into the role of patient.</td>
<td>Introducing the cast</td>
<td>Brief introduction of the participant demographics and medical history.</td>
</tr>
<tr>
<td></td>
<td>Conflicting roles</td>
<td>The mothering role is largely incompatible with the sick role. This sub-theme contains descriptions of treatment mothering decisions women make in the context of their illness.</td>
</tr>
<tr>
<td></td>
<td>The hospital scene</td>
<td>This sub-theme encompasses the experiences women have had of being hospitalised, baby boarding, continuing to breastfeed despite hospitalisation, and being visited by their children.</td>
</tr>
<tr>
<td>Playing the Part: The ill mother.</td>
<td>The Show must go on</td>
<td>In spite of sometimes severe illness women still considered themselves (and were often considered by others) to be primarily responsible for their children, and they continued to do whatever they could to care for their children.</td>
</tr>
<tr>
<td></td>
<td>Reviews and critics</td>
<td>Many of the women judged their mothering quite harshly, comparing themselves to well women. This subtheme also encompasses the outcome for the maternal-child relationship.</td>
</tr>
<tr>
<td>Supporting Cast: Heroes and Villains</td>
<td>The understudy</td>
<td>In most cases, where a woman became ill it was her partner who stepped up, and shouldered most of the responsibilities for child care and domestic duties.</td>
</tr>
<tr>
<td></td>
<td>Behind the scenes or</td>
<td>Support was also available from other relatives, teachers at children’s schools and professional support groups.</td>
</tr>
<tr>
<td></td>
<td>The chorus line</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Women in the wings</td>
<td>While women often isolated themselves from their peers, where there were girlfriends available they were a positive and validating source of support.</td>
</tr>
<tr>
<td>Re-writing the ending</td>
<td>Adlibbing the part</td>
<td>Where women were physically or emotionally prevented from the full range of normal mothering activities, they customised activities they engaged in with their children to care for their children to their full capacity.</td>
</tr>
<tr>
<td></td>
<td>The mostly happy ending</td>
<td>Women appeared to re-frame their mothering to show that despite their limitations their children had still turned out well, and had indeed even benefitted for the experience. Offering evidence affirming their identities as ‘good’ mothers.</td>
</tr>
<tr>
<td>Acts</td>
<td>Scenes</td>
<td>Explanatory Sentence</td>
</tr>
<tr>
<td>-------------------------------</td>
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</tr>
<tr>
<td>The Beginning: Cast into the role of patient.</td>
<td>Conflicting roles: <em>The patient mother</em></td>
<td>The mothering role conflicts with the patient role on many levels.</td>
</tr>
<tr>
<td></td>
<td>The hospital's core: <em>Nurses, relations and misunderstandings</em></td>
<td>Woman’s motivation to mother their children from their hospital bed was misunderstood by nursing staff, often resulting in tension between women and nurses and a lack of support for women in their mothering.</td>
</tr>
<tr>
<td></td>
<td>Encouraging the leading lady: <em>The familiar health care professional</em></td>
<td>This sub-theme describes positive encounters with health professionals and the value women place upon being known and validated as a mother by professionals.</td>
</tr>
<tr>
<td>Playing the Part: The ill mother.</td>
<td>The Show must go on: <em>The relentless nature of mothering</em></td>
<td>In spite of sometimes severe illness, women still considered themselves and were often considered by others to be primarily responsible for their children, and they continued to do whatever they could to care for their children.</td>
</tr>
<tr>
<td></td>
<td>Reviews and critics: <em>Outcomes, guilt and blame</em></td>
<td>Many of the women judged their mothering quite harshly, comparing themselves to well women. This subtheme also encompasses the outcome for the maternal/child relationship.</td>
</tr>
<tr>
<td>Supporting Cast: Heroes and Villains</td>
<td>The understudy: <em>The partner steps up</em></td>
<td>In most cases, when a woman became ill it was her partner who stepped up, and shouldered more of the responsibility for child care and domestic duties.</td>
</tr>
<tr>
<td></td>
<td>Behind the scenes: <em>Helpful others</em></td>
<td>Support was also available from other relatives, teachers at children’s schools and professional support groups.</td>
</tr>
<tr>
<td></td>
<td>Women in the wings, <em>Mothers and female friends</em></td>
<td>While women often isolated themselves from their peers, there were girlfriends available they were a positive and validating source of support.</td>
</tr>
<tr>
<td>Re-writing the script</td>
<td>Ad libbing the plot: <em>Doing what he can</em></td>
<td>Where women were physically or emotionally prevented from the full range of ‘normal’ mothering activities, they customised activities engaged in with their children striving to care for their children to their full capacity.</td>
</tr>
<tr>
<td></td>
<td>The mostly happy ending: <em>The children are okay</em></td>
<td>Women appeared to re-frame their mothering to show that despite their limitations, their children had still turned out well, and had indeed even benefited for the experience. Offering evidence affirming their identities as ‘good’ mothers.</td>
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<td><strong>Playing the Part:</strong></td>
<td>Conflicting roles: The patient mother</td>
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<td>The Show must go on: The relentless nature of mothering</td>
<td>In spite of sometimes severe illness women still considered themselves (and were often considered by others) to be primarily responsible for their children, and they continued to do whatever they could to care for their children.</td>
</tr>
<tr>
<td><strong>The Hospital Scene:</strong></td>
<td>Nurses: Misunderstanding mothers</td>
<td>Women’s motivation to mother their children from their hospital beds was misunderstood by nursing staff often resulting in tension between women and nurses and a lack of support for women in their mothering.</td>
</tr>
<tr>
<td></td>
<td>Doctors: Familiarity breeds content</td>
<td>The most supportive and appreciated health professionals are generally those that have had a long association with the woman, who the women felt “knew” them, and understood what was important in their lives and their domestic situations.</td>
</tr>
<tr>
<td></td>
<td>Children: Visitin Mummy</td>
<td>Issues surrounding children visiting on medical, surgical, and psychiatric wards, arranging alternate care, and missing significant events and milestones.</td>
</tr>
<tr>
<td><strong>Supporting Cast:</strong></td>
<td>The understudy: The partner steps up</td>
<td>In most cases, where a woman became ill it was her partner who stepped up, and shoulders more of the responsibility for child care and domestic duties.</td>
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<td>Behind the scenes: Helpful others</td>
<td>Support was also available from other relatives, teachers at children’s schools and professional support groups.</td>
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<td>Women in the wings: Mothers and female friends</td>
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</tr>
<tr>
<td><strong>Re-writing the script:</strong></td>
<td>Adlibbing the part: Doing what she can</td>
<td>Where women were physically or emotionally prevented from the full range of normal mothering activities, they customised activities they engaged in with their children striving to care for their children to their full capacity.</td>
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<td></td>
<td>Reviews and critics: Guilt and blame</td>
<td>Many of the women judged their mothering quite harshly, comparing themselves to well women. This subtheme also encompasses the outcome for the maternal child relationship.</td>
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<td>The mostly happy ending: The children are okay</td>
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</tr>
</tbody>
</table>
### Coding Stage 9

<table>
<thead>
<tr>
<th>Acts</th>
<th>Scenes</th>
<th>Explanatory Sentence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Playing the Part</td>
<td>Recoupling roles: The patient mother</td>
<td>The mothering role conflicts with the patient role on many levels. Sometimes women</td>
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<tr>
<td></td>
<td></td>
<td>treatments decisions were dictated by trying to reconcile these disparate roles.</td>
</tr>
<tr>
<td></td>
<td>The Show must go on. The relentless responsibility of mothering</td>
<td>In spite of sometimes severe illness, women still considered themselves (and were often considered by others) to be primarily responsible for their children, and they continued to do whatever they could to care for their children.</td>
</tr>
<tr>
<td></td>
<td>Aching: Doing the best she can</td>
<td>Where women were physically or emotionally prevented from the full range of normal</td>
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<td></td>
<td>mothering activities, they customized activities they engaged in with their children striving to care for their children to their full capacity.</td>
</tr>
<tr>
<td>The Medical Scene</td>
<td>Reading different scripts: Nurse misunderstanding mothers</td>
<td>Woman's motivation to mother their children from their hospital bed was misunderstood by nursing staff often resulting in tension between women and nurses and a lack of support for women in their mothering.</td>
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<tr>
<td></td>
<td></td>
<td>Receiving good direction: Health professionals supporting mothering</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The heartbeat scene: Mothering from hospital</td>
</tr>
<tr>
<td>Supporting Cast</td>
<td>The imperfect understood: Partners in the spotlight</td>
<td>In most cases, where a woman became ill it was her partner who stepped up, and shouldered more of the responsibility for child care and domestic duties.</td>
</tr>
<tr>
<td></td>
<td>Women in the wings: Others and female friends</td>
<td>While women often isolated themselves from their peers, where there were girlfriends available they were a positive and validating source of support. Mothers and female relatives were also discussed frequently and were notable relied on for their untiring support, or the poor example of mothering they provided.</td>
</tr>
<tr>
<td></td>
<td>Behind the scenes: Helpful others</td>
<td>Support was also available from other relatives, teachers at children's schools, and professional support groups.</td>
</tr>
<tr>
<td>Reviewing the Performance</td>
<td>Contemplating the chemistry: Internal/child relationship</td>
<td>The outcome for the maternal/child relationship.</td>
</tr>
<tr>
<td></td>
<td>A performance with poor reviews: Critics, guilt and blame</td>
<td>Many of the women judged their mothering harshly, and this was compounded by the thoughtless words and actions of others.</td>
</tr>
<tr>
<td></td>
<td>Re-writing the script: The mostly happy ending</td>
<td>Women appeared to re-frame their mothering to show that despite their limitations their children had still turned out well, and had indeed been blessed for the experience.</td>
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<td>Playing the Part</td>
<td>Reconciling roles: <em>The patient mother</em></td>
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<td>The show must go on: <em>The relentless responsibility of mothering</em></td>
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<tr>
<td></td>
<td>Ad-libbing: <em>Doing the best she can</em></td>
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</tr>
<tr>
<td>The Healthcare Subplot</td>
<td>Reading different scripts: <em>Nurses misunderstanding mothers</em></td>
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<td>The heartbreak scene: <em>Mothering from hospital</em></td>
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<td>Receiving good direction: <em>Supportive health professionals</em></td>
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<td>Supporting Cast</td>
<td>The imperfect understudy: <em>Partners in the spotlight</em></td>
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<td>Women in the wings: <em>Friends and female relatives</em></td>
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<td>Behind the scenes: <em>Helpful others</em></td>
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<tr>
<td>Reviewing the performance</td>
<td>Plot resolution: <em>The consequences for mother/child relationships</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A performance with poor reviews: <em>Critics, guilt and blame</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rewriting the script: <em>The mostly happy ending</em></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX 7: ETHICS APPROVAL

From: "Kay Buckley" K.BUCKLEY@uws.edu.au
To: "Debra Jackson" debra.jackson@uws.edu.au,15766191@student.uws.edu.au
Sent: Fri 23/10/09 11:59 AM
Subject: Fwd: HREC Approval H7473

Notification of Approval

Email on behalf of the UWS Human Research Ethics Committee

Dear Debra and Tamara

I'm writing to advise you that the Human Research Ethics Committee has agreed to approve the project. TITLE: Disrupted mothering: Australian women's stories H7473
Student: Tamara Vallido (Supervisor: Debra Jackson)

The Protocol Number for this project is H7473. Please ensure that this number is quoted in all relevant correspondence and on all information sheets, consent forms and other project documentation. Please note the following:
1) The approval will expire on 1 March 2012. If you require an extension of approval beyond this period, please ensure that you notify the Human Ethics Officer (humanethics@uws.edu.au) prior to this date.
2) Please ensure that you notify the Human Ethics Officer of any future change to the research methodology, recruitment procedure, set of participants or research team.
3) If anything unexpected should occur while carrying out the research, please submit an Adverse Event Form to the Human Ethics Officer. This can be found at http://www.uws.edu.au/research/ors/ethics/human_ethics
4) Once the project has been completed, a report on its ethical aspects must be submitted to the Human Ethics Officer. This can also be found at http://www.uws.edu.au/research/ors/ethics/human_ethics

Finally, please contact the Human Ethics Officer, Kay Buckley on (02) 4736 0883 or at k.buckley@uws.edu.au if you require any further information.

The Committee wishes you well with your research.

Yours sincerely
Kay Buckley
Executive Officer
On behalf of the Human Research Ethics Committee

Kay Buckley
Human Ethics Officer
University of Western Sydney
Locked Bag 1797, Penrith 5th DC NSW 1797
Tel: 02 47 360 883
APPENDIX 8: CONSENT FORM

Participant Consent Form

This is a project specific consent form. It restricts the use of the data collected to the named project by the named investigators.

Note: If not all of the text in the row is visible please ‘click your cursor’ anywhere on the page to expand the row. To view guidance on what is required in each section hover your cursor over the bold text.

Project Title: Mothering in Illness: Australian Women’s Stories

I………………………………………………… consent to participate in the research project titled - Disrupted Mothering: Australian Women’s Stories.

I acknowledge that:

I have read the participant information sheet [or where appropriate, ‘have had read to me’] and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I consent to participate in a conversation lasting from one to two hours, during which I will tell my story of a time my mothering of my child/children was disrupted by illness or disability to Tamara Valido. I understand that this conversation will be audio taped.

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future.

Signed:

Name:

Date:

Return Address: Attention: Tamara Valido, PhD Candidate.
University of Western Sydney
School of Nursing and Midwifery.
Locked Bag 1797 Panmitch South DC, NSW, 1797.