NURSING HOMES: THE EXPERIENCE OF WIVES WHO REMAIN IN THE COMMUNITY

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The University of Western Sydney - Nepean
PLEASE NOTE

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and the best possible result has been obtained.
STUDENT STATEMENT

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Lynne Brown
Abstract

Many older couples face the dilemma of one of them developing an illness that results in their inability to cope with everyday living activities. The well spouse may struggle for many years with an increasing workload, both physical and mental. Ultimately, there may come a time, when nursing home placement becomes necessary. The aim of this research was to find out what the experience was like for the wife, with a husband who is ill and faces placement in a nursing home, and to determine whether nurses could do more to help them to cope with this difficult situation.

Following ethics approval, nine wives were interviewed over a period of two years. Each of the experiences was unique, but there were some common problems that many of the wives mentioned. Loneliness was considered by most of the wives as being extremely upsetting, even when they were living with other people, for example their children. The absence of their partner and long term confidant was noticed particularly in the evening when, in the past, they had sat down together and watched television. Other reactions included guilt, grief, depression and a change in the husband/wife relationship. Many of the wives seemed to accept the situation, realising that they could no longer cope with their husband at home, they were also healthier than they had been when their husband was at home.

All of the wives spent a considerable amount of time visiting their husband or taking him out, they said they did this because they wanted to spend time with him. Relationships developed with the staff at the nursing home, and with very few exceptions the nursing and domestic staff were described as being absolutely wonderful. The nursing home environment was also an important factor in the acceptance of the situation, nursing homes were described as 'absolutely beautiful' 'clean and not smelly', 'light and airy' and a feeling of 'homeliness'.

This research has highlighted some important points when a wife finds herself in the situation of having to place her husband in a nursing home, although nurses are unable to assist with many of the effects on the wife of the placement, it is helpful to know that the friendliness of the staff, the care of the patient and the cleanliness and homeliness of the nursing home are helpful at this time.

The study is limited by the nature of the nursing homes in which these husbands reside (private not-for-profit), the selection of the wives by the Directors of Nursing and the size of the study. Some important information has been gained from discussing this experience with these ladies and the writer is extremely grateful for their time and expertise in this area.
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# TABLE OF CONTENTS

## CHAPTER ONE - INTRODUCTION

1.1 INTEREST IN THE TOPIC .................................................. 1
1.2. SPECIFIC OBJECTIVES ................................................... 2
1.3. CHAPTER OUTLINES ..................................................... 2
   1.3.1. Literature Review .................................................. 3
   1.3.2. Theory and Method ................................................ 5
   1.3.3. Data Analysis ...................................................... 6
      1.3.3.1. The Pre-Admission and Admission Experience .......... 6
      1.3.3.2. The Post Admission Experience ............................ 7
   1.3.4. Summary and Conclusion ......................................... 7
1.4. THE LINK WITH NURSING PRACTICE/THEORY ............................ 8
1.5. SUMMARY ............................................................... 8

## CHAPTER TWO - THE DEMOGRAPHY OF THE AGED IN AUSTRALIA

2.1. THE AGED IN AUSTRALIA .................................................. 10
   2.1.1. An Increasing Aged Population ................................... 13
2.2. MARRIAGE AND THE AGED .............................................. 15
2.3 AGEING FAMILIES ......................................................... 16
   2.3.1. Retirement ......................................................... 16
   2.3.2. Divorce ........................................................... 17
   2.3.3. Never Married ..................................................... 18
   2.3.4. Hidden Aged ....................................................... 18
2.4. EXTENDED FAMILIES AND RELATIONSHIPS .............................. 20
   2.4.1. Children in the Family ............................................ 20
   2.4.2. The Extended Family ............................................. 21
   2.4.3. Relationships and the family ................................... 23
2.5. LIVING ARRANGEMENTS .................................................. 24
2.6. THE AGED AND THEIR HEALTH PROBLEMS .............................. 26
2.7. HEALTH COSTS .......................................................... 27
   2.7.1. Ageing is precarious .............................................. 28
   2.7.2. Break-down occurs ............................................... 28
   2.7.3. Financial implications of nursing home admission ........ 29
2.8. SUMMARY ............................................................... 30

## CHAPTER 3 - LITERATURE REVIEW - CARERS AND NURSING HOMES

3.1. CARERS ................................................................. 33
   3.1.1. Problems for the Carer ............................................ 33
   3.1.2. Effects on the Carer .............................................. 35
   3.1.3. Who are these Carers? ............................................ 38
      3.1.3.1. Women in the Caring Role ................................ 39
      3.1.3.2. Men as Carers ............................................... 40
   3.1.4. What care is needed? ............................................. 41
   3.1.5. Coping Strategies ................................................. 43
      3.1.5.1. Assistance .................................................. 43
   3.1.6. Summary .......................................................... 44
3.2. THE DEVELOPMENT OF INSTITUTIONS IN AUSTRALIA .................. 46
   3.2.1. Institutions ...................................................... 46
      3.2.1.1. Poor houses ................................................. 46
      3.2.1.2. Nursing Homes ............................................ 47
   3.2.1. Residents of Nursing Homes .................................. 47
3.3. NURSING HOME ADMISSION ........................................... 48
3.3.1. Predictors of Nursing Home Admission ................................................................. 49
3.3.2. Reasons for Admission ......................................................................................... 50
3.3.3. Decision Making ................................................................................................. 50
3.4. EFFECTS OF NURSING HOME PLACEMENT ......................................................... 51
3.4.1. Demoralisation and Depression ........................................................................... 51
3.4.2. A Change of Responsibility ................................................................................ 52
3.4.3. The Changed Marital Relationship ...................................................................... 52
3.4.4. Other Changes .................................................................................................... 54
3.5. SUMMARY ............................................................................................................... 54

CHAPTER 4 - THEORY AND METHOD ......................................................................... 56
4.1 QUALITATIVE RESEARCH ...................................................................................... 58
4.1.1. Varieties of Approach in Qualitative Research .................................................. 59
4.1.1.1. Phenomenology .............................................................................................. 61
4.1.1.2. Symbolic Interactionism ................................................................................. 62
4.2. SYMBOLIC INTERACTIONISM .............................................................................. 63
4.2.1. The Self................................................................................................................ 64
4.2.1.1. ‘Me’ ............................................................................................................... 65
4.2.1.2. ‘I’ .................................................................................................................. 66
4.2.1.3. Summary ....................................................................................................... 66
4.2.2. The World ........................................................................................................... 66
4.2.3. Social Action ...................................................................................................... 69
4.2.4. Summary ............................................................................................................ 70
4.4 GROUNDED THEORY ............................................................................................ 71
4.4.1. Background of Grounded Theory ..................................................................... 72
4.5. THE SAMPLE .......................................................................................................... 73
4.5.1. Access ................................................................................................................ 74
4.5.2. First contact ....................................................................................................... 76
4.5.3. Ethical Considerations ......................................................................................... 77
4.6. THE METHOD ......................................................................................................... 78
4.6.1. The interviews ................................................................................................... 78
4.6.2. Data Collection and Analysis ............................................................................. 79
4.7. DEALING WITH THE DATA .................................................................................. 80
4.7.1. Transcription ...................................................................................................... 81
4.7.2. Memoing ............................................................................................................. 81
4.7.3. Coding ................................................................................................................ 82
4.7.4. Reference to the Literature ................................................................................. 83
4.7.5. Thematization .................................................................................................... 83
4.7.6. Saturation ........................................................................................................... 84
4.8. OVERVIEW OF THE SAMPLE ............................................................................. 84
4.9. SUMMARY .............................................................................................................. 85

CHAPTER 5 - THE PRE-ADMISSION AND ADMISSION EXPERIENCE .................. 87
5.1 THE ROLE CHANGING STAGE .............................................................................. 87
5.1.1. The Early Phase .................................................................................................. 88
5.1.1.1. Loss of Memory ............................................................................................ 89
5.1.1.1. Minor difficulties ......................................................................................... 90
5.1.2. The Busy Phase ................................................................................................ 91
5.1.2.1. Personal Hygiene Needs ............................................................................... 92
5.1.2.2. Incontinence ............................................................................................... 93
5.1.2.3. Falls and other mobility problems ................................................................ 94
5.1.2.4. Confusion .................................................................................................... 95
5.1.2.5. Wandering .................................................................................................. 96
5.1.2.6. Other Problems ........................................................................................... 98
5.1.3. BIRING SINGLE WITH RESPONSIBILITIES PHASE .................................... 99
5.1.3.1. Taking over day to day activities ................................................................. 100
# Table of Contents

5.1.3.2. Finding time. .................................................................................................. 101
5.1.3.3. Protective/monitoring activities. ................................................................. 102

5.1.4. Getting Worse Phase .................................................................................... 104
5.1.4.1. Increase in burden .................................................................................. 104
5.1.4.2. Support Services .................................................................................... 107
5.1.4.3. Family/other support ............................................................................. 108

5.1.5. Summary - Role Changing Stage ................................................................. 110

5.2. THE TRANSITION STAGE .............................................................................. 112
5.2.1. A Critical Event Phase ............................................................................... 112
5.2.1.1. The final straw ..................................................................................... 112
5.2.1.2. Illness of the wife ............................................................................... 114
5.2.1.3. An available bed ................................................................................. 115
5.2.1.4. Admitted from hospital ...................................................................... 115

5.2.2. The Initial Contact Phase .......................................................................... 116
5.2.2.1. Which Nursing Home? ...................................................................... 117
5.2.2.2. The day came!! .................................................................................. 118
5.2.2.3. First impressions ................................................................................ 119

5.2.3. The Adapting Phase .................................................................................... 120
5.2.3.1. A Role Change Again ....................................................................... 121
5.2.3.2. From care provider to care co-ordinator ............................................. 122
5.2.3.3. Effect of the placement on the husband .............................................. 122

5.3. SUMMARY ...................................................................................................... 125

# CHAPTER 6 - THE POST ADMISSION EXPERIENCE ..................................... 129
6.1 THE REALITY STAGE .................................................................................... 129
6.2. THE "TORN APART" PHASE .................................................................... 130
6.2.1. Devastation .............................................................................................. 130
6.2.2. No One to Talk To! ................................................................................ 131
6.2.3. Guilt........................................................................................................... 132
6.2.4. Sadness and grief .................................................................................... 134
6.2.5. The Husband/Wife Relationship .............................................................. 135

6.3. BECOMING 'FAMILY' PHASE .................................................................. 136
6.3.1. Visiting ...................................................................................................... 137
6.3.1.1. Visiting almost every day! ................................................................ 137
6.3.1.2. Assistance to visit ............................................................................. 139
6.3.2. Transport .................................................................................................. 140
6.3.4. Passing the Time! .................................................................................... 142
6.3.5. Developing relationships with the staff .................................................... 144
6.3.5.1. The Matron ......................................................................................... 144
6.3.5.2. Other Staff ......................................................................................... 145
6.3.5.3. Problems ............................................................................................ 148
6.3.5.4. The nursing home environment ......................................................... 148
6.3.6. Taking Responsibility ............................................................................. 149

6.4. THE ADAPTATION PHASE ....................................................................... 152
6.4.1. Family and friends support ................................................................... 152
6.4.3. The Result of the Experience ................................................................ 154
6.4.3.1. Acceptance ......................................................................................... 154
6.4.3.2. Health Issues ..................................................................................... 156
6.4.3.3. Coping or not coping? ...................................................................... 157
6.4.3.4. Accommodation choices for the wife ................................................. 158
6.4.3.5. Informal support ............................................................................... 160

6.5 SUMMARY ...................................................................................................... 161

# CHAPTER 7 - SUMMARY AND CONCLUSIONS ........................................... 164
7.1. OVERVIEW .................................................................................................... 165
7.2. THE FINDINGS OF THE STUDY ................................................................. 166
7.2.1. Pre-admission .......................................................................................... 167
Table of Contents

7.2.2. Nursing Home Placement ................................................................................. 169
7.2.3. After Placement Feelings ................................................................................ 170
  7.2.3.1. Loneliness .................................................................................................... 170
  7.2.3.2. Sadness and Grief ..................................................................................... 171
  7.2.3.3. Guilt ........................................................................................................... 172
  7.2.3.4. Changes in the Husband/Wife relationship .................................................. 173
7.2.4. The nursing care ............................................................................................... 174
  7.2.4.1. The care received ...................................................................................... 174
  7.2.4.2. Satisfaction with the care ......................................................................... 175
7.2.5. Family Help .................................................................................................... 175
7.3. APPLICATION OF THE FINDINGS .................................................................... 176
  7.3.1. The link between home and nursing home .................................................... 176
  7.3.2. The Staff/Wife Relationship ....................................................................... 177
7.4. LIMITATIONS OF THE STUDY - NEED FOR FURTHER RESEARCH ............ 178
7.6. CONCLUSION .................................................................................................... 180

REFERENCES ............................................................................................................. 182

APPENDIX 1 ................................................................................................................. 191

PARTICIPANTS’ CHARACTERISTICS ........................................................................ 192

APPENDIX 2 ................................................................................................................. 193

APPENDIX 3 ................................................................................................................. 194
CHAPTER ONE - INTRODUCTION

This introduction aims to give the reason why this particular topic was chosen and its relevance to the increasing older population in the Australian society today and the future.

This chapter will highlight how I became interested in the topic area and the development of the research question, its aims and objectives. This chapter will then conclude with a brief overview of the chapters that follow.

1.1 Interest in the Topic

I have had a number of years experience working in nursing homes in Sydney, NSW, Australia and have noted that wives and husbands often spent many hours, nearly every day, visiting their spouses. Most of these spouses had spent many years caring for their partner prior to placing them in the nursing home.

I was interested to find out why these carers spent many hours at the nursing home, and if there was anything more that nurses could do to help the wife cope with this apparently traumatic event in their life. I was also concerned that the spouses were spending all of their time with the resident of the nursing home because of feelings of guilt or anxiety about the nursing care that the family member was receiving.

As the aged population is increasing, and therefore the number of people who potentially will be placed in a nursing home by a family member will
increase, nurses need to take note of the changes that are occurring and consider what alterations in practice may be necessary to care for the older person (resident of the nursing home). In addition, nurses need to be able to assist the family member to cope within the circumstances that they are left with. The question therefore, to be explained in this thesis is Nursing Homes: The Experience of Wives who Remain in the Community.

1.2. Specific Objectives.

The main objectives of this research are to explore the meaning of nursing home placement from the wife’s perspective and to investigate the interactions, both positive and negative, that have occurred between the wives, their family, the staff and others. These interactions that have occurred, it is assumed, may have all made some contribution to the experience. An assumption may be made that there are many factors, both internal and external, that influence the experience.

1.3. Chapter Outlines

The chapters of this thesis will outline the steps taken in the research process, including a review of the literature surrounding the topic area, the theoretical perspective and method used, the experiences of the wives described and a summary and conclusions of the research is offered.
1.3.1. Literature Review

The literature review is divided between chapters two and three and includes the demography of the aged in Australia (chapter 2) and carers and nursing homes (Chapter 3).

The demography of the aged population includes a description of the number of people over 65 years of age in Australia which is increasing rapidly with an estimated 15.8% of the total population who will be in this age group by the year 2021 (Davis and George, 1993). This increase in the aged population will result in an increase in the number of couples who could potentially face years of caring for their spouse with a chronic illness, a small number of these couples will face the ultimate crisis of separation because of the need for one of them to be admitted to a nursing home due to the debilitating symptoms of the illness.

These chronic illnesses suffered by the older person are usually degenerative conditions such as arthritis, hearing loss and mental disorders (Donovan, 1995). Such conditions often result in problems such as immobility, confusion and incontinence (Isaacs, 1971) and the carers of people with such problems face great difficulties in managing care recipients, particularly if they are elderly themselves.

Carers are defined as those people who are over the age of 15 years, live in the same residence and are the main provider of care to the person in need (Commonwealth Department of Health, Aged Care Reform Strategy Mid Term review 1990-1991). There are a significant number of carers in
Australia today, many of whom are sons, daughters and spouses. These carers cope with great difficulties with limited physical and emotional support from others, and little financial support from the government. It is the older spouse carers who are the focus of this study and more particularly, the carers from this group who find themselves in the situation of having to put their spouse in a nursing home.

Nursing homes within Australia have a somewhat dubious past, with original institutions being set up for the poor and destitute within the society, with violence and mistreatment commonplace experiences (O'Brien, 1988). Nursing homes, having grown from this dubious past, have had their share of critics over the years (Braithwaite, 1990). This history does not help the image of these institutions today and it is little wonder that some wives may be apprehensive about placing their husband into a nursing home.

The reasons that residents are admitted to nursing homes, as outlined in the literature, include problems associated with chronic illnesses suffered by the elderly population. These problems include difficult behaviour, confusion, incontinence, debility and unwillingness to eat (Smallegan, 1985). The result of the placement on the wife can be extremely difficult with depression, low morale, poor health, sadness, loneliness and guilt being reported (Rosenthal & Dawson, 1991).
1.3.2. Theory and Method

Chapter 4 discusses the theory and method appropriate to the research topic and concludes that the best approach is a qualitative one given that a quantitative approach would not give the rich information that was required from the experience of placing a husband in a nursing home and perhaps more importantly, little is known about this phenomenon. The theory underpinning the research that was selected as being the most appropriate for this research, was grounded theory from a symbolic interactionist perspective.

Qualitative research can best be defined as that which does not produce data which is quantifiable. It is mainly used to explain and discover the meanings of a particular experience that patients or relatives may have in an area of nursing practice. It is therefore, an acceptable method of research to explain and discover the experience of wives who remain in the community after placing their husbands' in a nursing home.

There are a number of different approaches in qualitative research one of which is known as interpretive methodology, this is where the lived experiences of the participants is to be captured and to some extent explained. Within interpretive research there are a number of different approaches. one of which is symbolic interactionism.

Symbolic interactionism is where the interaction that occurs between people is considered more than just a reaction, it is an interpretation of the interaction based on the meanings that the person places on the
interaction (Manis & Meltzer, 1972), each person will therefore, interpret the situation differently depending on their individual life experiences. It is more than biological instinct and is based on a complexity of experience which is unique to each person.

This study is further based on grounded theory which is used to study social phenomena in order to develop a theory (Bowers, 1988). This theory is then discovered, developed and provisionally verified through systematic collection and analysis of data (Strauss and Corbin, 1990).

1.3.3. Data Analysis

Chapters 5 and 6 are the data analysis chapters which report and categorises the data. The data is divided into three periods of the experience - the pre-admission, admission and post-admission. The pre-admission and admission periods are discussed in chapter five and the post-admission period in chapter six.

1.3.3.1. The Pre-Admission and Admission Experience

Chapter five describes the pre-admission and admission experience and these two experiences characterise the periods in the husband’s illnesses. The two stages are identifiable here are the Role Changing Stage, where each wife gradually alters their relationship with their husband from that of wife to that of carer, and the Transition Stage. In the Transition Stage the wife is trying to cope with the thought that
nursing home placement is inevitable, a critical event occurs which speeds up the process and contact is made with a nursing home, the husband is admitted and there is a period of adjustment.

1.3.3.2. The Post Admission Experience.

In Chapter 6 the Reality Stage summarises the devastation that wives feel after the placement of the husband in a nursing home, the feelings of loneliness, guilt, sadness and grief and more changes in husband/wife relationship are identified. The problems of visiting one's husband, transport difficulties and taking responsibility for the husband by becoming a patient advocate are important issues for the wives at this time. There is also a positive consequence of this part of the experience in that these wives tend to develop relationships with staff other residents and visitors.

1.3.4. Summary and Conclusion.

Chapter seven presents the summary and conclusion. Major findings of the study are highlighted, an outline of the limitations of the study are given, together with the need for further research in the area. The application of the findings to nurses, particularly those working in nursing homes are identified.
1.4. The Link with Nursing Practice/Theory

The purpose of this study is to focus on the experience of the wife who has to place her husband in a nursing home and although it is envisaged that each experience will be unique, it is anticipated that there will be some common problems and even some common positive experiences.

It is expected therefore, that this research will add to the limited knowledge that is available, of wives' experiences of having to institutionalise their husbands at a time when both are ageing. Additional information will be available about the value of the interactions that the wife has with other people, especially with the nursing staff of the nursing home. This information will be helpful for planning care for the residents (the husbands) and will help identify wives' needs and problems relating to placement of husbands in long term care.

1.5. Summary

It appears that given the ageing population in Australia and elsewhere that there is a need for research to assist people, especially older wives and husbands, as they age to provide them with the best possible nursing care, should the need arise. This research utilises the methodology of grounded theory from a symbolic interactionist perspective in order to develop a theory of wives' experiences of placing their husbands in a nursing home.
To date it seems that there has been little research which focuses on the needs of the elderly in relation to caring and making decisions to place a spouse in a nursing home resulting in the dilemma of separation. This research attempts to address this problem and provide some insight into the experience so that both partners can be cared for by the nursing profession in an enlightened way.
CHAPTER TWO - THE DEMOGRAPHY OF THE AGED IN AUSTRALIA

The following chapter overviews a wide range of literature in order to provide a background for this study. This chapter covers background demographic information as it impacts on elderly couples in Australia today.

This thesis is concerned with describing the experience of admitting one's spouse to supportive care. While this experience will be constructed and lived differently for each couple within their life-world, general trends will be important. The demography of ageing in Australia sets a general context within which individual experience and life-cycle events are lived. This chapter introduces some demographic aspects of ageing - population numbers, marital status, family composition, housing arrangements, health and finances - selectively reviewed for their potential impact on nursing home admission and adjustment.

There are many life-cycle changes and transitions that occur during one's life. As one ages these changes can be difficult to deal with. With respect to the focus of the thesis, where a wife has to place her husband in a nursing home, there have been and continue to be, dramatic changes. For example in this research, the couple have generally been through a period of adjustment relating to retirement, there has been a decline in health status for the husband at least and an increasing dependency on the wife for activities of daily living.

Other changes include the changing role of the wife from that of partner to that of carer, often involving health professionals entering to the home to support the wife in their caring role. Sometimes care needs to occur out of the home situation, a round of doctors visits, day care and
sometimes respite care. The culmination of the changes occur when the husband enters the nursing home and the wife and the husband have to adjust to a very different living situation.

While this thesis focuses on the transition of the husband to the nursing home, this is clearly not an isolated transition. For couples this transition has a temporary location with the past and the future being constructed in an emergent present. Couples’ problems, at this particular stage of transition are centered around the immediate crisis of the illness, its implications and the near future, including the possibility and eventual reality of nursing home placement.

These uncertainties may cause great anxiety for the wife, the husband, the immediate family and friends. It is, therefore, important to consider in this chapter, the number of ageing people in Australia who might be affected by these problems, where these people live and whether they are married. The support from other members of the family, friends and community services, the health problems of this group of older people and financial concerns are also areas that need to be considered as these may have an impact on the experience of the spouse when she has to place her husband in a nursing home.

2.1. The Aged in Australia

Rowland (1991), a prominent writer on the ageing population in Australia, states that the image of a youthful Australia is said to be rapidly
changing, a new older society is emerging where foresight in planning is crucial if this transition from a youthful Australia to a more mature society is to be smooth.

A definition of the aged\(^1\) is not an easy matter. Teenagers believe anyone over the age of thirty is old, for people in the workforce aged people are those who are retired. Due to lower life expectancy rates of 56.9 years for males and 58.9 years for females, born in 1991-1996 (Australian Institute of Health and Welfare, 1998), Australian Aboriginal people consider those over forty five as old and for statisticians it is men over sixty-five and women over sixty. For the individual there is a tendency to keep pushing the margins of "old age", further away. Baruch, for instance, suggested that he would never be old as old was always fifteen years older than his current age (Report by the House of Representatives Standing Committee for Long Term Strategies, 1992).

Chronologically and legally, older age is usually described as beginning at 65 years. This description has further been categorised as 'young-old' (65-74), 'middle-old' (75-84) or 'old-old' (86+) (Staab & Hodges, 1996). These terms have also been used by the Report by the House of Representatives Standing Committee for Long Term Strategies (1992) to describe a person's functional capacity - 'Young-old' referring to people who can maintain an active life, 'middle-old' are those who have some functional impairments which may require assistance, but in general, are

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\(^1\) Ways of referring to the aged reflect the politics, cultural and personal values of ageing as much as demography. How we use language to symbolise the aged becomes an important issue - the aged, the chronologically gifted, the senior citizen etc., in constructing images of the ageing individual.
capable of living on their own, and 'old-old' who are frail and in need of constant care.

It is from descriptions such as the above that the concept of functional age has arisen. Functional age emphasises that abilities and changes occur uniquely for individuals, all older adults of similar chronological age do not function at the same level (Staab and Hodges, 1996). These functional groupings are arguably a more accurate reflection of the person's age than their chronological age.

2.1.1. An Increasing Aged Population.

The ageing of a population is influenced by a decline in fertility resulting in a reduction in younger people, increase in life expectancy and immigration (Shaw, 1991). One of the critical elements in the structure of a population is the changing birth rate, for example, the crude birth rate between 1901 and 1913 was 27 births per 1,000 population, and in the 1990's it is 15 births per 1,000 population (Australian Bureau of Statistics, 1997).

The 1996 Population Census found that almost a quarter of Australians were born overseas. Generally, the health of these overseas born people is better than the Australian born population, this may be due in part, to migrants having to meet strict entry criteria. Initially the social, cultural, environmental, biological and genetic factors also contribute to the migrants health status although with increasing time in Australia these
factors become less important (Australian Institute of Health and Welfare, 1998), and as the migrants age their health also deteriorates in a similar pattern to the Australian born population.

Alterations in birth rates, immigration levels and life expectancy lead to significant changes in the population. Recent indicators are that the Australian population over the age of 65 years has risen at about 50,000 people per year from the late 1980's. This increase will reduce to between 35,000 and 50,000 as the smaller number of people born in the depression years (1930's) reaches this age group. The decade to 2028 will see an estimated increase in the 65 year and over age group of more than 1 million people or an increase of nearly 30%. This is the period when the baby boomers reach age 65. At the same time (early 2020's) the numbers of children in the total population are expected to be less than the number of people over 65 years of age (Australian Bureau of Statistics, 1997). It is more meaningful to consider these numbers in terms of percentage of the population. At the turn of the century the population over 65 years of age was approximately 4% of the total, in 1996 this was 12% and predicted to increase to 15.7% in 2020 and 22.4% in 2050 (Australian Bureau of Statistics, 1997).

The Report of the House of Representatives Standing Committee for Long Term Strategies (1992) states that an increase in the number of elderly women is said to be the main reason for the increases in the aged population. Since the late 1800's the ratio of men to women over the age of 65 years has changed from a predominance of men to a predominance of women. At the present there are 73.8 males per 100 females in the 65
and over age group and by 85 years and above women outnumber men by nearly two to one. This then has implications for marriage and, at these ages, how many older people are one of a couple that could offer support in a time of need (The Report of the House of Representatives Standing Committee for Long Term Strategies, 1992)?

2.2. Marriage and the Aged.

There has been an increase in the representation of women in immigration and a greater increase in the life expectancy for females than males. These events are reflected in the marriage rates. In 1901, 54% of males (65+) were married and 27% were widowers, however by 1981 the proportions were 72% and 16% respectively. The corresponding figures for women have remained relatively constant. Those currently married (65+) were 36% in 1901 and 40% in 1986 and those widowed around 46%. We can conclude that the mean duration of widowerhood has decreased substantially while the mean duration of widowhood has remained fairly constant (Rowland, 1991). More men have married but also more of them have a surviving wife to care for them particularly in old age. Whilst women now live longer, men have benefited from this.

It is interesting to note that nearly three-quarters (72%) of males but less than half (40%) of females in the over 65 age group are currently married. Thus, men generally remain married until their life ends, whilst women are widowed for many years (Kendig and McCallum, 1988). The information from the United States (Eliopoulos, 1997) also reflects the
trend that men are more likely to have a wife to spend their retirement days with, as 75.1% of men over the age of 65 years were living with their spouse and only 39.9% of women live with their spouse.

It appears then, that with an ageing population more people remain married as they reach the older age group, particularly the older males. This brings a relatively new phenomenon in this age group of the older married couple.

2.3 Ageing Families

With more people living to old age, a new phenomenon, the aged family is increasing in number. This particular group of elderly couples who have the support of a number of children, can look forward to some free time and, in most cases, reasonable health (Bower in Krupinski and Stoller, 1980). These families also have special circumstances which require consideration, for example their retirement, health status, marital status and relationships with other family members.

2.3.1. Retirement

Retirement involves a partial or total withdrawal from the paid working environment, usually between 60 and 65 years, with only a small percentage of people, usually the self-employed working beyond these years. This experience is going to be shared by a growing number of people and for a larger proportion of their lives as this group increases in
size. In 1990, only 9% of the population over 65 years were currently employed (Minichiello, Alexander and Jones 1992).

Retirement, with its accompanying free-time, can affect relationships with others, and for most people, retirement means a significant reduction in income (Edelman & Mandle, 1994). Studies suggest that the key to “successful” retirement was keeping busy and remaining independent. Dempsey (1983, as cited in Minichiello et al, 1992), for example, also suggested that older people were respected and relied upon in the community as advisers, participants and fundraisers.

Over the last century significant changes have occurred that have had an influence on the position of the aged in our society. Self employment was no longer the major employment status as many people became employees and urban civilisation became dominant, with Australia being one of the most urbanised countries in the world (Bower in Krupinski and Stoller, 1980: Gilding, 1997). Family structure has also changed, although not as significantly as many people believe (Garrett, 1983: Kendig and McCallum, 1988: Kalish, 1975: Eliopoulos, 1980). There are a significant number of older people who remain in good health well into their retirement years, it is however a fact that as one ages they are more likely to suffer from one or more chronic diseases (see section 2.6).

2.3.2. Divorce.

The rapid rise in divorce rates over the last twenty years has been a concern to many, but marital breakup is so far relatively uncommon in old
age. The Australian Bureau of Statistics (1997) measured the divorce rate for the age group over 55 years and found that for males it was approximately 3 divorces per 1,000 population and for females 2 divorces per 1,000 population. Minichiello et al (1992) states that those who do divorce, however, even prior to retirement, can suffer from the effects of this well into their older years, particularly in terms of their financial independence.

2.3.3. Never Marrieds.

The number of people who have never married is likely to rise in the next century, with as many as 11% of the children born in the 1950's never marrying. Elderly single people in the future will have had vastly different experiences in life to elderly single people of today (Kendig and McCallum, 1988). It could be presumed that many of the 'never marrieds' might have chosen this lifestyle, had a successful career and be reasonably financially secure.

2.3.4. Hidden Aged.

There are relatively large groups of people who have not yet been identified in the ageing population. The increased numbers of people living in de facto relationships and the homosexual population are but two examples (Kendig and McCallum, 1988). The rise in the number of de facto relationships is currently seen in the younger age group with as
many as 56% of couples who married in 1992 living together before marriage, this compares with 16% who married in 1975 (Australian Bureau of Statistics 1997) and according to Bittman and Pixley (1997), 69% of this de facto group are under 35 years of age. Whilst this trend has not yet been seen in the older age group it is not unreasonable to assume that this trend may occur in older age cohorts.

The homosexual population also does not have significant numbers of elderly people accounted for. The only statistic that may be relevant is one that relates to ‘group households’ where these people are classified as co-habiting strangers. Again, this group is predominantly young with 76% under the age of 35 according to Bittman and Pixley (1997). One could also assume that this may change in the near future as this population ages.

Elderly people, who are usually retired from employment, can be married, divorced or single, having been widowed, or never married. They may also belong to small groups in the present aged population such as those living in de facto relationships or the homosexual group. Regardless of the elderly person’s current marital status, most can expect some support from their extended family or friendship groups should the need arise.

2.4. Extended Families and Relationships.

Families are traditionally described as a group of people related by blood or marriage, including their children and/or children from another marriage. An extended family will include grandparents, aunts and
uncles while a nuclear family consists of two generations of parents and children living together isolated from their extended family (Miller-Keane 1997). While these descriptions leave out other multiple types of families (such as de facto, homosexual families and self-defined families) this section considers the traditional extended families and linkages with other relationships.

2.4.1. Children in the Family.

Based on the suggestion that 27% of women will be childless, most (30%) women that have children will have two and 12% would have only one child (Australian Bureau of Statistics, 1997), it would be reasonable to assume that when considering married couples the majority will have the potential support of two children. The presence of children, particularly daughters, is important as they have been the providers of much of the caring for elderly people.

Hagestad (1986, cited in Rowland, 1991) suggests that in the United States, this is so since women are able to adjust their work environment to include caring for elderly parents just as they had to do to accommodate their own children, who would also still be placing demands on daughter/s (Johnson, 1990). Daughters tend to live closer to their parents, interact on a regular basis and also report a closer level of emotional involvement than that of sons (Alford-Cooper, 1993).

There is also a history of women in the caring role since women cared for both the old and the young in past years and work outside the home was
seen as the responsibility of the men. This culture of women being the
carers and the men being responsible for the economic aspect of the
family is a well accepted role, even in society today there is a belief that
women should provide the ‘emotional work’ (Alford-Cooper, 1993).

2.4.2. The Extended Family.

A type of modified extended family is suggested by Kendig, Gibson,
Rowland and Hemer (1983) where families are a significant form of social
organisation with the generations mutually supportive, even when they do
not live together. Such family support (Kendig et al. 1983) where it
exists, significantly reduces the likelihood of admission to an institution
and is an important consideration.

Many elderly people rely on assistance from relatives and friends.
Although it is widely believed that the numbers of relatives on whom
these people can rely has decreased over the years due to the demise of
the extended family and the decrease in family size, neither of these
beliefs are supportable according to Kendig, et al. (1983) and Bittman
and Pixley (1997). Kendig et al. (1983) suggest that there has been little
evidence to suggest that the traditional extended family, of generations
living together, ever existed, to any great extent in Australian society, and
even though the number of children being born into each family was
larger years ago the proportionally higher mortality rate has seen a
decrease in the average number of surviving children for each couple
from three to two in the last 100 years.
Bower, in Krupinski and Stoller (1980), states that as young people married and left home they settled in areas away from their parents and as their own children married and left home the continuity and family ties were no longer as strong as they used to be. The individual has to some extent lost their belonging to a wider family. However, the mobility of children needs to be balanced by how far they move and whether the closeness of their emotional relationship with their parents is affected.

There are many who dispute Bower's (cited in Krupinski and Stoller, 1980) view. Garrett (1983) states that even though the contact between generations in one family may be less intimate and less frequent but there is still a lot of it. Kalish (1975) describes a study by Shanas, Townsend, Wedderburn et al (1968) where nearly two thirds of the elderly people interviewed had seen at least one of their children in the preceding 24 hours. Eliopoulos (1997) also suggests most of the elderly have regular, frequent contact with family members and that the family can be a major source of support in times of need.

In the Australian context, Kendig (1986, as reported in Gilding, 1997) found that informal support of the older person was provided by 5 or 6 people who had close bonds with the individual. In terms of the older people themselves these authors found that they were keen to maintain independence as long as possible with a 'we will manage' attitude.

Interestingly, Kendig (1986, as reported in Gilding, 1997) also found that there did not seem to be any relationship between the bonds of the parent and child and the level of support provided. No matter what
financial or emotional support had been given by the parents to the children in the past, there appeared to be no obligation, on the children’s part, to give assistance to the parents. This was also true of the financial situation. Assistance was based on a decision to help - not obligation.

Close family relationships are the basis for the provision of assistance when it is required. The type of assistance that is required often differs between family members and others. There are two types of assistance according to Sax (1993), one which provides companionship and social contact and the other which provides some practical support when it is needed. The companionship and social support is frequently given by friends whereas the practical support is given by a diverse group of people including spouses, adult children, other relatives, friends and rarely neighbours (Sax, 1993).

2.4.3. Relationships and the family.

To many elderly people the family unit is of prime importance. Many of the aged become actively involved in family life when they retire, the vast majority of older parents have close ties with adult children and grandchildren (Kendig and McCallum, 1988), they have pride in seeing their children become independent adults, they experience great joy in grandchildren and great grandchildren, and this can be very satisfying in older age (Eliopoulos, 1997).
The closeness of the relationship between the generations of a family is borne out by the results of a 1981 study which asked whether a couple would be prepared to take in an elderly relative should the need arise. Ninety percent of Japanese couples were willing to take in their own mother and 87% their father, 84% of American couples were prepared to take in their mother and 90% their father. For other relatives the numbers were reduced - the more distant the relative the less likely the couple were to want to take them in (Report on a WHO Working Group, 1982). One could assume that the Australian figures would be similar.

2.5. Living Arrangements.

Housing is important to the quality of life of older people. The particular type of accommodation can affect independence, feelings of well-being, security and health. (Report of the House of Representatives Standing Committee for Long Term Strategies, 1992). Household composition is also important since members of the household can be the principal source of support in times of need (Rowland, 1991). Those living with a spouse or other family member are less likely to require outside support when faced with a crisis (Rowland, 1982).

Contrary to popular belief a significant number of older people live at home with the number doing so only marginally decreasing with increasing age - 99.1% (60-64's), 98.2% (65-69's), 96.5% (70-74's) and 82.7% (75 +) live at home. Problems occur however, when the spouse or family member is unable to provide the required support and as the
couples the spouse is going to become increasingly unable to care for their partner. It is clear that those who are living alone are going to experience the most problems when they are unable to meet their activities of daily living. Of those living at home 15.8% (60-64's), 19.8% (65-69's), 27.5% (70-74's) and 32.9% (75 +) live on their own (Report of the House of Representatives Standing Committee, 1992, p.143; Rowland, 1991).

Home ownership is arguably the single most important factor in providing a buffer in old age. According to The Australian Bureau of Statistics (1996) the number of people owning their own home varies considerably from state to state and from city to country areas, with a difference even within those regions. The highest level of home ownership being in Victoria (43.7%) and the lowest in the Northern Territory (17.8%). The majority of Australian families do not own their own homes and, in this absence may in old age, rely on family support or some form of government social support/pension (Minichiello, Alexander and Jones, 1992). The pension was originally meant to supplement home ownership and if the majority of Australian families do not own their own home, it stands to reason that many people are going to face financial difficulties when they reach the older age groups (Minichiello, Alexander and Jones, 1992).
2.6. The Aged and Their Health Problems.

Various definitions of health (eg. World Health Organisation, 1946) suggest it is a state of physical, mental and social well being and not just the absence of disease. Clearly, there are changes that create problems of varying degrees as one gets older.

Health problems in the aged are generally degenerative diseases such as ischaemic heart disease, cerebrovascular disease, respiratory illnesses, diabetes and musculoskeletal conditions especially arthritis and rheumatism (Davis and George, 1993). The most commonly reported chronic conditions are arthritis, hearing loss and mental disorders, with more women than men reporting arthritis and more men than women reporting hearing loss and circulatory-related conditions (Donovan, 1995). Rowland (1991) reports a somewhat different order for these common chronic conditions with illnesses of the circulatory system most common followed by hypertension and diseases of the musculoskeletal system.

Eliopoulos (1997) states that in the United States the most prevalent chronic illnesses of the over 65 population are arthritis, hearing impairment, heart conditions and hypertension. Other chronic illnesses include dermatitis and other skin disorders, visual impairments including cataracts, deformities or other orthopaedic impairments, ulcers, hernias, indigestion, constipation, diabetes, migraine, varicose veins, haemorrhoids, chronic bronchitis, asthma, hay fever and sinusitis.
Regardless of the nature of illnesses reported, it has been noted that by the age of 75 years, approximately 65% of people suffer from one or more chronic illnesses. Two thirds of these illnesses are functionally limiting and account for a significant proportion of hospital beds. In NSW, the aged (in this case those over 60 years of age) comprise 8.6% of the population but occupy 30% of acute hospital beds, consume 40% of prescribed drugs, use 70% of the available community services and occupy 90% of nursing home beds (Jamison Inquiry, (1980) as cited in Davis and George, 1993).

With an increasing older population, mental illness, in the absence of new preventative or treatment strategies, will also become an increasing problem. Byrne (1994) conservatively suggests that 15-20% of older people have mental ill-health, including dementia, that requires treatment. An Australian study that determined the prevalence of psychiatric disorders among inpatients of an acute Geriatric Hospital found that almost half were affected by organic psychosis and that 28% had syndrome case level depression (Ames, Flynn and Harrigan, 1994).

2.7. Health Costs

The costs associated with health care and subsequent nursing home admission can be significant. When a breakdown in the caring relationship happens and supportive accommodation is needed there can be significant alterations in the financial status of the couple.
2.7.1. Ageing is precarious

It is clear (Kendig et al, 1983) that the majority of aged people in Australia are reliant on the pension and, as already stated, most of older people do not own their own home. This means that there is a reliance on the pension for all daily financial needs. Older people who are living in private accommodation and disabled people on low incomes are at particular risk of ill health and therefore, access to services remains limited where costs are involved or the services are geographically inaccessible. The majority of old people do not have health insurance and the rate of membership of health funds declines with age (Davis and George, 1993). The result is that older people on low incomes or reliant solely on the pension are situated in an difficult situation should they suffer ill-health and require services that incur some payment

2.7.2. Break-down occurs

When one member of a couple becomes ill and the need for nursing home placement is identified there are adjustments that need to be made by both people. This occurs when the aged person and their family can no longer cope with the handicaps that they have. It appears that the family, together with community support, can at best, cope with mild to moderate self-care, mobility and mild communication deficits (Rowland, 1991). When deficits reach the severe level in areas such as sight, hearing, restricted physical activity and mental disabilities the family and
community support services can no longer cope and the aged person is placed in a nursing home.

There are adjustments that have to be made when one member of the couple is placed in a nursing home and both may suffer from the feared problems of loss, loneliness and fear of dependency as documented by Davis and George (1993).

2.7.3. Financial implications of nursing home admission.

Included in the areas that require adjustment are those related to financial concerns, costs associated with a move to a nursing home for one of a couple can be considerable. The couple's aged pension now becomes a single pension for the person trying to maintain a home, and the other single pension is almost completely used to contribute to the cost of care in the nursing home. For example, currently the aged pension is $347.80 each per fortnight (Department of Social Security, Personal Communication, January 24th, 1998), the contribution to the nursing home for care is generally set at 85% of this amount, leaving approximately $50 per fortnight for additional requirements such as medications, toiletries, extra clothing, personal items, sheepskins to prevent pressure areas and other miscellaneous items.

The partner, who often remains in the family home, has their pension reduced to the single amount of $347.80 per fortnight from the couple's pension of $580.20 on which the couple used to manage their affairs
(Department of Social Security, 1998). When the household costs are considered the reduction of this income of $230 a fortnight can make it difficult to make ends meet and may make the decision to place the spouse in a nursing home a more difficult one.

In addition to these problems that the couple may have, the Australian Federal Government has recently introduced an accommodation bond for people who are entering nursing homes, this has, like most new legislation, caused a great deal of confusion to many people who may be placed in the position of entering a nursing home themself or placing an elderly relative in one. In order to deal with this confusion the Federal Government has produced 24 Fact Sheets to explain this new legislation in detail (Commonwealth Department of Health and Family Services Fact Sheets 1 - 24, 1997). The fact sheets provide details on the funding arrangements between the nursing home and the individual. It becomes obvious that explanations and reassurance of the costs involved in nursing home placement will need to be given to these older people.

2.8. Summary.

The elderly are generally described as those people over the age of sixty five years and these people, in Australia and other countries, are increasing in number at a rapid rate due to an increasing life expectancy. Older people are living longer, often with accompanying chronic illnesses. Many of the elderly are married with women being widowed at an earlier
age than men. In the over 65 year age group nearly three-quarters of men and less than half of the women are currently married.

With more people living to the older age groups there is a new entity, the older family. Older families can expect live independently in the community, supported by their two children. They may have many years of retirement to look forward too and suffer from one or more chronic illnesses. These chronic illnesses include, for example, heart disease, cerebrovascular disease, arthritis and mental illness. Financially the elderly, if solely reliant on the old age pension, will have difficulties with paying the costs associated with any illness that they might develop. If the illness, of one partner, becomes so severe that nursing home admission is contemplated there are considerable financial implications.

Prior to nursing home admission the well-spouse has often cared for their partner, in the home, for many years. Carers form an important part of the community and it seems that wives, who are the focus of this study, play an extremely important part in the health and wellbeing of their husbands who are ill. The identity of carers, problems that they face, the effects that caring has on individuals and husband/wife relationships, coping strategies and the assistance that is given to the carer are included in the following chapter. Chapter three also deals with the development of nursing homes in Australia, the residents of nursing homes, predictors of nursing home admission and the effects that an admission to a nursing home has on the wife.
CHAPTER 3 - LITERATURE REVIEW - CARERS AND NURSING HOMES

This second literature review chapter relates to information available on carers and their problems prior to the admission of the ill person to a nursing home. A relevant brief history of institutions in Australia and some information about the effects of the placement of a spouse in a nursing home is included.

The focus of this study is women who have had to make a decision, usually in conjunction with other people, to place their husband in a nursing home. Many wives in this situation have had to care for their husband under difficult circumstances for a long time, in some cases, many years. These wives have had to modify their role as a wife and take on the role of carer in order to meet their husband’s needs.

3.1. Carers

There is an increasing awareness of the role that families play as primary carers of people with chronic illnesses (Sammut, 1995). The focus of this research is ageing couples, where the husband may have one or more illnesses which results in a nursing home placement. The wife carer can also be suffering from chronic illnesses and may be deteriorating in her ability to perform her own activities of daily living as well as caring for her husband. The nature of the care problems associated with the husband’s illness can also become more difficult as his illness progresses.
3.1.1. Problems for the Carer

Many studies have shown that the elderly in need of care are generally looked after at home by their families until the patient's disabilities become overwhelming, for example, immobility, incontinence and mental illness (Isaacs, 1971; Sanford, 1975; Maclennan, Isles, Macdougall and Keddie, 1984; Jones, Victor and Vetter, 1983 and Sheldon, 1982). Hirschfield (1983) noted with respect to illness and institutionalisation that it wasn't the degree of physical or mental impairment that was the indicator for seeking institutionalisation but the satisfaction, or lack thereof, that was found in the relationship. Deimling and Poulshock (1985) also found that the health of the older person was not the major factor in the decision to place the person in the nursing home concluding that it was the attitude towards nursing home care that was the important factor. These arguments however are not common in other literature where physical and mental impairments were the main contributing factor to reaching the point of nursing home placement (Isaacs, 1971; Sanford, 1975; Maclennan, Isles, Macdougall and Keddie, 1984; Jones, Victor and Vetter, 1983 and Sheldon, 1982).

Much recent literature relates to the problems that carers face when looking after a relative at home. Some of this literature is related to specific groups of people - carers of people with dementia (Brown, Holmes and Mitchell 1991; Pratt, Schmall, Wright and Cleland, 1985; Lund, Pett and Caserta, 1987: Brown, Williams, Mitchell and Brown, 1992); carers of the frail elderly (Stone, Cafferta and Sangl, 1987: Zarit, Reever and Bach-Peterson, 1980); carers of the mentally ill (Sharp,
1990). Other literature focuses on the problems that carers face in day to day activities and the effect that this has on their own well-being (George and Gwyther; 1986; Robinson, 1989; Gallagher, Rose, Rivera, Lovett and Thompson, 1989).

3.1.2. Effects on the Carer

Caring has physical and emotional effects. Levine, Dastoor & Gendron (1983) report that a third of the carers in their study considered their own health good and about half had disabilities which affected their activity. However, the average age in her study was 61 years, which for an elderly spouse carer is young.

It is generally agreed that carers experience a level of physical exertion far above that of other people (for example Fengler and Goodrich, 1979). This is so regardless of whether the sufferer has physical or mental disabilities. The physical work that is required in caregiving - extra washing, protecting the person from injury or getting lost, assisting with showering and other personal hygiene - produces physical exhaustion and possibly a high level of stress. Stress is a prime factor in the development of other illnesses such as high blood pressure, heart disease and stroke (Sommers & Shields, 1987, as cited in Ade-Ridder & Kaplan, 1993) and inevitably impacts on the well-being of the carer.

Gilleard, Boyd and Watt (1982) studied the effects of caring for the elderly mentally ill at home and found that there was an association between the
negative mood of the carer and the presence of emotional and attentional demands of the ill person. Chenoweth and Spencer (1986) considered the experiences of caring for a family member with dementia at home and found that the stresses associated with this experience varied throughout the illness. It could be assumed therefore, that the mood of the carer and the needs of the patient are going to vary considerably from one day to the next and even from one hour to the next and this is going to have an effect on the stress of the caring situation. Interestingly, and related to the mood of carers, Irvin and Acton (1997) found that where there was a high level of hope in the carers - hope related to the fact that a cure would be found for Alzheimer's disease or that the cognitive impairment would be related to a potentially improvable condition of stroke - there was a higher level of well-being and obviously less stress, compared to those carers with little hope. This was so even if these 'hopes' were unrealistic.

Isaacs (1971) found on interviewing 280 people and their relatives after admission to a geriatric unit that one of the main reasons for the admission was "relief of strain". There were multiple causes for this strain - factors in the patient, such as incontinence; factors in the carer, such as their age and physical condition, and factors in the carers' life-space, such as other sick relatives, surrender of employment and many others.

As well as the difficult situational factors that carers need in order to cope there are other factors connected to coping with the physical and mental impairment of their loved one on a day to day basis, particularly as the disease progresses.
Lund, Pett and Caserta (1987) have looked at the effect on the carers of looking after a person with dementia at home with the attendant social and financial burdens associated with this role. Kapust (1982) described living with a loved one suffering from the advanced stages of dementia as an "ongoing funeral" accompanied with sometimes overwhelming financial, social and physical hardships. One family member in the study by Lund et. al. (1987, p.126) wrote:

"My father tried very hard to care for my mother but an 84 year old man cannot go without sleep and cannot force her to take care of her personal cleanliness. A man his age does not easily learn to cook and balance the budget, and he becomes bitter. He did not want to put her in the nursing homes he visited, so he reluctantly sold his house and moved to a city he didn't like, so that his children could help with her care. It has been a nightmare but the real victim is dad, his meagre income eaten away by the nursing home, separated from his wife of 50 years stripped of his house, car, acquaintances, and his dignity. He is the real victim."

It appears from this study (Lund et al, 1987) that the likelihood of institutionalising a person in a nursing home was influenced by several factors including the characteristics of the carer and the elderly person, their relationship, and the impairment. The likelihood of institutionalisation was greater if the elderly person was older and their impairment was progressing rapidly, if the care giver perceived more burden and the care receiver was not the care giver's spouse.

Carers then are subjected to a range of physical and mental stressors each day. This stress can lead to health problems, often stress related, within the carers themselves. Some carers, it seems, have a reduced stress level due to the hope of some improvement in the patients condition. There are many such carers in the community today.
3.1.3. Who are these Carers?

Carers (as defined by the Commonwealth Department of Health, Housing and Community Services Aged Care Reform Strategy Mid Term Review 1990 - 1991) must be over the age of 15 years, live in the same residence and be the main provider of care to the person in need. A severely handicapped person is defined as one who requires another person to assist in one of the activities of living, communication, transport and home maintenance.

Fifty four per cent of severely handicapped people in the community (aged 60 years and over) had a co-resident carer. A total of 73% of carers were spouses (40% wives and 33% husbands), 16% were daughters, 5% were sons and 7% relatives or friends. Many of the men (91%) had wife care givers but only 60% of the women were cared for by husbands (Commonwealth Department of Health, Housing and Community Services Aged Care Reform Strategy Mid Term Review 1990-1991). Although the relationship of the co-resident carer varied, a great proportion (90%) in the 60 - 69 year group were spouses, this reducing to 62% for people over 70 years (Commonwealth Department of Health, Housing and Community Services Aged Care Reform Strategy Mid Term Review 1990-1991).

Clearly, the major groups of carers are spouses or partners, adult children and parents caring for handicapped children. Spouses and children care mainly for elderly people and adult children caring for elderly parents form the largest group of carers (39%) (Howe, 1995; Cox
and Spalding, 1995), with 23% of carers being of the same generation as the care receiver, most of these being spouses or partners (Rosenman, 1995).

3.1.3.1. Women in the Caring Role.

The majority of carers are women (Cox and Spalding, 1995) with spouses and daughters providing the main source of help (Rosenman, 1995). Caregiving has been characterised as being 'more natural' to women because of their marked tendency for nurturance and intimate social bond developed through socialisation from an early age. Caregiving also shares a number of characteristics with other domestic work and like housework, it is considered unskilled (Stoller, 1990), it is repetitive and has no sense of completion (Oakley, 1976 in Stoller, 1990). Young and Kahana (1989) also suggest that women are more likely than men to be involved in the caring role, experience more negative consequences of the role and contribute more time and commitment to caregiving.

Studies investigating the effect of caring from this gender and/or generational perspective tend to agree that while the caring role is difficult for all, and while each situation is unique, there are some common factors amongst specific groups of people. Barber and Pasley (1995), for example, found that caregiving wives and daughters, did not experience the same negative impacts, although giving similar types of care. Daughters experienced strain in family relationships whilst the wives had problems with restrictions in social activities.
Amongst elderly couples the caregiver is more likely to be a woman, and because of her age, is more likely to be in poorer health, receive lower income and spend more time giving care than other carers (Killeen, 1990). Elderly spouse carers also have transport difficulties which limit their independence (Department of Health and Community Services, 1995), are more likely to be retired and living with the person that they are caring for (Howe, 1995).

Care for elderly men then, is mainly provided by women. This reveals inequality related to gender as government and the community increasingly rely on informal caregiving, predominantly by women, to maintain the elderly (and indeed other groups) outside of institutions. This in the main is because of the need to reduce government services and public spending (Cox and Spalding, 1995) through capitalising on the taken-for-granted unpaid work of women. Women continue to find themselves caught between marriage, motherhood, family, self fulfilment and work commitments (Jutras & Veilleux, 1991) to varying degrees in their life cycle.

3.1.3.2. Men as Carers

Men, caring for their wives, are more likely to be older and still employed (Cox and Spalding, 1995). The National Long-Term Care and Informal Caregiving Survey (1982) estimated that only 13% of carers were men (Gallagher, Rose, Rivera, Lovett & Thompson, 1989).
While the literature on men as caregivers is scarce, indications are that men have no less problems associated with caregiving than do women (Vinick, 1984), but these may be problems of a different sort. Miller (1990) found that there were no gender differences among spouse caregivers except for a small, but significant difference in health strain. Pruchno and Resch (1989) found that wives were more depressed and were more burdened than caregiving husbands and that the husbands adapted more easily to the caregiving role and were more likely to be receiving help from others.

Spouses are a high risk group for adverse effects associated with providing care at home for a family member with dementia (Brown et al. 1991, Brown et al. 1992). In couples, if the man is required to provide care to his wife he is more likely to be older, suffering from ill health and, in contrast to the studies by Pruchno and Resch (1989), Barusch and Spaid (1989) and Stoller, 1990) found that the husband makes use of fewer social supports.

3.1.4. What care is needed?

The Commonwealth Department of Health, Housing and Community Services Aged Care Reform Strategy Mid Term Review (1990-1991) categorises the need for help into three categories - high, medium and low frequency needs. High frequency needs included verbal communication, personal affairs, self care, meals, mobility and health care. Medium frequency needs were transport and home help with low
frequency needs being those related to home maintenance. The suggestion is that medium and low frequency needs could be met by non-resident carers whilst those relating to high frequency needs usually required the carer to be a co-resident. Over half of the 60 years plus age group and two thirds of the 70 years plus age group living in the community required some kind of help, with five percent requiring help with verbal communication and self care and ten percent requiring assistance with mobility, meals, health care and personal affairs.

In this same study many carers (nearly 50%) reported receiving help with their caring responsibilities although parents caring for severely handicapped children and people caring for parents were more likely to receive help than spouse care givers. Many (86%) of the care givers reported that they needed no help or no more help than they were currently receiving (Aged Care Reform Strategy Mid Term Review 1990 - 1991). For spouse care-givers this response may be related to the perception in older people particularly, that caring for a spouse is a natural extension of a long term interpersonal relationship and therefore, has to be accepted. Another explanation for the perceived lack of need in caring is that these spouse care givers were often interviewed with the care recipient present so that a need for extra assistance may have been played down (Aged Care Reform Strategy Mid Term Review 1990 - 1991).
3.1.5. Coping Strategies

Lund, Pett and Caserta (1987) identify four coping strategies - "problem focused", "reframing", "regressive" and "avoidant-evasive". Problem focused coping strategies were described as attempts by the care giver to control the environment by attempting to change it. Reframing coping strategies involved looking at the environment in a different way, and regressive and avoidant-evasive strategies were more maladaptive leading to negative outcomes, for example, worrying, getting nervous and crying. These coping strategies may be mediated by the level of meaning and gratification in the relationship between the carer and the impaired person which tended to reduce the stress associated with caring (Goodman, 1986) and the risk of nursing home placement (Hirschfeld 1983). Another mediator maybe the hope of a cure, or at the very least an improvement in the patient's condition, reducing stress for the carer as previously discussed (Irvin and Acton, 1997). Isaacs (1971) found that there were some negative strategies that carers had employed in order to cope with the impaired person at home. Abuse of the older person and giving their impaired person insufficient basic care were identified as reasons for admission to a geriatric unit.

3.1.5.1. Assistance

Help for carers may come from many sources, and as previously discussed is often informal where the need is met by children, grandchildren, friends and neighbours and comes in the form of
assistance with housework, shopping, repairs, help with transport, social, emotional and moral support and help with personal care (Howe, 1995).

As well as those levels of informal support, formal support such as that provided by the Home and Community Care Program (HACC) is generally available. Such formal support broadly adheres to the principles of the Nursing Homes and Hostels Review (as cited in Rowland, 1991, pp. 202, 203) which suggests that:

"1. Aged and Disabled people should as far as possible be supported in their own homes, in their own communities.

2. Aged and disabled people should be supported by residential services only where other support systems are not appropriate to meet their needs.

3. As far as possible, services should promote rehabilitation and restoration of function. The manner in which services are provided should develop and enhance personal freedom and independent functioning of all residents."

The formal support services that are available to people in order to promote independence and avoid admission to long-term accommodation include: home help and personal care, home maintenance and home modification, meals on wheels, respite care, transport and home nursing (Rowland, 1991).

3.1.6. Summary

The focus of this research is the elderly wife who faces the decision to place her husband into a nursing home. As the carer, the wife will face physical and/or mental problems with her husband each day. These problems can lead to an increase in stress and possibly a deterioration in the wife’s own health. Women, spouses and daughters, are the major
providers of care in the home. Elderly women are more likely to be suffering from an illness themselves, receive a low income, spend considerable time giving care and have limited independence. Men also have problems in adapting to the caring role but their problems are likely to be different from that of women.

There are many ways in which carers cope with their responsibilities and several of those have been identified in the literature, for example: attempting to change the environment, maintaining a hope of a cure or at least an improvement in the care-receivers illness, worrying, getting nervous, crying, elderly abuse and giving insufficient care. Assistance is provided by family, friends and neighbours as well as the formal sources such as the Home and Community Care Program which is aimed at maintaining elderly people at home.

When the assistance is unable to meet the needs of the elderly couple, or the wife is unable to care for her husband due to ill-health a nursing home has to be considered. Nursing homes in Australia have evolved from institutions that were set up to care for poor, sick and old members of early Australian society. Even as late as the mid 1900’s this type of housing was still directed at the poor and as such developed a negative image in society. It is this negative image that many older people have become accustomed too. For this reason it is important to briefly outline the evolvement of institutions within Australia.
3.2. The Development of Institutions in Australia.

There is a somewhat chequered and unusual history to the development of institutions and nursing homes within Australia. It is important to briefly consider this since the history may affect the way in which an older person perceives nursing homes.

3.2.1. Institutions

In the late 1800’s and early 1900’s in Australia there were many different types of institutions, Goffman (1961) identified five such groups. Those set up to look after people who are thought to be incapable and harmless, for example homes for orphans, the aged and the blind, those institutions for people thought to be a danger to the community and also incapable of looking after themselves such as mental hospitals, others set up to protect the community from danger such as prisons and those set up to pursue a work related task such as army barracks and boarding schools. The focus of this section will be those institutions that were developed for the care of the aged.

3.2.1.1. Poor houses

In the latter half of the 1800’s, typically the aged in Australia were immigrants, unmarried with no family and unskilled. These elderly people were placed in the gaol system as they had no means of support
(O'Brien, 1988). Subsequently asylums were developed to cater for the poor and were often referred to as ‘poor houses’ (O'Brien, 1988). These asylums were overcrowded and violence and mistreatment was frequently reported.

In the mid 1900’s the Government granted subsidies to the charitable sector to build housing for the poor and, as they found this a cheaper alternative to maintaining their own asylums, many people were transferred to this kind of institution (O’Brien, 1988). Families were still expected to provide care for relatives at home as this housing was specifically directed at the poor (Russell and Schofield, 1986).

3.2.1.2. Nursing Homes

The private charitable nursing home sector grew rapidly as a continued source of income was assured by the government. The number of beds increased by 50% between 1963 and 1968, the main occupants being the elderly although there were psychiatric patients and also some physically and mentally handicapped younger people (Russell and Schofield, 1986). The numbers continued to grow and, in 1982, Australia had 1,400 nursing homes or 4.7 beds per 1000 population (Davis and George, 1993).

3.2.1. Residents of Nursing Homes

There was little information available on the 67,000 residents (in 1981) of nursing homes throughout Australia prior to 1984. Various States gathered information through surveys and census details at different
times for the development of a Comparative Analysis of Nursing Home Populations in Australia (Howe and Preston, 1985).

The nursing home population which was identified by Howe and Preston (1985), found that the age category which had the largest group of nursing home residents was the 80 - 84 year olds (26.7%), followed by the 85 - 90's (24.5%), the 90+ (16.9%), the 75 - 80's (15.9%), the 70 - 74's (10.7%) and finally the younger age group the 65 -69's making up 5.3% of the total nursing home population. Females outnumbered males by three to one (Howe and Preston, 1985). The marital status was also measured in this study, and there were consistent differences between the sexes and over the age groups. There were higher proportions of males who were currently married compared to females, therefore, more females were widowed (Howe and Preston, 1985).

The most common age groups therefore, were the 80-90 year olds (over 50%) with nearly three times more women that men. The men that were residents of nursing homes were more likely to be currently married than were the females (Howe and Preston, 1985). There appears to be some consistent reasons why these current occupants of nursing homes are likely to be admitted.

3.3. Nursing Home Admission

The residents of nursing homes are unable to be managed at home, either because of lack of support or their carer is no longer able to cope.
A number of writers have identified these reasons. There is also the question of who makes this decision to place their family member in a nursing home.

3.3.1. Predictors of Nursing Home Admission

Rowland (1991) described a concept of vulnerability to institutionalisation where various factors interact to identify a person's vulnerability to institutionalisation, for example a very old widowed female is more vulnerable to institutionalisation than a younger married male. This concept appears to be borne out by the numbers in each group within the nursing home population.

Pruchno, Michaels and Potashnik (1990) set out to determine the predictors of institutionalisation amongst people with Alzheimer's disease who had caregivers that were spouses. Their study found that there is indeed a very complex set of variables, but there were some identifiable predictors of nursing home placement such as those of 'desire' to institutionalise where the caregivers decided that they were not able to manage any longer. Other predictors in the Pruchno et al (1990) study included religion, length of time as a caregiver (less time caring and less caring investment equates with a greater likelihood to institutionalise), spouses who have a severe memory problem, lack of positive experiences, total number of children and use of services.
3.3.2. Reasons for Admission

There are common health-related problems that may lead to a carer's inability to cope and hence increase the risk of institutionalisation. Typically, these health related conditions are multiple. Smalley (1985) identified confusion (43%), cardiovascular disease (42%), frequent falls (40%), general debility (25%), fractures (17%), strokes (13%), incontinence (13%) and difficult behaviour (13%) as reasons for institutionalisation. The health problems that were seen to be the major cause of admission to intermediate care facilities were difficult behaviour, confusion, incontinence, debility and unwillingness to eat.

Isaacs (1971) identified ‘therapeutic optimism and medical urgency’ as reasons for the admission of the elderly people in his study to a geriatric unit. Therapeutic optimism or the belief that the person would be treated for their problem and be discharged home was stated as one of the major reasons for admission in one third of his sample. Medical urgency, was given as a reason for admission in 7% of the group even though many of them had a poor prognosis.

3.3.3. Decision Making

The question of who makes the decision to place their relative in a nursing home is an interesting one. Usually, it appears, the decision is made in conjunction with a number of people and with specific requirements in relation to the nursing home selected. Bell (1996)
conducted interviews with ‘the decision maker’ of the family. The people involved in the decision included the doctor, the social worker and the family but most of all the caregiver. The important considerations for the family in respect of the nursing home admission included the anticipated care of the patient, cleanliness and the proximity of the home to the family. While cost was of minor importance, of no importance was food, activities, qualifications of the staff and number of staff per patient (although there were certain expectations about individual care).

3.4. Effects of Nursing Home Placement

There are some studies that identify the effects of placing a family member in a nursing home. Some of these identify particular groups of people or particular problems, others are more general.

3.4.1. Demoralisation and Depression

Grau, Teresi and Chandler (1993) examine the aspect of demoralisation in relation to sons, daughters, spouses and others who have placed a family member in a nursing home. They found that the various family members experienced this placement differently, but all family members experience significant burden and other stresses. One study (Rosenthal and Dawson, 1991) that focuses specifically on the wife’s experience found that wives experienced depression, low morale, poor health, sadness, loneliness and guilt. They also reported feelings of satisfaction
with current arrangements for their husband's care and there was overwhelming support for the staff doing a good job in treating the patient (96%), making the patient happy and comfortable (95%) and being very caring (96%). The wives were able to trust the nurse (94%), knew who to call if they couldn't come to visit (73%) and knew which staff to ask for information (88%).

3.4.2. A Change of Responsibility

Zarit and Whitlatch (1992) examined the effects of the placement of a relative in a nursing home. Whilst after placement carers felt less tired, less overwhelmed, less pressured and had more time for social activities the effect of institutionalisation on the carer's well-being was more complicated. Basically Zarit and Whitlatch (1992) determine that caregivers do not abdicate their responsibilities when placing a relative in a nursing home, they are just changed.

3.4.3. The Changed Marital Relationship.

There are a number of authors who have described the changes associated with the couple's marriage since the placement of a spouse in a nursing home. 'Married Widowhood' was a term used by Rollins, Waterman and Esmay in 1984 to describe this relationship, they suggest that both widows and widowers may experience the reactions to loss that a person experiences on the death of a partner but some of the responsibilities remain. The well spouse also has to deal with roles that
they may not have had to deal with before, such as financial manager, decision-maker and household manager. Rollins et al (1984) commenced a spouse support group which for some of the well spouses provided the support that they needed.

Bartlett (1994) continued the use of this term in 1994 describing the wives of men in long term care as 'Married Widows'. The wives, Bartlett (1994) identified, passed through two different transitions, one being their husband's illness and the other being the move to the nursing home. Throughout the experience the wives remained loyal to their husbands and although the placement of their husbands in a nursing home relieved some of the physically exhausting aspects of care it also lessened the time spent with their husbands on a day-to-day basis. One could argue, of course, that the time spent with their husbands when they are not so physically exhausted, might be of better quality.

Gladstone (1995), in a study of 161 married people who had their spouse living in a nursing home, found three main conclusions when looking at the effect of institutionalisation on the marriage. Firstly, the marriage is not necessarily affected as long as the spouse can continue to be involved with the resident, even if on a psychological level. Secondly, the marriage is changed by the illness rather than the move to the nursing home. Thirdly, both spouses can support each other, assisted by the staff in the nursing home.
3.4.4. Other Changes

Ade-Ridder and Kaplan (1993) considered the changing roles of the wife following the husband's move to a nursing home. This includes the change in the marriage relationship. Ade-Ridder and Kaplan (1993) also agree that the experience is highly individual, but during the illness experience the relationship between the husband and wife changes and the caregiving wife has to deal with the physical, emotional and financial strains associated with the illness and the subsequent move into the nursing home.

Rosenkoetter (1996) describes the changing relationship between the husband and the wife when one of them is moved to a nursing home, she emphasises the change in roles that occurs and the friction that may arise because of this change in relationship. Rosenkoetter (1996) also gives a guide to assist in the assessment of couples in this predicament so that nurses can be aware of the changing relationship should problems arise.

3.5. Summary

It appears then, that a definition of the aged varies widely in the literature from chronological definitions to categories of physical capabilities. All authors, however, agree on a substantial increase in the aged population over the next few decades, an increase in the number of elderly women is said to be the main reason for this increase due to immigration and an
increase in their life expectancy over and above that of men. There are far more married males than married females in the aged population partly due to this increase in the elderly female population.

The majority of the elderly live independently in the community, however, as these people age, particularly if they are single or widowed, the risk of being institutionalised in a nursing home increases. It remains, however, that there are a significant number of nursing home residents who have an elderly spouse who may be in need of some support from the nursing home staff.

Families play an important part in the support of older people in the community, and indeed even where the older person is institutionalised. Where community support is not possible or there is no family available, there is a substantial increase in the likelihood of the chronically ill older person being institutionalised in a nursing home.

Chronic ill health, as suffered by a proportion of the elderly can also lead to the person being unable to be cared for at home, especially where the spouse is also elderly and ill. Spouses form a great proportion of the carers of the chronically ill elderly and cope under great physical and emotional stress.

The potential for progression from being cared for in the community to being placed in a nursing home is high, yet the problems that the spouse experience appears to be a very neglected area of research (Rosenthal and Dawson, 1991).
CHAPTER 4 - THEORY and METHOD

This chapter details the methodology of the research project. Specifically, a qualitative study using a modified Grounded Theory from a Symbolic Interactionist perspective.

The aim of this thesis is to investigate the wife's experience of the illness and subsequent admission of her husband into a nursing home. Being ill, often over a lengthy period of time, to a degree leading to placement in a nursing home is inarguably a difficult and traumatic experience. While nursing knowledge about these experiences is critical if nurses are to adequately care for the resident of the nursing home, this thesis acknowledges a broader context surrounding nursing home admission, mainly the familial and social context, particularly that which includes the spouse of the ill person.

How events surrounding nursing home admission are experienced not only influences the adjustment of the person who is now 'resident' of a new accommodation setting but also impacts on the adjustment of the spouse of this person. It is in its focus on spouses' experiences, adjustments and 'co-residency' that this thesis is distinguished.

For nurses working in nursing home settings insight, even if only partial, into these experiences and the meanings that they have for spouses who remain in the community, is central to holistic nursing. This is so since holistic nursing, which pertains to the total person, encompasses the physiological, psychological, intellectual, spiritual and sociocultural aspects of the person (DeLaune & Ladner, 1998).
Chapter Four: Theory and Method

The issue taken up by this thesis is simply put - the spouse's experience of an illness and eventual placement of her husband in a nursing home. However, although simply put, the issue is complex and the placement of one's spouse in a nursing home will clearly be experienced differently by each individual wife. These differences are likely to come about from the type, course and trajectory of the spouse's illness. This research did not restrict itself to a particular illness that the person should have, nor could one assume that even two people with the same illness could be expected to present the same problems, or for the illness to be experienced by the wife similarly. Illness is not a singular problem experienced as it is in the context of many factors. In this thesis the important context is the family and spouse relationships.

Despite these anticipated differences in experience one might also expect that there will be at least some similarities due to social images of nursing homes, institutional requirements, government policies and financial situations. Experiences occur in social contexts and these are the source of both difference and similarity.

This thesis demands a methodology which is sensitive to both difference and similarity in experience. How, then, one might ask, is this world to be investigated? In seeking an answer to this question the choice of methodology must, in terms of the aims of this thesis, be sensitive to, recognise and incorporate, the uniqueness of the experience of wives in this situation, but at the same time be capable of generating a more generalised, even if impartial and imperfect, model of the experience which is capable of being shared.
No methodology is capable of thoroughly satisfying these competing, dialectical demands. However, as Strauss (1987) suggested, grounded theory is a method which gives some organisation to data in order to develop a theory which can be used to capture the meaning of experience.

This chapter begins by outlining grounded theory and its links to qualitative research in general. In making application to the topic of this thesis, interpretive methodologies and symbolic interactionism are outlined in order to tease out central concepts. The second part of this chapter explains the way in which this research was conducted.

4.1 Qualitative Research

Grounded theory is included in an increasing variety of methodological approaches termed collectively as qualitative. Qualitative research is variously defined. At the simplest level and in opposition to quantitative research, qualitative approaches are seen as those which do not have findings related to statistical procedures or any other means of quantifying the data. However, qualitative research is distinguished, not only in opposition, but by its own set of assumptions about knowledge and how knowledge is generated. Many authors, in a variety of disciplines, including nursing, have addressed these methodological assumptions (see for example, Leininger, 1985; Morse, 1991) and it is not intended to repeat them here other than to point to two matters: 1. the "data" is derived from "experiences/meaning" in a particular situation and
2. we have moved beyond the need to justify using qualitative research methodologies in nursing research. Qualitative research, therefore, is an acceptable method of research used, often by nurses, to explain and discover the meaning of experiences that patients or their families have in a particular field of nursing practice.

Qualitative nursing research is said to have been introduced to the nursing profession through nurses who undertook their graduate degrees in fields other than nursing, for example, sociology, anthropology or psychology. These nurses, when returning their focus to the nursing profession, continued to use methods associated with a qualitative approach, such as grounded theory, ethnography, phenomenology, life histories and conversational analysis (Strauss and Corbin 1990). Indeed, this cross-disciplinary “slippage” has in itself been advanced as criticism, particularly to nursing research where, it is believed by Mitchell and Cody (1993) that nursing should have its own particular methods of research.

4.1.1. Varieties of Approach in Qualitative Research

There are a number of different approaches included under the umbrella of qualitative research. One such approach has come to be known as an interpretive approach which is research that has the individuals and their action as the focal point (Leininger, 1985). Fundamental to the process of interpretive research, is the recognition of the meanings and cognitive processes inherent in all social life (Lowenberg, 1993) and this extends to the research process itself. Therefore, all people involved in the
experience, including the researchers, have an influence on the interpretations and the meanings of the research.

In interpretive research the lived experiences of the participants is to be captured and there is an attempt to understand the deeper meanings that comprise a specific phenomenon. There is also an emphasis on interaction, social context and the social construction of reality (Lowenberg, 1993; Berger & Luckman, 1976). This emphasis is persistent and some (e.g. Leininger, 1985) suggests that the ideal type of interpretive research is that in which the researcher lives, or at the very least spends a considerable amount of time, among the people that they are "studying" in order to understand their way of life.

Despite seeming agreement about what constitutes the fundamentals of interpretive approaches this does not lead to a regular or singular method. Interpretive methods involve a number of quite different approaches. Bowers (1988) considers functionalism and symbolic interactionism, Morse (1991) elaborates the phenomenological perspective, ethnography and epistemology as interpretive and Patton (1990) describes ethnography, phenomenology, heuristic inquiry, ethnomethodology, symbolic interactionism, ecological psychology and a systems approach, as being encompassed by the broader concept of interpretive methods.

While Lowenberg (1993) describes the basic divisions within interpretive research methodology as phenomenology, grounded theory and ethnography, she points out these categories are simplistic, arbitrary and
overlapping and she offers a more complex diagrammatic explanation, based on two divisions - phenomenology and symbolic interactionism.

One would be rather foolish, given the types of interpretive methods described in the literature, to believe that the proponents of these approaches would necessarily agree with Lowenberg's (1993) interpretation which she argues represents only a basic mapping of the relationships between the interpretive methodologies.

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<table>
<thead>
<tr>
<th>Interpretive Research</th>
<th>Everyday Life/Hermeneutics</th>
</tr>
</thead>
<tbody>
<tr>
<td>➔ Phenomenology</td>
<td>➔ Symbolic Interaction/Cultural Studies</td>
</tr>
<tr>
<td>Ethnography (Sociological)</td>
<td>Ethnography (anthropological)</td>
</tr>
<tr>
<td>Existential Sociology (e.g. Douglas)</td>
<td>Grounded Theory (e.g. Strauss, Glaser)</td>
</tr>
</tbody>
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### 4.1.1.1. Phenomenology

The aim of phenomenology is to accurately describe the experience of the phenomena which are being studied. There is no requirement to generate theories or models or to develop any sort of explanation for the experience (Mitchell and Cody, 1993). With its emphasis on description, phenomenology concentrates on difference at the expense of similarity which is more adequately developed when one wishes to develop explanation for experience and (sometimes), as a result, generate theories and models which move beyond descriptive approaches.
4.1.1.2. Symbolic Interactionism

Symbolic Interaction, in contrast to phenomenology, allows the possibility of explanation since it relates experience to the generation of shared meaning by its focus on how meaning is derived through interaction - by definition, a shared process. Between humans, it is argued, this interaction is often symbolic and this is peculiar. The peculiarity occurs because people interpret and define one another’s actions instead of merely reacting to them. They also attach meaning to other people’s actions. Human interaction occurs with the use of symbols, interpretation and by attaching meaning (Manis & Meltzer, 1972).

Grounded theory owes much to symbolic interactionism. Strauss, one of those who in partnership formalised Grounded Theory, was inspired by interactional and pragmatist writers such as Park, Thomas, Dewey, Mead, Hughes and Blumer (Strauss and Corbin, 1990). As well as seeing the need for a theory based on reality and an evolving experience (difference), Strauss saw the role of people in shaping their own world, the change and process that occurs in life and an interrelationship between conditions, meaning and actions (similarity). Symbolic Interaction allows for an explanation of difference, even if the circumstances were similar, by each wife who finds herself caring for her ill husband and resulting in his placement in a nursing home. Interaction is able to account for difference and similarity since it takes into account how humans act and react within themselves and towards each other.
Grounded theory, flowing from a base in symbolic interaction, offers a systematic and legitimate way to study the richness and variety of human experience and to produce relevant, plausible theory that could be used to help understand similar human behaviours (Munhall and Oiler, 1986).

The following section expands on the premises of symbolic interactionism and grounded theory with particular application to the thesis topic.

4.2. Symbolic Interactionism

Symbolic interactionism stems from the works of Cooley (1902), Dewey (1930), Mead (1934,1938), Park (1915), Thomas (1931) and others. Mead, more than others, has been identified as central to the development of symbolic interactionism and Becker (1961, 1968), Blumer (1962, 1969) and Hughes (1958) are credited with applying Mead's analysis of this perspective as described in 'Mind, Self and Society' (Mead, 1934).

According to Blumer (1969, p.2) there are three basic premises, of interactionism:

- Human beings act toward things on the basis on the meaning these things have for them;
- The meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows;
- These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters.
Symbolic Interactionists have translated these premises into three corresponding concepts: the self, the world and social action (Meltzer, Petras & Reynolds, 1975; Bowers, 1988).

4.2.1. The Self

The self is conceptualised in symbolic interactionism as having two components - the 'I' and the 'Me' (Mead, 1969; Meltzer, Petras & Reynolds, 1975). The 'I' is the reflector or the self as a subject who considers the available information, evaluates it and then relates the new information to the 'me' component of the self. The 'me' is the object of self reflection. This is often visible to others in terms of the roles that the 'me' plays. The 'I' according to Meltzer et al. (1975) is the beginning of an act and it ends in a 'me'. 'Me' is the person that everyone else sees. The 'I' provides the instigation and the 'me' provides direction. The 'I' however is not divorced from the 'me' as the 'I' is built on individual 'me's' and the person always sees themself in relation to the community (Rose, cited in Riehl and Roy 1980).

4.2.1.1 'Me'

The 'Me' component is the part of the self that can be identified and talked about. In this sense it is the objective, indicative component of the self, the part that is visible to others (Bowers, 1988). The 'Me' is visible to others and often, too simplistically reflected in the language of roles: wife,
mother, carer, sister, patient. The 'me' component of the self is clearly multiple, and can be present alone or jointly. With respect to the thesis topic, for example, the 'me' that plays the role of 'wife' may have to change to incorporate the 'me' of 'carer' when her husband's illness levels increase and he requires increasing care and attention. Indeed, over time, and particularly following admission of ones' spouse to a nursing home, the 'me' that was known as the wife may be so radically restructured as to disappear altogether.

Multiple 'me's' can, at times, be in conflict (Turner, 1962), although, as Bowers (1988) points out, resultant uncertainty is not so much due to conflict of which role to perform, or what particular role is being performed at the time, but an uncertainty as to 'who I am'. Multiple role demands may be particularly pertinent when a spouse changes from being wife, supporter, friend and companion to one who is caring for the total person and their safety, security, hygiene, nutritional and spiritual needs. This multiplicity and change over time in the 'me' component of the self may mean greater difficulty in caring since "spouses with multiple role demands may have the most difficulty in navigating the caregiving passage" (Langner, 1993 p.591).

4.2.1.2. 'I'

The second component of the self is the 'I'. The 'I' is the mobile, interactive, vital, interpreting component of the self. The 'I' interprets the
cues that are given from the environment, synthesising and relating them to the 'me' part of self (Bowers, 1988).

The important concept of the 'I' is that it interprets and synthesises based on all previous social experience. In essence this means that each 'self' will react differently to others in the same situation depending on previous social experience (Bowers, 1988). In connection with the admission of one's husband to a nursing home it might be expected that each wife will react differently, according to her history of social experiences. The disease trajectory will be an individual experience as will the nature of the marriage relationship and the support from family and friends.

4.2.1.3. Summary

One concept of symbolic interactionism is therefore, the self which is conceptualised as including the 'I' and the 'me' components. This premise of symbolic interactionism offers a means of looking at the 'world' - the second concept from an interactionist perspective.

4.2.2. The World

The 'world' derives from Blumer's postulate that meanings are developed from meaning that is placed on objects. The world, in this symbolic interactionist view is, above all a social world. The world, not physical but social, needs to be interpreted and experienced by the individual. At this point the world becomes 'object-ive', not objective in the traditional
sense, but with reference to anything that can be reflected upon or directed towards the individual (Mead, 1969; Bowers, 1988). Thus, the world of objects will include not only the nursing home or the bus that transports them to the nursing home but also objects like loneliness and guilt.

Objects, in this symbolic sense, have no meaning in themselves, meaning is derived from the way in which others act towards them (Bowers, 1988). For example, the nursing home has no meaning in itself but its meaning is derived from the way others react towards nursing homes and the consequent object-ification of nursing homes for spouses. If people act towards nursing homes as if they are simply a place to die, where there is no individuality, poor care and dumping grounds for old people then that becomes part of the meaning structure of the nursing home for the spouse who is about to place her husband in one.

It becomes obvious therefore, that the object meaning of the 'nursing home' is socially derived, contestable and negotiated through interaction. Sometimes this object meaning is experiential and therefore different for each spouse depending on the past and present interpretation of the actual experience of nursing homes. For some there will have been no experience of nursing homes prior to their husband’s present illness, whilst others may have visited people on a regular basis in nursing homes, or even that one in which they are about to place their husband.

For some objects there is a commonly understood meaning between some people and social groups. In such uncontested instances
interpretation and the making of meaning is more easily derived. In relation to this thesis, an example of an uncontested meaning might be that caring is a difficult role to take on. It may be understood, as an uncontestable object, that people who care for others in the home are subjected to stress and anxiety. In such cases it is predictable that people who assume the role of caring will experience stress and anxiety, this would be an uncontested object.

On the other hand, there are also objects about which people find themselves in contested meaning worlds. In unfamiliar territory, with no understandings or meanings that can be attributed to the current situation, it can be very difficult to jointly predict or anticipate or construct an ‘object’. In this thesis the wife who is looking for nursing home accommodation for her husband may not only have no idea of what to look for, what questions to ask, how to access the philosophy of the nursing home, the standards of nursing care that can be expected, the qualifications of the staff, etc. but also have no way to reach jointly shared meaning in this situation.

4.2.3. Social Action.

The third and final concept of Symbolic Interactionism is social action or interaction and symbols. Symbols, whose meanings are shared, can be used by people to interact in an anticipated and explicit manner. This interaction will depend on whether the symbols are shared. One such shared set of symbols is a common language, this allows fast, and in
most cases, efficient communication between people. Actions are therefore adjusted, according to how others act and react towards the individual or the object. Individuals, in the process of interaction, continually allocate symbols to each other and to themselves (Bowers, 1988).

Through this communication of symbols people learn meanings and values and therefore ways of acting from other people. They also learn how others perceive them, how they may act in a particular situation and, as a consequence, make a decision about their actions. The fact that one takes on the role of the other person to determine how others are perceiving them, and interpreting their actions, means that the other person's perception/s of their actions are very important. In addition the other person's perception/s of individual cues which are accepted and interpreted from other sources, such as the environment are also important.

The process of symbolic interaction therefore, includes an attempt to take on the role of another and predict his or her reaction as well as the assignment of a common set of symbols and an evaluation of the action and how it is interpreted by others (Bowers, 1988).

In this thesis the wife who is trying to interpret the world of nursing homes may be influenced by others as she attempts to understand what others would do in similar situations. There may not be a common set of symbols to be relied upon, as many elderly people would not have had experience with placing a friend or relative in a nursing home. The
object, the nursing home, has little meaning, the past experiences may only be reading newspaper articles or talking with others.

4.2.4. Summary

Symbolic Interactionism describes what happens between and within people and what influences their unique behaviour or reaction to a particular set of circumstances (Minichiello, Aroni, Timewell and Alexander, 1990). Symbolic Interactionism therefore, is an explanation of the way that individuals react to a situation, based on the background of each individual and the input from other people, together with the meanings which they have applied to the situation.

In the situation where wives face placing their husband in a nursing home, each has an individual experience which contributes to her behaviour or reaction to the illness of her husband and ultimate institutionalisation in a nursing home. Symbolic Interactionism therefore, seems an ideal approach with which to research the experience of wives coping with the illness and eventual placement of their husband in a nursing home.

There still remains however, the problem of collecting and interpreting this information and the possible development of a theory to explain the situation. Grounded theory provides a way in which this information can be collected, interpreted and developed - particularly in areas where research is scarce.
Grounded theory enables the researcher to track and hopefully, find an explanation or theory of a nursing problem and to use this to assist with a solution to the problem in the nursing setting (Stern in Leininger, 1985). Grounded theory has a well defined set of guidelines and has been used for many years to generate theories relating to human behaviour and has been productive in nursing research. In this thesis a modified Grounded Theory will be used.

4.4 Grounded Theory

Grounded Theory is a way to discover and develop a theory through simultaneous data collection and analysis. In Grounded Theory there are no traditional verification methods and the aim of this type of research is to make sense of social life (Charmaz, 1983). Grounded Theory therefore is used to generate theory from empirical data - data shapes the process and products of the research - rather than to validate existing theory through theory testing (Bowers, 1988).

4.4.1 Background of Grounded Theory

Grounded Theory was developed by sociologists Glaser and Strauss. Strauss, from the University of Chicago where a number of scholars were developing a focus on qualitative research methods, contributed the ideas that: the researcher needs to get out into the field - “field immersion”; grounded theory approaches are important in the developmental stages of a discipline; persons’ experiences are
continually evolving and their world is constantly being reshaped and that there is a resultant emphasis needed in methodology on the complexity and variability of life and the interrelationships between conditions, meaning and action (Strauss and Corbin, 1990).

Glaser was trained at Columbia University and was influenced by Lazarsfeld, a quantitative researcher. Glaser saw the need to have a very explicit and systematic way of coding and hypothesis testing for qualitative research.

While initially a single method, over time two different approaches to Grounded Theory developed. The differences, according to Stern (in Morse, 1994) are that Glaser focuses on the data questions and what is in the data and Strauss asks the question “What if” of the data. It appears then that this grounded theory method has evolved over time by two different people, who were instrumental in the initial description, and this alone requires people to spend a great deal of time understanding the history of the method and the steps of the process before applying it to the research they have in mind in order for the research to be traditional Grounded Theory.

Like the more generic term - qualitative research - grounded theory has broadened to encompass a variety of research methods, each having its own rules, and like the more generic term grounded theory may be viewed as a blend of scientific and artistic imagination (Sandelowski, 1986).
This blend of the scientific and the artistic finds expression in grounded theory in openness and flexibility, processes which were useful in adapting the method to suit this research topic.

There is a kind of glass called end-of-the-date glass, made up by taking all colors and throwing them in a pot and stirring it up. It is quite a beautiful thing, but it is not any particular style or pattern - it is just whatever you get...and they call it grounded theory (Stern, cited in Morse 1994, p.212).

This is the very blend of openness and flexibility, and of the scientific and artistic, that created the methodological environment in which the experience of placing one's husband in a nursing home was investigated. This environment was a modified grounded theory.

4.5. The Sample.

Each potential participant needed to be identified, contacted and given information about the researcher, the research and her role in the research. In order to accomplish this access was gained through the Director of Nursing in a number of nursing homes who gave each potential participant a copy of the research information sheet. There were also a number of ethical considerations that needed to be addressed at this point. These processes are outlined below.

4.5.1. Access

The nursing homes to be contacted for participants were the "not-for-profit" sector of the nursing homes in the Greater Sydney Metropolitan
area. In line with general Grounded Theory guidelines, no specific number of participants were required initially, as the research was to be continued until ‘saturation point’ was reached (see section 4.6.2.).

Initially, five such nursing homes were contacted, where the Director of Nursing, or the Deputy Director of Nursing were known to the researcher through professional liaising. Subsequently, another two nursing homes were contacted, a total of seven. All agreed to give some thought to wives who would fit the criteria and might be willing to participate.

In expanding contact to other nursing homes for subsequent interviews, there was a varying degree of success in contacting potential participants. Three Directors of Nursing stated that they had no possible participants and it seemed from their response that they were not interested in having their resident’s wives taking part in the research project. Not surprisingly, where the researcher was known to the Director of Nursing, entry to the environment was much easier. Each Director of Nursing was sent copies of the information sheet to pass on to wives who met the criteria for selection.

The inclusion criteria were that the wife should be over 65 years of age and able to speak English, and for the husband that he was over 65 years of age and living in the nursing home for less than 12 months.

Although it is recognised that there are many residents of nursing homes that are from the ethnic or indigenous populations of Australia it was decided to contain this particular research to a group of participants that
were identified by the Director of Nursing as fitting the criteria. It is acknowledged that these indigenous and ethnic groups may have great difficulties with placing a family member in a nursing home, these difficulties however, may be quite different.

The Directors of Nursing that were willing to respond contacted ten appropriate possible participants and gave them a copy of the information sheet and, in some cases, offered to contact the researcher to give their telephone number. There was only one potential participant who refused to take part. This finalised the role of the Director of Nursing and this was conveyed to the potential participant in the information sheet and verbally by the researcher.

In seven instances the Director of Nursing of the nursing home telephoned the researcher and gave her the telephone number (with their permission) in order to set up the interview and the other two participants made contact with the researcher themselves. All of the nine potential participants who initially agreed to take part in the study met the criteria and participated in the research with the understanding that they could withdraw at any time.

4.5.2. First contact

When speaking to the potential participants for the first time there were a number of important issues to discuss and an opportunity was given for participants to ask questions about the research. The information sheet (see Appendix 2) contained essential details about the research for the
potential participants to read at their leisure, thus ensuring that they had the details to review, to give to significant others to discuss their participation, and to ensure that they were aware of their right to withdraw, at anytime, without affecting their husband’s stay in the nursing home. It was also emphasised in the information sheet that the staff of the nursing home in which their husband resided, were not to be given any details of the discussion. Hopefully, this information increased their perception that they could discuss any details without fear of repercussion on their husbands’ care.

The consent form (see Appendix 3) was also developed for the participants to sign just prior to the interview and even though the information on this sheet was limited, it again reinforced their ability to discontinue at any time.

4.5.3. Ethical Considerations

Ethics approval was sought from the University of Western Sydney, Human Ethics Review Committee. Approval was granted, subject to editorial changes to the information sheet to ensure that wives who had recently been through a stressful time had the potential for confusion minimised.

Apart from the requirements for informed consent there were three specific ethical considerations in this research. Firstly, since the Director of Nursing was the initial contact point for recruitment of participants the information sheet and subsequent verbal communication needed to
stress that the Director of Nursing did not have any active part to play in the research other than to provide a point of contact with the researcher. Ethically, wives had to know that the nursing care that their husbands were receiving could not be impacted by their participation, or not, in the research. Secondly, issues related to the ability of the wife to withdraw from the research at any time needed emphasis. Thirdly, it was felt there was a need to have support services for referral should the wives find the situation difficult to cope with, or in the event that the ‘re-telling’ of experiences caused emotional upset.

4.6. The Method.

The data was to be collected through interviewing. The length of the interview was to be approximately one hour. Data collection, analysis and reference back to the literature was to occur as an ongoing process throughout the interview stage.

4.6.1. The interviews

The method of collection of data in qualitative research may be formal or informal interviews, participant observation or from documents or sometimes from a combination of these sources (Stern in Leininger, 1985). Interviews for this research took place using a minimal number of unstructured questions, such as "What is it like to care for a spouse who has a health problem?". It was reasoned that the use of broad, unstructured questions would allow the researcher to enter 'the world' of
the carer, with minimal researcher intrusion or pre-conception. Observation of the participant occurred during the interview and diary notes made.

The first interview took place very shortly after initial contact with the first nursing home. In this interview as in all which followed, it was ascertained that the spouse had read the information sheet that the Director of Nursing had given her, understood that she could withdraw at anytime and both her husband and herself met the inclusion criteria.

As each interview was conducted the taped conversations were transcribed and a tentative map of the experiences being investigated was developed. This process of emergent interviewing followed in each case to develop the findings of each interview in subsequent interviews. In this way a larger map of themes was generated. This process occurred until nine participants were interviewed and the data were analysed with the findings of the final interviews yielding very similar experiences and adding little that was "new". This experience indicates that "saturation" was reached, a period when no new themes are being added to the material, when each theme is well developed in terms of its density and when the relationships between themes are well established (Strauss & Corbin, 1990).

While each interview was planned for about one hour many, particularly the ones that were held in the participant’s own home, were longer. This was so as they would often have planned a cup of tea and a general chat before the interview was conducted. Each interview was concluded by
emphasising the researcher’s contact numbers should any further details
be remembered or should contact be necessary for any other reason.

4.6.2. Data Collection and Analysis

There were only minor difficulties experienced as interviews progressed -
difficult addresses to find, two friends from the same nursing home who
both met the criteria for selection who wanted to be interviewed together
which presented a challenge in both interviewing and transcription.

A small number of wives became upset when talking about their husband
and the way in which he had deteriorated. When this occurred the tape
recorder was turned off and the participant given the opportunity to regain
their composure. They were also given the offer to discontinue the
interview which they declined. Each of these wives was also offered
further information about counselling options within the community in
which they lived.

For each interview notes were kept in the memo book to add a further
dimension to later transcription. Taped interviews were transcribed and
memo notes added, preliminary analysis and reference to the literature
was undertaken at the conclusion of each interview to allow subsequent
interviews to be informed as the study progressed. Each of these
components is outlined in the following sections of this thesis.
4.7. Dealing with the Data

In grounded theory data collection and analysis can occur simultaneously. There are no hard and fast rules about what should occur or when. Strauss and Corbin (1990) suggest that analysing data and data collection are 'tightly interwoven' because the process of analysing the data directs the collection of the data. This interwoven process is evident in the manner in which this thesis data and analysis were dealt with.

4.7.1. Transcription

As each interview was concluded it was immediately transcribed and data obtained was analysed in a preliminary way. Audio taped, hard copy transcriptions and memo notes were separated from identifying details of participants which were stored separately.

As previously indicated during the collection of data some analysis was also occurring. Reflection on the material, even whilst the interview was being conducted was the rule not the exception. More often than not, however reflection on the data occurred after the interview, particularly during the transcription of the interview and the integration of memo notes.
4.7.2. Memoing

As interviews were happening and during the reflection and analysis on the data, notes or memos were written in order to remember the details of ideas that occurred to the researcher during or shortly after the interviews. These memos and diagrams were a very special written record of the analysis which proved critical later in this process - memos of written forms of ideas and diagrams of the graphic representations of the relationships between concepts (Strauss and Corbin 1990).

Memoing proved itself important as a record of important decisions made in the process of selecting interviewees (theoretical sampling), changing directions in the interviews and subsequently identifying the themes in the tapes and transcripts. Memoing was also important as a note of other non-verbal information that occurred during the interview process - a few tears, long gaps before continuing the 'story', and emotional responses.

4.7.3. Coding

As information was gathered from the interviews it was coded into one of three types - open, axial and selective. Interview transcripts were examined in open coding by examining line by line, and often phrase to phrase. In this coding phase interviews were broken down, examined, conceptualised and categorised. Many hours were spent with each transcription and taped interview to try to understand the emphasis of each point. Coding in the second phase - axial coding - involved a
process of bringing the previously developed open codes and categories together in order to make connections between the developed categories. It is through the final process of coding - selective coding - that core categories were selected and related to the other core categories. The thesis results as presented are the result of selective coding. In these coding processes the guiding principles as outlined in Strauss and Corbin (1990) were followed. Open coding being the breaking down, examining, conceptualising and categorising data. Axial coding is where the data are put back together to make connections between the categories and selective coding where one selects core categories and relates them to other categories (Strauss and Corbin, 1990).

4.7.4. Reference to the Literature.

In grounded theory reference to the existing literature has a very specific function. Unlike quantitative research, the literature is not used to discover the categories and the relationships between those categories since if one begins with a preconceived idea of the categories and relationships under investigation it may well colour the results in a particular direction.

In this study, the literature was used both for background information and as an integral part of the process of analysing the data. In this way, understanding of the material and comparisons and contrasts between the results of this study and other studies around emerging themes assisted in the general process of coding and analysis.
4.7.5. Thematization

The raw data, once coded by open and axial processes, were brought together in patterns or themes - selective coding. Leininger (1985) assisted to direct this latter process, which consists of synthesising several patterns to achieve a broad view of the data, formulating theme statements to test other (nursing) ideas and a use of the themes to generate other hypothesis, decisions or (nursing) interventions.

In this way the clustering together in broad patterns related to the effect of the husband's placement on the wife and emotional responses, for example, were arrived at. These experiences were then considered in the broader categories of the pre and post admission experience.

4.7.6. Saturation

In Grounded Theory sampling is theoretical because, rather than sampling people, sampling occurs in the basis of concepts. Sampling (interviewing) continues until theoretical saturation of each category is reached (Strauss and Corbin, 1990), that is, until there is no new conceptual information which indicates new codes (at any level).

In this study, I began to realise that saturation point had been reached, for example, when I was hearing that the wives were all experiencing a feeling of loneliness, regardless of their individual situation, and the next couple of interviews confirmed this. I remain conscious, however, of
Rorty's (1991) comment (cited in Atkins, 1998) that I may have merely become tired or unimaginative.

4.8. Overview of the Sample

Each of the wives had a story to tell about the onset of their husband's illness. These illnesses were different from each other and the disease progression had taken a different pathway in each case. The illnesses were varied - cancer of the bowel, Pagetts disease, an acute cerebrovascular accident (CVA), Parkinson's disease and Alzheimer's disease. The husbands with Alzheimer's were all suffering from dementia as was one of the husbands with Parkinson's disease. The range of onset of illness to placement of the husband in a nursing home also varied considerably. One wife, for instance, had managed, to varying degrees with her husband's illness for 35 years before she acknowledged she could no longer have him at home. Another wife had lived with her husband's illness for just a few months.

The table (Appendix 1) gives the relevant information about each of the nine participants and their husbands. Several observations can be made on the basis of this information. Wives range in age from 68 to 82 years (average = 74.5 years), husbands from 67 to 88 years (average = 77 years). The nature of the illness clearly has an impact on the length of the illness (range: 3 months to 35 years; median = 5.5 years). All of the wives had at least one surviving child and had been married for an average of 47 years. It should be noted that this description of the
The respondent group is not intended to relate to the population of wives whose husbands have been admitted to nursing home residency. It is the experience of wives which is focussed on here and no subsequent processes of population generalisation will be engaged in.

4.9. Summary:

This thesis seeks to explore the experience of nursing home placement from the perspective of the wife who remains in the community. This chapter has explained how this exploration was undertaken. Qualitative research was chosen as the general method of this thesis, and Symbolic Interactionism as the particular form of describing how the world was experienced by wives. At the lower methodological level, Grounded Theory was selected as a way in which to research, in a systematic and rigorous way, and subsequently develop a theory of the experiences of wives. Interview data was gathered, transcribed and variously coded. It was through these processes that an emergent theory dealing with the aim of this thesis was developed and it is to an explication of this theory that the following chapters turn.
CHAPTER 5 - THE PRE-ADMISSION AND ADMISSION EXPERIENCE

There are a variety of circumstances that affect the experience of the wife during the period of their husband’s illness and the preparation for nursing home placement. The world is different for each couple but there are some individual experiences that are similar. This chapter describes the wife’s experience along a time dimension of pre-admission and admission of her husband to the nursing home.

This chapter describes the similarities and differences in the experiences of wives. Firstly, in the pre-admission period characterised by a number of phases and changes and secondly, the experience following admission of the husband to the nursing home. The third the post-admission period will be discussed in the following chapter. The information for these stages was collected from interviews conducted with wives of recently admitted men to not-for-profit nursing homes in the Greater Metropolitan area of Sydney.

5.1 The role changing stage.

This stage is characterised by a gradual change in the relationship between the husband and wife, where the wife has to cope with multiple and sometimes subtle alterations in her husband’s condition, resulting in a change of her role. During this pre-admission stage of the husband’s illness each wife had different problems to cope with. The wives generally managed with the help of other people either professionals such as doctors, nurses, respite care or others such as children, friends and other relatives.
There are number of phases that characterise the role change stage which the wife passes through before reaching the next stage of placing her husband in a nursing home. These phases include the Early Phase where the illness becomes apparent and symptoms are first recognised, the Busy Phase where the physical and/or mental problems are the focus of the days activities. The 'Becoming Single with Responsibilities' Phase during which there is a recognition that the role of the wife is changing to that of carer and the final phase -The Effects of Change - where changes accumulated over the past months or years are beginning to have an effect on the wife-carer to the extent that there is an increase in burden, a greater reliance on health professionals and increased need for family and other support.

The following sections outline these role-change phases and the characteristic events which mark them out.

5.1.1. The Early Phase.

In the early stages of the disease process there were symptoms which were relatively minor and included loss of memory and other minor difficulties and generally, were able to be overcome with little alteration to daily activities. Illness processes in this early phase did not cause major disruptions to the household or established relationship patterns.
5.1.1.1. Loss of Memory.

The symptoms relating to loss of memory were difficult but mostly bearable. One husband was described by his wife as remembering some things and not others another would get out of bed and remake the bed and everything. In one instance there appeared to be some recognition by the husband that his memory was deteriorating - he knew he was losing his memory and it really hurt him. There was one husband who couldn't remember how to do things, he was always one to use his hands, he'd undo his plane and then he couldn't put it back together.

In this early phase of symptoms one husband went to Melbourne on his own, to visit someone and he got lost in Melbourne. For another according to his wife, was that he couldn't think anything, he didn't know what he was saying or what he was doing and another husband who had problems with simple things like at the breakfast table, you know jam and honey and all that, the lids would be off and he wouldn't register, he'd try and get the lid off and there was no lid on it, you know and he used to get so frustrated and he'd look around to see, if you were looking at him, yes, after he realised what he was doing.

For Mrs. Fraser re-orientating her husband was a constant job, they had lived in their house for eight years and yet, when the couple returned from a holiday with their son, there was no recognition of the house by the husband, we went down to my son's...once and when we came home with the luggage I said oh if you'd just put them by the ah back door we can go and - we can't stay here, this isn't our place, you know it was awful
really and I couldn't convince him when we got inside, he'd say I haven't been here before, this isn't our place, and yet we'd lived there for 8 years.

5.1.1.1 Minor difficulties.

The minor difficulties included, for example, one husband whose voice began to go and one who could read big print only another husband had difficulties in walking, I used to say to him pick your feet up Barry, you're shuffling and he'd say oh that's just the poor circulation, another had difficulties with co-ordination activities such as being unable to clean his teeth - you know and you'd have to hold his hand to clean his teeth.

Mrs. Rigby had noticed a change in her husbands ability to communicate and she stated that:

he seemed to recede into himself and um, ah, not look at me when I was speaking to him, rather look vaguely in another direction and ah, sometimes not answer unless I sort of, not that I insisted but I sort of expected an answer which he would give me but it was always a little bit vague...it wasn't just a mood.

One husband had the symptoms of his disease starting quite early and at age 56 couldn't continue with his work...he didn't have the co-ordination, his mental ability was failing. This problem was accompanied by a reduction in income, a significant but not an insurmountable problem, and with adjustments to their life, the problem did not continue.

The symptoms and accompanying problems of this early phase were relatively minor and in most instances did not cause major disruptions to
the daily activities of the couple. Each wife made adjustments - a little help was given to carry out activities such as teeth cleaning, tops on jars and some explanations about surroundings - but generally life for the couple did not change dramatically. As the disease progressed, however, greater changes took place and the wife found herself being a little busier with an often slow deterioration of her husband's ability to carry out his own activities of living. These changes ushered in the Busy Phase of the Role-Change Stage.

5.1.2. The Busy Phase.

The progression of the illness and the accumulation or worsening of related symptoms, commenced in the Early Phase, become extremely difficult to deal with on a daily basis. Worsening symptoms included physical problems such as personal hygiene needs, incontinence and falls, mental problems such as confusion and wandering as well as other problems. While perceived by the wife as being difficult for both her and her husband, this period is distinguished by disruption. The nature of these disruptions changed the couple's general life activities and also marked the beginning of the gradual change of role from wife to carer.

The Busy Phase is also characterised by an increase in contact and reliance on health professionals. An endless round of doctors visits is indicated by Mrs. Howe who had to take him to so many doctors appointments...he had umm prostate...they thought he might have had prostate problems and umm went into...hospital for and operation..., then
there were visits to doctors to do with his motions and umm...he had to have two trips for that.

5.1.2.1. Personal Hygiene Needs.

Personal hygiene is typically a private matter, even in intimate relationships, such as marriages. It becomes difficult for most people to take over this role for someone else.

For Mrs. Fraser the issue of policing the personal hygiene of her husband was hard for her to manage:

I suppose 76 years he's always looked after himself and had privacy and we've always respected one another's privacy...I mean you know it hasn't been easy and even when he started to get, you know bewildered, and not knowing where things were, I used to have to turn the shower on, put his clothes in for him, say there are your clothes, you know, I'd say now go into the shower. Oh I've had my shower, I'd say of no you haven't, no you haven't because your towel's dry...

For Mrs. Fraser it was obviously difficult to take over this role of maintaining Mr Fraser's personal hygiene. Another wife said that her husband has always been a very sort of private person, I don't mean that he was ever, not modest so much but you know things like that upset him. Mrs. Smith had trouble with John trying to get him into the shower and go to the toilet. Mrs. Fraser added that it was hard, I can't really remember much about the first time (showering and toileting him), he seemed to accept it but I think those were the times that he resented it, I
think when it was the bathing, showering or toileting I think that was the main thing...it was rather embarrassing.

These personal hygiene needs, difficult as they were, often occurred as a precursor to the greater problem of incontinence.

5.1.2.2. Incontinence.

Incontinence was by far the most common difficulty. One wife described it as a distressing thing, another was concerned about her husband when he used to get so upset when he made, you know, when he was incontinent and I said stop worrying, he knew I was a nursing sister anyway and he said I know, but it’s not very nice for you.

The work load for Mrs. Pearce was hard since it became very very difficult trying to keep the place clean and keep him clean and look after him and just do everything. For Mrs. Keegan the load was described as making many adjustments to her routine and coping with Mr Keegan’s reaction to the problem of incontinence; we had to go through all kinds of adjustments for that you know adjusting the beds ‘n getting kylie sheets and coping with the huge amount of washing and all that sort of thing because it was not only incontinence, but very unpredictable and very embarrassing for him too and all the time he was confused sometimes very confused, sometimes lucid sometimes aggressive and sometimes like a lamb... Mrs. Howe also mentioned the workload associated with Mr Howe’s incontinence at night yes I had kylie sheets to wash...so that was

91
a help and umm but every night he wet the bed so there was all that washing...well I worked it so that it was just a nylon sheet he didn't wet the top section.

The problems of incontinence created a cyclical process summed up by Mrs. Keegan as she described the dilemma of the continuous round of cleaning her husband up, doing the washing, cleaning the house and then starting again: sometimes I'd just couldn't...you'd clean him up and clean up the house and try and get the washing out and so forth and then ahhh there it is just staring at you all over again and then the 'phone would ring. Occurring day after day, week after week, the work load for these wives was enormous, often causing a disruption to sleep at night - he'd be disturbed he'd want to go to the toilet 2 or 3 times a night and he couldn't get himself to the toilet I'd have to take him.

5.1.2.3. Falls and other mobility problems.

While Incontinence was a major problem where it occurred, for others immobility and the consequent falls seemed to be the biggest dilemma: I remember one girl coming in and telling me that he had fallen over out in the back lawn and ahh he didn't fall very often but he had to...he couldn't have got to the bathroom without my help I'd have to take him.

Mr McDonald used to have a lot of falls at home, the family were always terribly afraid you know, it was a miracle that he didn't break his bones, used to wander and he'd fall over a terrible lot, fall over a lot, he'd just get up and walk around and walk outside and then I'd have to go and get him and that It was tiring but when your married to them you've got to help them haven't you?
For Mrs. Keegan falls and subsequent immobility relate to independence and called for creative coping strategies. *He’s always falling over* she reports and she was determined that once he was put in a wheelchair that she would eventually get him walking again to retain as much independence as possible:

> he’s got to walk even a little bit you know...I’ve had to fight...for him to have physiotherapy treatment and ah they were wonderful they got him walking between the bars...now we don’t use the wheelchair at all except if I have to take him any distance and now he can walk you know, up and down a hall from room to room...and short distances like that from the car he can walk inside then sit down and gets up and walks around the house, falls. I yank him up because he knows how to fall now and he sort of goes down rather than falls except every now and then he has a little disaster, just a month ago...he smashed his glasses...but by and large you know that is how we cope.

While the main immobility problem, at least initially, was related to the falls, it was more easily managed where there were others to assist in getting the husband up when he’d fall over, *Brad...used to pick him up and put him into bed*. For many wives this stage introduces a more constant monitoring in knowing that her husband had fallen, stopping what she was doing and helping her husband up.

5.1.2.4. Confusion.

In addition to personal hygiene needs, incontinence and falls, confusion and memory loss was the more constant problem for some wives. Where confusion and memory loss occurred, it was not always predictable: *-its incredible. he remembered some things and not others*. One husband lost the car when he went driving, *he took the car, parked it near the old*
house, locked it and handed (his wife) the keys when he got back...he didn't know where the car was.

Some husbands had difficulty knowing where things were. He didn't know where the bathroom was, you know...so confused "I can't find the bathroom". Another started to get bewildered and not knowing where things were, while another was described by his wife as telling stories, you wouldn't want to know the great stories that he tells.

Mrs. Keegan had some terrible nights with her husband where he had hallucinations and he attacked me on several occasions because he thought I was...it was strange he thought the Japanese were attacking me and yet he knew it was me and he was trying to defend me but at the same time he was trying to kill the Japanese, he was very muddled. The night time was also difficult for Mrs. Fraser as Mr Fraser would often get up and dressed in the middle of the night and I was always aware of it and I'd try and persuade him to go back to bed.

Confusion and memory loss, then, was a problem for a number of the wives and for Mrs. Keegan the night times were awful, and this confusion, in some instances, led to wandering which could have had more severe outcomes and increased the level of monitoring required.
5.1.2.5. Wandering.

It is one thing to lose the car, as described above, but Mrs. Fraser lost her husband several times and this was a very worrying time for her and her family...I spent all that night wondering where on earth he was till the early hours of the morning and the police brought him back, they said will you come and fetch him and I said yes I will come and fetch him, it was after midnight and they said oh look we'll bring him back and they were very good...and the second major excursion by Mr Fraser was also taken at night time - they hadn't notified me by, until quarter to five the next morning and then they said um, a policeman came around and I said oh you haven't got my husband with you and he said no he's in Liverpool Hospital...he must have caught the Liverpool train and walked.

Nights created particular 'business' for Mrs. Fraser, they called for increased levels of monitoring and checking, accompanied by loss of sleep. When absent, because of her husband's wandering, she also was subjected to increased levels of anxiety - unsure whether her husband had been injured or even killed by a car or train.

Night problems are a feature of wandering behaviour. Mrs. McDonald reports how her husband didn't know where he was...he used to get up through the night, before he went to bed I used to put him to bed, and he'd get out of bed and remake the bed and everything, he'd just get up and walk around outside and then I'd have to go and get him and that.
Having a husband who wanders caused additional problems with some having to keep their husband under almost constant supervision so that they would not "lose" them. This meant locking front doors and side gates as well as taking on the caring role and policing their husbands personal hygiene needs.

*I kept a chain on the side gate, and a chain on the front door,* Mrs. Smith says, *so therefore he couldn’t get out you know...he hadn’t sort of got out because I had the place sort of locked, you know but it was just the matter that he couldn’t remember how to do things...*

5.1.2.6. Other Problems.

Other problems that some wives had to cope with included deafness, terrible headaches and near blindness and loss of communication skills, *his voice began to go but he could still whisper and we could still follow him.* There was also a change of character for many where, *his whole character has totally changed* and some problems with aggressive behaviour, *it is very hard to accept and to deal with...and aggression,* he wanted me to open the front door, and I wouldn’t and he said if you don’t open it I’m going to punch it, because I’ve got double glass doors at the front, *he said I’ll punch the glass through and get out that way.* Mrs. Fraser, who had a deadlock on her front door, used to keep the key herself and, *at one stage...he’d come and stand and say would you open that door, and I said no I’m sorry I can’t open the door,* he stood by me, *I want that door open.*
The Busy Phase is characterised by many problems that had now begun to cause an intensive workload for the wives. While the major ones were incontinence, immobility and the consequent falls, the busy phase also included problems associated with confusion, wandering and other problems such as headaches, deafness, loss of communication skills and aggression. During this phase the wife in many cases, was gradually taking over the duties that her husband used to perform and also deal with added duties of sorting out his personal affairs now that he was unable to do this for himself, the key mark of Becoming Single with Responsibilities.

5.1.3. Becoming Single with Responsibilities Phase

Whilst the busy phase is still taking place the wife is also adjusting to being like a single person, after many years of marriage. Not only has the wife had to take on the role of carer but in many cases, has had to take on the tasks that her husband once performed. This includes taking over the day to day activities, running the household and the family home, finding time to do the shopping, pay bills, protecting and monitoring her husband and other roles associated with caring and sole responsibility for a household. There was inevitably the loss of the role of spouse in the partnership. This change of roles also sees increasing assistance by various health professionals and family, relatives and friends.
5.1.3.1. Taking over day to day activities

Day to day activities were gradually taken over by the wife increasing the level of felt responsibility. One woman stated that she had gradually been taking over everything in the home while for another she had to take on tasks that she had not had to cope with before - now you've got to turn round and do it, filling in forms, banking and all the finance and everything, he always took care of everything.

Mrs. Pearce had to take out Power of Attorney for her husband and cope with problems such as his overseas pension:

I had to write, our pensions come from UK, come in about now, June, and they came in and we get a form which we have to sign and send back to them, so I signed Bill's, I put in a copy of the Power of Attorney, I sent it to them...I got it back to say that they had, it had to be a witnessed one, well it was a witnessed one but it was just photocopies so I took it down to the solicitor again, he said oh I'll put the seal on it this time and I sent it back again and they accepted that and the only thing is they send me a lot of forms which I have to send in each year.

As the stories reveal, over a period as short as 3 months and as long as 35 years, the wife took over the responsibility of running the household as well as the day to day care of her husband. There was a decrease in the wife's ability to have any sort of leisure activity herself and a substantial increase in the responsibility of caring for her husband across multiple dimensions.
5.1.3.2. Finding time.

There was usually no time left for the wife to pursue any type of social activity for herself, the total time available was taken up in looking after her husband and the increasing level of responsibility. Even when time was taken to do essential activities like paying bills and going to the bank it proved to be difficult. Many of the wives did not voice the need for their own personal time as they felt that the role of carer was the important one, at this stage, and if the situation was reversed he would have done the same for me.

Mrs. Pearce adequately summed up the personal cost of caring for a totally dependent husband at home in a way which reflects the experience of many wives:

It just disrupts your whole life...everything you know. I used to like to play golf and umm have people here and so forth, but I don't ask, I don't have anybody here other than the family because they understand that he's incontinent and that he dribbles and that he can't talk and he mumbles, and if it's anybody you don't know you're continually sort of apologising or trying to control the sick person...It just, just total disrupts your life and there's no way, I could go to golf because umm that means to be away four or five hours and even though, or so to go shopping locally or something like that, but sometimes when I came back you know he'd pulled things down or he'd had an accident or he'd soiled the floor or hadn't got to the toilet in time and we had some horrible accidents in that regard...It became very difficult you know socially and it was a big problem and there was no end to it you know, there was no end to it.

Time creates its own tyranny. Coping, in many cases, twenty-four hours a day, seven days a week, becomes an all consuming task. As suggested by multiple experiences at exactly the same time that carer
responsibilities increase so too do the responsibilities of managing daily
tasks alone.

5.1.3.3. Protective/monitoring activities.

The change of roles and the change in the relationship -becoming single
with responsibilities- meant that the marriage to all intents and purposes
you know ceased to exist, it also meant that there were some protective
mechanisms that the wife, and/or the children had to put in place, this
was not always received well by the husband. Monitoring previously
everyday activities, like driving a car, is an indicator of this change in
roles. Two of the wives reported that they, and their children, had to ask
the doctor to recommend that their husbands' driving licenses be revoked
as they were driving dangerously.

Mrs. Smith reports:

I was a bit scared with him in the car. He always had been an
excellent driver but I began to get a bit scared of him in the car
because he was going so slowly and eh, Jane, my daughter felt the
same way so I'm afraid we went to the doctor and dobbed him in,
which is the word and eh, the doctor sort of said yes it probably is
better that he stops driving so we cancelled his licence then...he's
never forgiven us for that.

Mrs. Pearce had a similar story:

when he retired I just let John drive you know and I found out he
was going through red lights all the time, and I thought, the first
couple of times I thought, oh you know sometimes you do these
things not thinking, but it got that way he was going through, you
know, red lights and I couldn't take anymore so I took him to the
doctor's...and the doctor said you have to promise not to drive again and poor old John used to say to me, it's through you that I can't drive.

As the caring role becomes the major focus for the wife the role of the wife alters. This leads to some confusion and ambivalence. The spouse is still there but not able to function as a spouse in any way at all and yet you still have to relate to a spouse you know legally and emotionally and err...day to day activities and I find that very hard to cope with. Mrs. Keegan voiced that although the spouse was still there he offered no support knowing that you've got a spouse but no support with all these other problems that I have.

Adjustment to role changes that the wife has had to cope with during this 'Becoming single with responsibilities phase' was a particular problem. Husbands' daily activities were been gradually taken over by the wife to the extent that the wife was running the entire household as well as caring for her husband. There was also the role of protecting the husband and other family members by acting as an advocate and carer by ensuring the husband’s safety. This involved, in two instances, having the husband’s driver’s licence revoked. Also, finding time to fit all of the necessary daily tasks into a busy program as well as a little recreation for the wife was just impossible so the recreational activities did not happen. These changes, took place over a long period of time and had some consequences for the wife and indeed for the rest of the family which will be described next.
5.1.4. Getting Worse Phase

While in this pre-admission stage the husband's disease was not causing too many problems, the role changes associated with increasing dependence of the spouse were becoming more difficult. Moreover, the knowledge that these symptoms would not go away, only get worse, *he has just got worse and worse* led to a change in usual relationships.

In a long-term marriage, with established interpersonal and interactive patterns, the recognition that *you've got a spouse but no support with all these other problems that I have...being able to discuss finances with him and you've got like a single person has to look after themselves...but I also have to look after the spouse as a spouse with all his needs too* created ambivalence and difficulty.

These two factors, the deteriorating health of the husband and the change of role for the wife resulted in many alterations in the way in which each wife coped with the situation. These alterations included feeling an increase in burden related to the changes, an increasing reliance on health professionals, an increasing acceptance of the need for family and friends support and the accumulating effects of these changes over time.
5.1.4.1. Increase in burden.

Many of the wives were recognising the increasing dependence of their husbands on them for their daily care and well-being. Coupled with the recognition that they were also getting older and becoming unable to provide the move to twenty four hour a day care that her husband required, takes its toll.

Mrs. Keegan stated that her husband was *getting weaker and weaker and more incontinent and I was getting exhausted, I was finding myself going right into the ground* and Mrs. Rigby stated that *I'm only a small person, and I've lost a stone in weight just recently, oh not just recently, over about the last six months or so.* Mrs. Smith was *getting spasms of great weakness* and Mrs. Fraser also vocalised the weakness that she was feeling, *the weakness was the main problem, draining of strength, I just couldn't depend on myself.*

Unlike these carers not all had a husband who was suffering from dementia, but their problems were no less severe. One such carer was Mrs. Kaye who had been caring for her husband since the diagnosis of Pagett's disease 35 years earlier.

Mrs. Kaye had a negative experience with a health professional who took it upon himself, in the early days, to discuss Mr Kaye's illness with her on her own and he gave her a rather horrific picture of the suspected progress of her husband's disease. *They told me all sorts of things that really haven't eventuated and the doctor tells me every time never to*
discuss this, what he does or his condition, in front of him because he said you don’t know how much he knows.

when I went up he said now look, [your husband] has Pagett’s disease, and I had never heard of it and I thought it was some terminal illness you know...I was quite upset about it, he said now look I’ll tell you, he said, it won’t kill him but he said I have a book here and I’ll show you the results of it in later life if he lives to that age and he showed me these horrific pictures you know, these skeletons and the poor men with their great big heads and legs bowed and everything...but he said he probably will never live to that stage you know.

This was an introduction to the multiple problems that Mrs. Kaye faced in order to help her husband cope with the disease over the following thirty five years. This disease caused physical problems - stones in the kidneys, total deafness, near blindness and severe mobility problems. One of the more severe physical symptoms was ‘parasite phobia’ where Mr Kaye scratched at his skin constantly.

day and night, and I’d here him rattling around through the night you see and I’d go in and there’d be bleeding - every morning I’d have to strip his bed, the pyjamas, sheets had blood every day...for about 3 years we had nothing but blood, blood, blood.

The stress of caring for a person with a chronic illness had affected wives in many ways. Some complained of weakness and loss of weight, whilst others blamed the caring role for other illnesses such as the flu and a breakdown. There had been a dramatic, even if it was slow, change in their role from that of wife to that of carer. In that change period some of the wives increasingly relied to a greater or lesser extent on the support of health professionals and other family and friends. Clearly the burden related to the role of caring was hard for these women.
5.1.4.2. Support Services

Wives took on the increased burden of care as best they could and often without help from professionals. It seems that many of the community services that are available, services such as home help, community nurses and meals on wheels, were not used by these wives. Two had made use of services such as community nurses and day care with mixed success. One day care service required a telephone number where they could reach the wife if the husband became too difficult to handle. As a consequence this service proved to be of little use to the wife. One wife that did use what was available found the community services in this area anyway, were excellent they kept saying you know what can we do and how can we help you and the umm district nurse came down once a week to shower him and cut his toe nails and just check him.

Mrs. Howe found that she could get somebody to look after him for a day so I could go out, they'd come to the home and look after Gordon, sort of, look after him the way I was looking after him and it enabled me to go out to the show with my sister one time...I didn't prevail myself of that very often though.

Some wives had made use of respite care which also met with mixed success some found it valuable, whereas others found that it was an experience which they would have preferred not to have.
The assessment team came down and they were able to arrange for respite leave for me for a couple of times, but that was very difficult because the people where he went...didn't seem to be able to keep him comfortable because his communication skills are about nil, and one place...he had a very serious bladder infection...and the urine stains on his singlet were right up to his shoulder and the smell was just awful, and I...discussed it with the matron there...and she said it had been very difficult to give individual attention to a lot of the patients.

For Mrs. Pearce it was her daughter who sort of pushed our GP and we put him into a Nursing Home for 3 weeks...to give me a break and...he was so unhappy, he was so desperate, and when I went to see him he was scared he was losing me and I said no you're not losing me, it's just that I needed a break...I just needed a break for 3 weeks. I decided to take him out much against my daughter's disgust...

For Mrs. Kaye the experience was more positive, her daughter wanted to take her away for a holiday so we put him in here, they were good enough to take him for respite care for 4 weeks, and ah, when we came back, my daughters had been talking, had been talking to matron and she said ah, really your father is in need of full time care, which of course I knew but I, I wouldn't give in to it.

There was then, a mixed use of community based and other health services and a mixed reaction to the services that were used. Reactions were related to the care standards that the husband received.
5.1.4.3. Family/other support.

As well as the support services that wives used, family based support was relied on for assistance. At least one of the children, if needed, and for some grandchildren, other relatives and friends also provided some support during the illness, decision-making for nursing home placement and in providing ongoing support of the wife post placement.

people said ohh I'll come and sit every week for four or five hours. That's virtually a whole day. Its impossible and apart from that you'd be under a great obligation to that person and that's a real worry. You know it worries you when you're out playing golf and its just not a pleasure any more...

Sometimes it was a combination of the service provided and the assistance of a relative, the sister used to come at night time and put him to bed when they'd go I had it and Dianne(daughter) had it...they all helped.

It was comforting for one wife to be able to rely on a neighbour sometimes for assistance, I was always having to get a neighbour in to help me pick him up. Mrs. Pearce received assistance from people out shopping when she had difficulty in getting her husband to the car, we usually knew someone in town and a number of times I got help back to the car with him. One wife rang my brother(in Canada), I was always ringing him when I'm in strife.
At the stage where a second opinion was requested to put the husband’s name down at a nursing home, a diverse group of people offered assistance we went there and Rose (daughter’s mother-in-law) came with me and I walked round and I had a look at it...For others it was relatives my brother took me around the nursing homes. My daughter-in-law...she’s a very helpful girl and she would do anything, you know.

Family support was not always possible. Mr Pearce would refuse the assistance of other people when he was incontinent, if he was caught he wouldn’t let any of the others take him to the bathroom...it had to be me or no one.

It was obviously valuable to be able to call on the help of other people at times when this was required. The variety of people ranged from other close family members to those living overseas, professional people and strangers in the street. While this was a comfort to the wife in no way were these people providing on-going daily support.

5.1.5. Summary - Role Changing Stage

The role changing stage has been characterised by an early phase, where the initial symptoms of the husband’s illness became evident and these minor problems did not cause much disruption to the wives or the
husbands themselves. The second phase of this role changing stage, the busy phase, was much more difficult for the wives as they found themselves coping with worsening symptoms of their husband's illness. There were physical demands as husband's personal hygiene needs had to be policed and assisted when required, problems associated with incontinence and falls and the emotional needs of husbands related to confusion and wandering.

The third phase of the role changing phase is the becoming single with responsibilities phase where all of the day to day activities had to be taken over by wives as husbands were no longer able to contribute to the household tasks and decision making. When all of the daily activities were completed, and the husband's needs were cared for, there was no time remaining for wives to socialise or plan for any type of recreational activity. Finally, the effects of change where the changes that have occurred are having an effect on the carer increasing burden, need for support services and assistance from family members.

The experience, at this stage, could be described diagrammatically as follows:
Following this role changing stage is the transition stage where a critical event occurs either with the husband's illness, an illness of the wife/carer or a bed becomes available in the selected nursing home. There is also the selection, initial contact and admission to the nursing home included in this phase.

5.2. The Transition Stage

The second stage of the experience of caring for and eventually placing one's husband in a nursing home is the Transition Stage. A critical event occurs in which something happens to either the husband or the wife resulting in placing the husband in the nursing home. Secondly, the initial contact phase occurs, which includes the selection and contact with the nursing home and finally, the experience of admission.
5.2.1. A Critical Event Phase.

There always seemed to be a critical event that led to the next stage of the passage through to the admission of the husband to the nursing home. In some cases, this was a change in the level of dependence of the husband, an event which was 'the final straw', a change in the wife's health or the availability of a bed in the nursing home of their choice.

5.2.1.1. The final straw.

Recognising the 'final straw' was often an assisted process. In the deterioration in the husband's symptoms, or an increase in aggressive episodes, children were instrumental in helping the wife to recognise the significance of the situation and to point out the wife's inability to cope. For Mrs. Fraser her son decided that the situation needed to be addressed and suggested to her that he be moved to a nursing home: it's terribly trying but I think I could have coped longer. But my son said, no, he said look I'm not just round the corner and he said, if you had a fall or if anything happened to you, you know, where would dad be.

For Mrs. Smith the event centred around an aggressive episode (described previously).
One morning it really got drastic you know, he wanted me to open the front door, and I wouldn't and he said if you don't open it I'm going to punch it, because I've got double glass doors at the front, he said I'll punch the glass through and get out that way and you know, I mean he went out the side gate and shut the daylights out of that you know and I was in tears and I rung up my son you know, and Barry come home from work and he rang his other brother and they both come home and they said mum you can't, you can't go on like this you know so then we straight away rang the doctor up and the doctor said you'll have to put him somewhere because he'll finish up hurting you, you know.

This was deemed to be the turning point of the caring situation for Mrs. Smith. The sons had become involved and then assisted Mrs. Smith to come to the decision of placing her husband into care.

The 'final straw' situation was marked by the involvement of others, often children and nursing home entry followed quickly.

5.2.1.2. Illness of the wife.

For some wives, their own illness led to their inability to care for husbands, and became the critical event. Mrs. Kyle developed the flu...and the doctor said to me you'll have to go to bed, you know, for 3 days. Well I couldn't go to bed, because I had to see to Harry and um, anyway ah, I developed pneumonia because I just couldn't go to bed and I, you know was just getting round doing things as I normally did, and I suddenly went down with pneumonia.

Mrs. Rigby had an angina attack after her husband's stroke and...well a week after that (husband's stroke) I got a very severe angina attack and
my doctor rang, I was in her surgery, the day after I'd had it and she rang
the heart specialist, I had been in before with my heart and they admitted
me...well I was there for a fortnight myself.

Mrs. Howe attributed her illness to the caring role and it manifested itself
in her having a breakdown...I'm afraid it was that I had a breakdown and I
just couldn't keep going so I was put into the...hospital

As the primary and often only carer, when the wife became too ill to look
after the husband, both wife and husband ended up in hospital. From
there it was decided, usually by the children, that their mother could no
longer cope and arrangements were made to have their father placed in a
nursing home.

5.2.1.3. An available bed

For some wives the critical event was the availability of a bed in a nursing
home that they knew of. Acceptance of this bed was often actively
encouraged by the doctor. Mrs. Keegan says:

_I didn't want him to go into a nursing home until next year...because
financially I thought that's when I could cope better at home but it
became very very difficult trying to keep the place clean and keep
him clean, and look after him and just do everything and a bed then
became available in...and when the bed became available our local
doctor said take it take it take it and I have to tell you he was
admitted._

For Mrs. Pearce the availability of a bed was also a crucial turning point
but in this instance the doctor was not quite as influential. _I'd been told_
by the doctor it was going to be increasingly worse and, it would be better if I put his name down, they had a bed so I thought well I’d better take it.

This decision reflects that the time of admission was not of their own choosing depending as it does on bed availability, but they were aware that it was a possibility as both had placed their husband’s names down on several waiting lists.

5.2.1.4. Admitted from hospital.

For the remaining wives there was a critical episode which required the husbands to be admitted to the local hospital from where they were transferred to a nursing home. Mr James had some rectal bleeding which meant that he was admitted to hospital for tests: I noticed some blood on the bathroom floor and insisted that Mr James go to the doctor’s, from there he went to the specialist and was admitted to hospital...and then to the nursing home. Mrs. Rigby had to call the ambulance for her husband and whilst he was in hospital they started to hint that I would have to find a nursing home bed for him.

Mr. McDonald had problems with his blood pressure, as well as suffering for many years from Parkinson’s disease, and had to be hospitalised. He couldn’t get his blood pressure down and they put him in...hospital and he was in there for about a fortnight and they said he had to go into a nursing home...I said if I don’t say yes now I’ll never say it.
Each husband was admitted to a nursing home through a critical event. This critical event may have been a particular episode at home, an illness of the wife, an available bed in the nursing home or the husband was admitted to the nursing home from hospital following an acute episode or illness. This critical event causes a change for wives as they, and their children, select, make contact with and finally admit their family member to the nursing home.

5.2.2. The Initial Contact Phase

Eventually, through the circumstances outlined above, the decision was made to put the husband into a nursing home. The next question for most wives was which one? The traumatic experience of the day of admission and the families’ first impression of the nursing home is included here as it is often the first point of contact with the nursing home for the majority of the family.

5.2.2.1. Which Nursing Home?

The selection of a nursing home could come before, at the time of, or after the decision was made to place the husband in a nursing home. Some wives had made preliminary arrangements and placed their husbands’ names down on a number of waiting lists: about the middle of last year I went around about half a dozen nursing homes, putting his name down. Some were hoping that they wouldn’t have to use the ones they weren’t impressed with...they wouldn’t take a booking unless I went
over to see the nursing homes myself... a couple I wasn't at all impressed and I was hoping that he wouldn't have to go to them um, one was very, very nice, but they didn't have any physiotherapist there and I felt he needed that.

When considering these nursing homes two of the wives made interesting comments about how a nursing home was selected or rejected. I felt you had to be careful to look at a little deeper than just the first interview - to look what facilities were available and the cleanliness of the place and uhh what the food was like and to find out if possible if there had been a staff turnover or just to speak to people who had relatives there, which I had been able to do. Another wife was looking at the reputation: this nursing home has an excellent reputation and a long waiting list and the local doctor recommended it.

Each wife dismissed any bad publicity in the press about nursing homes as being rare or isolated cases with no one, it seems taking much notice about media stories about badly cared for residents in nursing homes. I just thought those were isolated cases, and I just thought that was one that probably was out of the ordinary and I really just dismissed it as sort of isolated case with the one that had the publicity.

For some wives they felt very fortunate to get a bed in the nursing home of their choice, his name was on the waiting list for respite. It was just a miracle the way it happened. There was a vacancy and we couldn't believe it, it was just like a blessing, someone was looking after us that day. Mrs. Rigby felt that she was so terribly lucky I'll be forever indebted
to Matron for letting him come in here. Matron rang the following week and said there's a bed available. I was tickled pink you know.

With a number of the wives feeling as though the nursing home that they had wanted had a bed for their husbands, they were not as apprehensive as they might have been. However, they also recognised that the day of admission itself was not going to be easy.

5.2.2.2. The day came!!!

Inevitably the day for admission came with very little preparation time. The nursing home would ring and the bed would need to be filled very quickly. There was no time to adequately prepare the husband for admission, or for the wife and the children to come to terms with their feelings on the matter. A bed became available in...nursing home which is just 5 minutes around the corner and its very difficult to get a bed in...Nursing Home its ummm has a long waiting list, John was admitted. For another wife and son it was awful Paul came with me and umm you know Paul's forty and I think Paul had a tear in his eye too cause he realised how bad it was.

Mrs. McDonald did not have the time to even look at the nursing home prior to admission as her daughter-in-law went around to different ones and some was five year waiting and one of the nursing homes give her this address, she rang here on the Friday night...there was a vacancy on the Monday night, so he come in on the Wednesday...no one saw it.
The admission day arrived rather quickly after the decision had been made due to the need to fill the bed in the nursing home. The impressions on that visit - the day of admission - the first for some of the families, was important.

5.2.2.3. First impressions

It is perhaps surprising that so many of the wives made many positive comments about their first impressions of the nursing home. Mrs. Kaye reports, the nursing home is well run and it's very clean and this nursing home is unique I think it's so beautiful all the time, I was so pleasantly surprised, it was very pleasant. Other comments included: I really liked this one it's so light and airy, and it was important the nursing home was clean and not smelly, there was no hustle and bustle. Mrs. Rigby found that the atmosphere created homeliness, that was the first impression I got. One wife thought that the nursing home was the one I liked best because...it just looked like a motel walking in.

The first impressions that staff gave to the wife and family were also important. The Director of Nursing was so helpful and you know she showed us right through and explained things and you know and she seemed to be very helpful and she always has been. There were a few comments about the nursing home that the wife felt needed some improvement you know sharing a room the way he does, there isn't that sort of facility...it's a hospital and you have to take the drawbacks and I think the physiotherapy side could be improved. When I first met the
physiotherapist there...she said I haven't had a great deal of experience...with stroke patients. She said most of my experience had been with post natal and I felt that would be the last experience that would help Frank.

Generally, the first impressions were very positive. The main focus was on the physical environment but also the favourable impression given by contact with staff. After admission the wife now ceases the role of carer and now becomes a care co-ordinator.

5.2.3 The Adapting Phase.

The nursing home had now accepted the husband as a resident. For the wife this involves multiple adaptations - living in a house by themselves, travelling to and from the nursing home and trying to help her husband adapt to the new situation.

5.2.3.1. A Role Change Again.

Many of the wives had managed the role of carer well. They were used to a life of being busy, washing, cleaning, cooking and an endless round of doctors visits and sometimes visits by community services and others. This carer role, which had been taken over gradually, had to change again. Now wives find themselves without the person who required so much attention and this change was more dramatic as it occurred suddenly. This change was marked by feeling alone and lonely: I felt
terrible - I still do and I found it very lonely, I mean despite the fact I've got the two of them here, I still...it's not quite the same.

Mrs. Smith summed up the feelings that she had when her husband was admitted to the nursing home:

Well I don't know, it's hard to explain isn't it. Devastated. You just don't think it will happen to you, you know, these things happen to other people. You feel as if your life's torn apart. Oh that's it, because you depend on them so much you now, it's so hard now without them.

5.2.3.2. From care provider to care co-ordinator.

As well as these dramatic changes in roles the wife now has to become the co-ordinator of care for her husband. Any changes in her husband's condition require her to make decisions, in some cases to become the patient advocate: they were sedating him too much. I spoke to the doctor about it, they knocked off the Valium.

Many of the wives also seemed to try to replicate the home environment as much as possible. I don't think he's all that keen on the food, I occasionally take him in a sausage roll. Mrs. Rigby bought a television for Mr. Rigby so that they could both watch the usual programs together like they used to do:

we used to look at certain television programs leading up to the news, just those diversional little things like the Wheel of Fortune or that, just because they led up to the 6 o'clock news, so I thought now, I bought him a colour television after he was there for a while.
Wives seemed to be trying to create an environment as similar as they possibly could to the home environment. Their role then had changed dramatically from care provider to care co-ordinator.

5.2.3.3. Effect of the placement on the husband.

When husbands adjusted easily to nursing home placement wives often attributed this to husbands' personality, describing them as: a very placid man, and he's the sort of man that will accept things, he had a very, very hard life. Most husbands, however, reacted badly to their move to a nursing home. One husband was described as being absolutely devastated another being terribly upset. Another husband was absolutely miserable and another not at all like the husband I knew, he's just so miserable.

Mr. Rigby didn't, didn't adjust terribly well at first, not any trouble ever but just withdrawn and silent...I think he was still in a state of shock from the fact that he'd had the stroke and, but gradually I noticed an improvement. One wife admitted that she had been a bit of a problem to her husband as she was just, just in a bit of a mess. I think in a way he was almost pleased to get away from me.

One husband tried to make his wife feel guilty by stating that he thought that I had abandoned him. He said...he told me that if it had been the other way around he wouldn't have done that. Other husbands seemed to accept this move as being necessary and still others realised that their
wife could no longer cope, he realises that he's too much for me to look after now and when they brought him in Debbie came up and he was settled in the bed and everything...he just said something and I said well do you like it here love? and he said yes, yes its nice.

Eventually the husband appeared to accept the move and settle into the nursing home he calls this home now and gradually I noticed that he seemed to be getting more relaxed and ah, he's now been here um, six months, bit over six months and I do think he adjusted well and I encourage him to go out on any of the bus trips or attend any little entertainments they have.

One husband, according to his wife, would still like to come home and still others are not capable of acknowledging acceptance of the nursing home as their place of residence but seem to accept it by their reactions.

I don't know that he's accepted...I don't know that he's capable of accepting anything, but he seems to have settled into the routine and he doesn't fight it or he doesn't object and he just goes to the nursing home when I take him back at night...and he always smiles at them and nods his head...and he just toddles off with them...

After a while at the nursing home, some husbands recognised it as their permanent home and after being out for a while wanted to go 'home', a reassurance for the wife that the husband was quite comfortable in the nursing home, that it is viewed as his home:

we took him home at Christmas, he's been here eight months this month, we took him home at Christmas and about three o'clock he says I want to go back and I said go back where? he says I want to
go back home, he said they might lock me out and I won't be able to get back in

This Transition Stage includes the critical event which led to the decision to place the husband in a nursing home, the first contact with the staff and the introduction to the facility and is represented by the following diagram:

**Transition Stage**

![Diagram of Transition Stage with phases]

**5.3. Summary**

This chapter has described the Role-Changing Stage and the Transition Stage. The husband and wife relationship gradually changed, and the wives became carers of their husbands. The wives also coped with the transition from caring for their husbands' at home to selecting and placing their husbands' in nursing homes. Each stage was characterised by a number of phases in which the problems that these wives had in caring for their husbands in these stages have been identified.

The Role Changing Stage includes the Early Phase where the wives begin to come to terms with the fact that their husbands have illnesses which may cause ongoing problems. The early problems were of a
reasonably minor nature and included loss of memory, difficulties in walking, teeth cleaning and co-ordination. As the husbands' illnesses became more severe the symptoms became more difficult to cope with and the wives found themselves in the Busy Phase. These symptoms included physical and mental problems such as incontinence, and other personal hygiene needs, falls, confusion and wandering behaviour. This phase was also characterised by an increased reliance on health professionals.

The Becoming Single with Responsibilities Phase is occurring parallel with the Busy Phase. The wives were busy with their caring responsibilities and were beginning to adjust to not having a partner to rely on for sharing the responsibility of a relationship, a household and a family. This meant that the wives were taking over the day to day activities, finding time for their own needs as well as monitoring and protecting their husbands from further difficulties associated with their illness.

The changes that have occurred in this Role Changing Stage had considerable effects for the wives and these included an increase in burden, an increasing reliance on health professionals and an increasing dependence on other family members for support.

The second stage outlined in this section was the Transition Stage where there was a Critical Event Phase, an Initial Contact Phase and an Introduction Phase. This included the problems for the wife associated
with the transition from caring for the husbands on a daily basis to, and incorporating, the actual placement of the husbands into nursing homes.

The Critical Event Phase was one in which a critical event led to the realisation of the need for, and actual placement of the husbands, into nursing homes. The critical events included a deterioration of the husband’s illness, an illness of the wife, an available bed in a nursing home of their choice or admission from hospital after an acute episode of the illness. The Initial Contact Phase described the selection of the nursing home, the day of admission and the first impressions that the staff gave to the wives of the facility.

The Introduction Phase incorporated the change of roles for the wives, again, as they coped with being a care co-ordinator instead of a care provider. This phase also considered the husbands’ reactions to their placement in a nursing home.
The Role Changing and Transition Stages have been described in this chapter. The following chapter deals with the Post Admission Experience incorporating The Reality Stage where the phases of being 'Torn Apart', Becoming Family and Adaptation are identified.
CHAPTER 6 - THE POST ADMISSION EXPERIENCE

The wife has coped with a changing role and the movement of her husband into the nursing home. The experience post admission or the reality stage is the focus of this chapter.

Chapter five identified the experiences of elderly wives when they are confronted by their husbands' illnesses, and subsequent need for care, initially at home, and eventually in a nursing home. This chapter describes the experience of the wife following the husband's placement in a nursing home. The stage identified at this point is the Reality Stage where the wives explain their feelings associated with such an experience.

6.1 The Reality Stage

Each wife has supported her husband through his illness and placement in a nursing home and now she has her own feelings to deal with. She now has to face the reality stage where the physical and emotional distance from her husband becomes indisputable. This stage can be described in a number of phases. Feelings of physical and emotional distance, are described by one wife, as like being torn apart and this phase includes such things as loneliness, guilt, grief, and feelings related to the changes in the husband/wife relationship. Many of the wives choose to take some action, and they soon become part of a new “family” - the nursing home family. In this phase problems relate to visiting their husband every day (or nearly every day) and for some this required assistance from others with transport. Visiting also created problems with
what to do whilst they were spending long hours at the nursing home, and whilst there, they quickly developed relationships with the staff of the nursing home which they report as helpful. The final phase - adaptation - considers the support that the wife receives from other members of the family, how the major problems were dealt with and acceptance of the situation which resulted in the health of the wife improving.

6.2. The ‘Torn Apart’ Phase

This phase of the Reality Stage was difficult for all the wives with one wife coining the phrase you feel as if your life’s been torn apart to describe her feelings at this time. There was the immediate reaction of devastation, loneliness, guilt, sadness and grief and the effect on the relationship between the couple.

6.2.1. Devastation

All of the wives found that the admission of their husband to a nursing home was a particularly stressful time. These descriptions give some insight into just how difficult is was for them: Mrs. Keegan felt as if she just wanted to have a great old howl which I do every day almost. Another wife was disappointed that I had to put him in here and Mrs. Pearce said that she finds it terribly depressing...It’s just so depressing.
Mrs. Rigby summed up the experience by saying that she felt inadequate:

"not hopeless, um well inadequate because of my own health at that stage and I felt terribly dependent on other people and that doesn't go down easily with me...I was dependent on being taken to wherever he was, I was a dependent on being taken to do my own housekeeping messages and when I came out of hospital I was so weak for so long, not a physical weakness just ah, shock I think it was...nothing they gave me helped me. That weakness was my main problem, it was a terrible um, draining of strength. I felt as if every bit of strength was running out of me and I just couldn't depend on myself."

Other wives found the experience equally as difficult: I don't know, it's hard to explain isn't it? It was an awful readjustment or it's a real wrench and another described it as feeling devastated and you just don't think it will happen to you...these things happen to other people.

This period of time has been described as devastating and many of the wives found recalling this particular time during the interview difficult as it was still a very emotional topic. These wives have finally been separated from their husband after marriages ranging from 30 to 57 years. Although all of the wives described their marriages as "good", three mentioned some hard times that they had been through together and how they had coped with difficult periods. Their husband's admission to the nursing home was far more traumatic for them than any previous experience as it was being faced alone.

6.2.2. No One to Talk Too!

Loneliness was quite a problem. This was so even when the wife was living with a child and their family: I felt terrible, I still do and I found it very
lonely despite the fact that I've got the two of them here. Others described loneliness as being a problem, at least initially, originally it was the loneliness and I do miss him, lonely of a night...so lonely isn't it?

Mrs. Rigby, who expressed feelings of devastation, also summed up the experience of loneliness as missing the person who was always there, someone that she could talk too and share things, however small:

it was the loneliness, even though he was never a very talkative person, the presence was there and looking at the empty bed at night when I was going to bed and ah...sometimes he would sit where you are and I'd sit here and um...we'd be looking at television. Sometimes automatically I'd turn over to the chair to say something...my daughter being quite a distance away and being very limited because of her girls and her husband's work and her own work.

Nor did it seem to matter who else was around, it was their husband who they were used to - when it comes around you know, 11 o'clock and that, I just want to come and see him that's all about it. I mean we've been together a long time. These couples had spent so many years together and shared so much, there was no one to take their husband's place, I'll be sitting here and thinking I'd love to have someone to talk to and it's then that you feel lonely.

6.2.3. Guilt

Along with loneliness, guilt was also one of the major effects of this enforced separation of the husband from the wife, although not as easily
talked about. Only one wife actually said I did feel guilty, but she was the only one.

One husband tried to make the wife feel guilty about placing him in a nursing home. This seemed to work as this wife ended up taking her husband out of the first nursing home he was in and taking him home for a while before everything got too much for her again: I decided to take him out of (nursing home) to Jane's (daughter) disgust and so I had him at home for about 3 months until he went into (another nursing home). He thought I had abandoned him. He said he told me that if it had been the other way around he wouldn't have done that. He really made me feel guilty and I mean, I know, his attitude was I was a nursing sister, I should have been able to cope.

Another wife, when asked about the amount of time that she spends with her husband taking him out of the nursing home, responded with the suggestion that she feels guilty about enjoying herself as her husband is only pacing the corridors of the nursing home:

it is a commitment, and it is a commitment financially too, but umm it gives it puts a bit of quality into his life and I'm still not used to the idea that if I that if I'm home doing things or wanting to go out or have a day free I think gee it shouldn't be much trouble for me to bring him home and I fell almost obliged to bring him home because I know that in the nursing home he's just sitting in a chair or walking up and down a corridor...if I thought he was in the nursing home and reading a book or being entertained or engaged in some activity I wouldn't bring him home so much....any activity organised in the nursing home he can't participate.

Although these wives are not using the word “guilt” many express this emotion stating that they felt “guilty” about putting their husband in a
nursing home or enjoying themselves now that their husband is in a
nursing home.

6.2.4. Sadness and grief.

Sadness and grief was also a strong reaction to the placement. There
was a sense of loss of the partner of many years, you depend on them so
much - it's so hard now without them; you've seen this happen to
somebody you've loved and cared for...and...it is, it's just sad. There
seemed to be a sense that the wife would like to turn the clock back,
you'd give up everything if you could bring them back and a questioning
of why do they have to suffer? Why should they end their days like this?

One wife pointed to this grieving as ongoing: a widow grieves but in time
there's consolation because the grieving ceases, but it's not fresh all the
time. When the spouse is still there...it's the grieving is still fresh you
know. It's not like the end of the story if you can put it that way. There is
not a period where this grief can stop because the husband is continuing
to suffer, and therefore, the grief continues, you're sort of grieving all the
time.

One wife felt that she had let him down and another stated I was
disappointed that I had to put him in here. The sadness and grief that
had been their experience since their husband's illness led to nursing
home admission was very difficult to talk about. A number of the wives
became upset, and this whole experience had been extremely stressful to all of the wives.

6.2.5. The Husband/Wife Relationship.

As previously pointed out many of the wives spoke of dramatic changes in the husband/wife relationship that had occurred because of their husbands’ illnesses, *you haven’t got the same relationship as you had before*. They also described further changes that had occurred since the nursing home admission of their husband. Mrs. Rigby described the closeness of her relationship with her husband now as opposed to the past, *because he’s been in business, we never had a lot of time together...it took a terrible strain on us because I never saw him very much...I felt that we could have been a lot closer than we were. I feel we’re closer now than we were when he was healthy.*

Mrs. Fraser missed the closeness of the relationship with her husband as she felt unable to demonstrate her love for her husband in a public environment:

*I think it’s the feeling that you can just, you know the contact sometimes putting your arms around, the feeling that you can’t do it here, the most you can do is to hold their hand, put your arm around them. I mean we were never over demonstrative and never publicly, we know we’d have got embarrassed if we ever, well we wouldn’t...yes, just every now and again he says I love you and that makes my day...it does and I put my cheek right beside his face and you know he’ll give me a little kiss and I’ll say do you love me, he says yeah.*
Relationships then, changed by illness are now impacted on by the absence of the husband from the family home. Only Mrs. Rigby mentioned a positive change to the relationship. Mrs. Howe said that it's just not being together just the companionship that we, we don't have all the time, yes I think that's it, there's a complete change in our way of life. It's this business of living alone that has caused this, if something was to happen I don't know what it would be like then, it could be even worse but...

The relationship between the husband and the wife had changed and for most, worsened. There were however, in the midst of this crisis, new relationships to be made.

6.3. Becoming ‘Family’ Phase

With the husbands’ admission to the nursing home, the busy process of caring altered. There was now time to think and adjust. Each wife found her own way to deal with this but all spent many hours with their husband, visiting most days. To implement visiting strategies, wives had to solve transport problems, find ways to pass the time whilst visiting their husbands, develop relationships with the staff and take a monitoring responsibility for their husbands’ care and treatment. During this time they all became part of a new family - the ‘Nursing Home Family’.
6.3.1. Visiting.

Wives spent many hours visiting their husbands. For most this was every
day or nearly every day. Others had set routines where they planned
visits to occur on regular days. Children and other relatives tried to help
out by visiting and sometimes this was appreciated and sometimes the
wife felt that she wanted to visit anyway.

6.3.1.1. Visiting almost every day!

Each of the wives spent a considerable amount of time at the nursing
home - for most every day or nearly every day. I visit him practically
every day, sometimes a couple of hours, recently, it's been a bit shorter
because I've had to go and do something else. Another wife come(s)
about half past eleven for a couple of hours...every day.

For some wives, such as Mrs. Rigby, the only days that they missed
visiting their husbands were days when they had other commitments,
such as doctors' appointments for themselves - the only days I've missed
have been when I've had, perhaps a, the eye specialist and I've had to fit
in with him and of course, um, you're with these specialists so long,
particularly with your eyes because you have to wait for drops to wear off
and all that and when I've got home I've been a bit out of sorts, and I
haven't gone over, but I've always told him the day before that if I didn't
get over I'd only be at the eye specialist so he wouldn't worry. Mrs. Smith
visits every day bar Thursday...that includes weekends...get here about
ten to twelve and leave about ten past three My son comes in on 
Thursday when I don't come in, he comes in.

Other wives had a routine which means that they visit on a regular basis 
but not every day. Mrs. Fraser used to come Mondays, Wednesdays, 
Fridays and Sundays and then if I found sometimes if I was asked out to 
lunch or I'd have to go out on a Wednesday I'd come on a Tuesday but 
he's just recently had a carcinoma removed from his face and I've been 
coming more frequently because um, you know, just want to see how he 
is. He's been so very heavily sedated, he had a local anaesthetic and a 
skin graft and the specialist said that he had to sedate him very heavily.

For Mrs. McDonald the routine was not quite as set as for Mrs. Fraser, 
sometimes it's four and five days a week, sometimes it's three days a 
week. I get a bit tired all the time, I just come in at anytime. I was up here 
Saturday and Sunday, and I missed yester..., no Sunday and Monday I 
was up here, I missed yesterday and I'm here today and tomorrow. 
Sometimes I get here at eleven o'clock sometimes it's quarter past and I 
stay with him while he has his tea.

Mrs. Howe saw her husband every day as she lived fairly close to the 
nursing home, she took him back to her home for a meal frequently:

every day I see him I don't have him every day for the midday meal. 
For instance today is my washday I don't have him on a Monday 
but I have him on Tuesdays. Wednesday is my art day and 
snooker day, so I don't have him Wednesday and then I'd have him 
after lunch on Thursday because on Thursday I go to spinning, and 
then he comes here on Friday Saturday and Sunday (pick him up 
at) about 10 (to). about half past four, there was one day I didn't 
see him what was that...oh yes I went to the art gallery for our 
Christmas party, so I didn't see him that day, so I bring him back
here and we'll have afternoon tea and he sits in that chair and relaxes...but if I went to visit him there this is what I would find very difficult cause you don't umm its very difficult to know what to talk about and cause this will, this will eventually happen where he'll be bedridden I suppose I don't know. I'll, I'll find that most difficult yes while he's still mobile its wonderful...sometimes I take him for a drive over to our daughter's.

Wives, it is clear, spent many hours still caring for their husband, even though the nursing home took over the main physical care responsibility. They did not consider the amount of time visiting their husband as a commitment, rather as something that they wanted to and enjoyed doing. Wives have a need for the company of their husbands and also a need to help with their care. This is not surprising since most of the wives have spent so many years caring for their husbands. Some of the wives have also found other things to occupy themselves in addition to spending some part of every day with her husband.

Many of the wives recognised that the amount of time, or the number of days, spent at the nursing home was not required or even needed by the husbands. It was however something that they wanted to do, not a commitment as such - although one wife admitted it makes me a bit tired but I get over it.

6.3.1.2. Assistance to visit

Assuming that visiting everyday was a burden children tried to relieve their mother of this perceived burden by arranging other visitors, suggesting their mother have a day off, or just filling in for them when
they couldn't make it: my grandson came in after work, cause I couldn't get here, the funeral was the afternoon, and you know it was late.

Sometimes this help was well accepted. For others though, the wife felt as though she just missed that opportunity to spend some time with her husband: Well now the girls have said, since Christmas, a couple of weekends, they've said Mum, Donna said I'll come on a Saturday and, if Mary can come on the Sunday, you have the weekends off. Well I, a couple of weekends I've had off, but I've sort of missed not seeing him.

For Mrs. Kaye it was a similar situation

ah, the girls rouse on me for coming in every day and they said mum you don't have to go every day - I said I know I don't have to go and I'm not even going out of a sense of duty, I want to go...when it comes around you know, 11 o'clock and that, I just want to come and see him that's all about it. I mean we've been together a long time...we've always been very close - well I naturally want to come and see him - that's why I'm happy that it only takes me 10 minutes to get here.

The wives, without exception, spent many hours at the nursing home, even if this was only on three or four days a week. They seemed to reluctantly accept limited help from their children or grandchildren, where this was offered preferring to visit themselves.

6.3.2. Transport

Contrary to what might be expected, none of the wives experienced great difficulty getting to and from the nursing home. Some of the wives had a car and had no difficulties, I had a car...I could be...I'd be lost without my car, and, where the wife was unable to drive or didn't have a car
themselves, the relatives, usually the son or daughter, would help and transport their mother to and from the nursing home, nearly every day. On rare occasions the wife would have to rely on a taxi or a bus, *my daughter brings up the car...yes her or [Raymond] picks me up...if they've got to go out urgent I get a taxi and then they pick me up of a night.*

Two of the wives lived close enough to walk and Mrs. Fraser had plenty of experience driving: *I drive...well I used to drive in the city for Meals on Wheels, it was a good initiation. I intend to drive as long as I possibly can, providing I'm still alright. Well I have driven round a lot and you know, we always, I always used to drive myself if I went anywhere. Well we used to take it in turns you know, if, if we went any distance at all, we'd do perhaps a 60 mile stretch each and you know we didn't get tired then.*

Mrs. Rigby worried initially that there would be a problem if her husband was admitted to a nursing home that was a long way from where she lived but she considered herself fortunate that the one he was put in was close to where she lived *it was a real nightmare to me, to wonder how I would get to see him if he was any distance away, and well of course when the bed and the room came up here he was admitted straight away.* Mrs. Keegan had a car and a back up if required: *I have my car and also (the nursing home) is on a bus route so I'd just get a bus if I really had too, if I didn't have the car.*
While a number of wives had cars and drove themselves, those who did not managed with public transport, or a lift from a son or daughter, to get them backwards and forwards to the nursing home, whilst others walked.

6.3.4. Passing the Time!

Generally, when visiting, each wife had her own routine and ideas on what she could and couldn't do to keep herself occupied. Some wives found that chatting to their husbands, other patient's relatives and other patients and staff was useful. Mrs. McDonald used to just sit and talk to him and he has a sleep and I read a book...and I just sit there and say come on eat it (his meals) and I start him off with it and then he'll eat it...I go round and have a talk to the other people.

Mrs. Howe read to her husband as conversation was difficult. I would read to him. He's got a book there 'Deal Me In' by David McNichol...he has written a couple of books and that's a pleasant thing. But as for conversation that is very strained.

Sometimes they would help with the day to day activities of their husbands, such as feeding. We feed them because they're very short staffed here and...they are very slow. Sometimes a little physiotherapy, I try, the elbow remains rather bent more or less permanently, I try to gradually ease the arm out so that the elbow is straight then I settle it on a table and I massage the fingers to try and straighten out the joints that are starting to curl up and I find it varies, sometimes they become very
flexible and relaxed and then for no reason at all, they curl up again...there’s some stiffening...I’m a bit nervous about doing anything else...because I feel I might raise it at the wrong angle...I’ve seen the therapist do it, and I’ve watched her.

Some of the wives helped with the nursing home activities program. I obviously talk (laugh), we have a cup of tea, tea and biscuits and then we go down to activities and...we play games...do a bit of cooking and say we’ll make this and that and I’ll...we play housie and drafts. Others tried to create a 'homelike atmosphere'. For example, Mrs. Rigby tried to create their usual routine:

I started off by going over about 3 o’clock and staying with him to his tea hour...so what I used to do, go over 3 o’clock about, take my knitting with me and then, tune into his programs, his tea would come at 5, and then I would stay...and then leave him with the program that he was used to having at home...now I go over sometimes in the morning and sometimes in the afternoon, I vary it a bit so that he sort of gets a bit of a surprise to see me or something like that just to make a bit of a difference to him.

Wives, generally, did not tend to share nursing home activities with their husbands - except for watching television and reading to their husbands. This arrangement seemed to satisfy the majority of the wives, maybe they just enjoyed the time together. Another wife suggested that she would have liked to do other things but wasn’t encouraged to do so, I’d like to (do things for other people), but I’m not allowed...I go round and have a talk while he’s asleep, talk to the other people.
Each of the wives had developed a routine that seemed to satisfy her. One thing they did have time for was to talk to staff when the staff had time to listen.

6.3.5. Developing relationships with the staff

Whilst at the nursing home for long periods of time the wife not only spent time with her husband but had the opportunity to develop relationships with members of the staff. The matron would often be available to speak to. The registered nurses and assistants in nursing would be friendly to the wives which, most of the time, proved to be extremely helpful.

6.3.5.1. The Matron

Relationships with the staff of the nursing home seem to be crucial in the wife feeling comfortable with the acceptance of the nursing home placement. Many of the wives described the nursing home as a home like environment and the staff were just like extra family members, and she {Matron} was quite wonderful and I found the whole nursing staff over there were just like an additional family. There was nothing stiff or didn't like about them, they sort of um, well just accepted Freddie and myself as a member of a big family, that's how I felt about it.
Much of this positive attitude began with the initial encounter with the Matron or Director of Nursing of the nursing home - the Director of Nursing was so helpful and you know she showed us right through and explained things and you know and she seemed to be very helpful and she always has been.

In the nursing homes where these husbands were residing the Directors of Nursing were seen to be both approachable and helpful, she's very helpful and she always, any queries or anything she encourages you to ask, and the Director of Nursing there is a very approachable person.

The matron, then was held in very high regard by each of the wives in this study and there were no complaints from any of the wives about the her, I've known the Matron ever since we've been here and I have a very high opinion of her, she's with the staff but she's always in charge and I like the Director and the Deputy Director, I liked them. I didn't meet the Director until [Barry] was actually admitted but I'd spoken to [Peter] who was the Deputy Director and he was very nice.

6.3.5.2. Other Staff

As well as the matron of the nursing home there are many other staff with which the wife came into contact on a daily basis. The whole of the staff are very good and helpful and they're so good, nothing seems to be a

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2 The terms Director of Nursing and Matron are used to describe the position of the person in charge of the nursing home. Each nursing home determines their own label for such a position, there is no difference between these terms.
trouble to them. Sometimes the contact with these people occurred more often than with the Matron, the sisters and the nurses, they're wonderful, this is a beautiful home and they're lovely, and it's always a pleasure to talk to the sisters and the nurses.

Positive comments, from the staff, about their husbands also helped the wives feel more comfortable, he's absolutely no trouble, all the nurses and sisters, the domestic staff, seem to have just taken him to their heart because he's a very gentle person. Mrs. Rigby was comforted by the staffs' attitude towards her husband: she said we all, you know, think the world of him, so that made me feel great because I felt even if I couldn't get over there occasionally, um, they would sort of nurture him a little bit or give him a little bit of ah. what he needed. Mrs. Keegan felt that the welcome they gave her husband on return from going out indicated their kindness, they're very kind and they receive him and they say hello John did you have a nice day and he always smiles at them and nods his head and they say come on John we'll put your jammies on and put you to bed and he just toddles off with them.

There was nothing but praise for the staff who had taken over the role of caring for the husband, I think the nursing staff they've got over there, I don't think they could be better. Mrs. Rigby and Mrs. Kaye, summed up the attitude that the wives had towards the staff of the nursing home and although Mrs. Rigby did not specify nurses, the atmosphere that she talked about included all staff:
the domestics have quite an input into the whole place because they, they might be doing the floors and they'll put their head in the door and say hello and they call him by name and he knows them all by name now and the domestic, the kitchen staff, now for instance, Matron said to me, if you ever feel like coming over and have a meal with your husband she said you do it by all means. Well if I put my head in the door of the kitchen and say would it be OK if I come over for lunch tomorrow? Oh welcome, yes you know, love to see you or that sort of environment you know, well I don't know that that would exist everywhere.

I fell oh well these (the staff) they're all my friends as far as that goes, and I've made friends with Mrs. Robinson and Mrs. R's sister and we often have a little chat about things that are going on, you know, just everyday things and they're really lovely people and so it's a pleasure to come here, you know I've got, I don't ever think, oh gosh, I've got to go, I've got to get ready and go, I've never felt like that.

It seems, then that the attitude of the staff, their friendliness and their acceptance of the husbands was crucial in the way in which the wives found comfort in leaving their husbands at the nursing home, they're very caring, very helpful and ah you know it's really very, they're very kindly too.

The fact that the husband felt happy was also important, he likes it here, and one husband was capable of telling his wife how good the nurses are, he tells me how wonderful the nurses are sometimes.

Relationships with all of the staff, therefore, were important to the wife. She often spent many hours with her husband who could not communicate well and to have someone else to talk to seemed to help. These relationships improved when the staff had good things to say about her husband. It is important to the wife that he was accepted and people were kind to him.
6.3.5.3. Problems

The staff seemed to be very good and almost all of the wives found little to complain about. The rare complaint seemed to be what could only be described as of a reasonably minor nature. One staff member, for instance, upset one of the wives by being too familiar with her husband: she was stroking his arm and this was in the dining room, and I had come to see him, she said oh he's my special fellow aren't you darling? And I just thought well what a cheek, she's intruding on my time...I was annoyed with her for saying he's my special fellow aren't you darling. I just felt that was an impertinence.

Another wife would have preferred her husband to have his own bathroom and a more comfortable bed. The only thing I have against it is that he hasn't got a bathroom. He shares with four people, that, that I thinks a shame and another thing is his bed. The rubber sheet underneath doesn't seem to be comfortable and the mattress itself is hard you think the poor old thing with his...and you know the cover that he has its a sort of doona and its really more like a quilt, it would be nice to have say two blankets and maybe needing one blanket one night and two another night, but he has just this one quilt that he puts over.

6.3.5.4. The nursing home environment

It seems that the physical environment was also important for the wife to feel comfortable with her decision to admit her husband to the nursing
home. The environment of the nursing home has been described by each wife and all agree that these particular nursing homes were very comfortable (apart from minor comments), it was the one I liked best because as I said it looked like a motel walking in.

Cleanliness and a home-like environment were valued. He always looks clean and his bed's lovely and everything and a homelike environment, the whole environment is like a home. These were significant factors, they keep it beautiful it's the nicest place I've visited and I've visited a lot... Homeliness, that was the first impression I got... it's become stronger. Mrs. Fraser was encouraged to help make her husband's bed more homely:

my son brought in a doona you know, so I brought that in and put it on his bed which they didn't mind, they try to make it look more homely don't they by just putting different you know, even if it's a quilt or something just to give it more of a personal touch, and now I can sleep at night knowing John's warm.

6.3.6. Taking Responsibility

When the husband was a resident in a nursing home there were other responsibilities that may have been addressed before but now became more important. Being an advocate for her husband with medical treatment, asking for particular treatment options, like physiotherapy and also handling the finances associated with the nursing home, were examples of changed responsibilities.
On many occasions the wife would have to take responsibility for decisions about her husband’s illness and medical treatment: I felt that, they were sedating him too much, being Valium, I spoke to the doctor about it, they knocked off the Valium. For Mrs. Fraser the decision about treatment was hers alone, I was worried at the time, I was under strain because I had to decide on his carcinoma being operated on you see.

There were many occasions also when wives mentioned that they had to be an advocate for their husbands. They had physiotherapy only once a week there I think from memory, only once a week, and I felt he needed more than that so I asked if I could see the physiotherapist who went there to arrange for private sessions for him.

Sometimes the wife had to be the information - giver when her husband wanted answers, I said to him one day, I felt I had to be honest with him, I said, it’s not ever going to get to what it was Freddie...and this is what I tried to tell him. Mrs. Pearce had some major decisions to make in regards to her husband’s possible cancer and the subsequent treatment. For someone who had been under a lot of strain this was not easy for her:

He’s always been you know, sort of fairly heavy and then about a couple of months before Christmas I thought, he’s losing an awful lot of weight, it just seemed to be falling off him in front of me so I went back to the doctor and I said look, I said I’m worried about Barry, I said I know he’s not eating as much as he was but I still think he’s losing too much weight and when he saw him he said mm, he’s not very well is he?...they decided he had cancer of the liver...so I didn’t tell him. I rang my brother...I rang him and read out the report...I said they want to do a biopsy...now I don’t want to put him in a situation where I let him go downhill if I can help I said but my attitude is, he’s not well at the moment, he is going downhill
rapidly. If they find that it is cancer when they do a biopsy, liver operation is a very big operation. I said I've considered whether I would put him through that or not I said but at the end of the road we're still up against the Parkinson's and I said it's the Parkinson's that's taken away the sort of value of his life...so we didn't have the biopsy...I got the feeling that the doctor didn't think he was going to live very long.

There was only one instance mentioned, where the wife was placed in an awkward situation regarding finances. According to Mrs. Pearce it was because she was not on the aged pension:

when I got to the nursing home they asked me if we were on the pension and I said no, we were taken off last year because we're just over the pension limit now. Well that was alright and I had to give the bank account and that sort of thing to take the money out and em, and then they said to me that his back was sore, would I buy a mattress - over $400...and I thought - that's odd - you know in a nursing home. They wanted a water - one of these sort of water beds and things like and I'm still not sure whether it's because - he, he took me to show me one, they had one and he told me that they had gone to, oh what do you call them, people who sort of look after nursing homes, you know the committee to get some money to buy one...so I thought well why did he have one bought and you're asking me and I wondered then if it was because I wasn't on the pension?...Financially it has been very difficult.

Wives became part of the nursing home family over time. Most agreed that this was important to them especially since they spent many hours at the nursing home. The 'family' included other residents and visitors, the Matron, nurses and other staff. The pleasant nursing home environment was also mentioned as being an important contribution to the 'homely atmosphere'. All wives were very happy with the nursing home in which they had placed their husbands.
6.4. The Adaptation Phase

The Reality Stage has included the phases of being ‘Torn Apart’ where the physical distance between the husband and wife had caused devastation, loneliness, guilt, sadness and grief and changes in the husband/wife relationship. The second phase in the Reality Stage was Becoming Family where wives found new relationships in the staff and other people associated with the nursing home in which their husband had been placed. This was important as the wives spend many hours at the nursing home nearly every day.

This phase the Adaptation Phase includes long term aspects of the placement, such as the on-going support from family and friends, wives acceptance of the situation and their health issues. This phase also includes coping strategies, their own accommodation choices and other informal support.

6.4.1. Family and friends support

There were many people who were supporting the wife at this stage, some to a greater extent than others. Children were a great source of support at this time. Some of the wives are living with their children, other children provide transport, interact with the doctors, try to care for their mother as well as their father and generally act as a support person. Some family and friends are also elderly themselves and that, of course, makes it very difficult: when I was in a bit of trouble I would say to her oh
what do you? (laugh) and she's helpful, she's older than I am and she's almost blind but she's been, you know she can obviously, she's got her wits about her.

Talking about their problems to someone helped, we talk things over and perhaps if we had something that...or we feel worried about, and this was particularly helpful if they had been through a similar experience themselves, it does help doesn't it, (knowing what) others are going through.

The telephone was a useful way of keeping in touch with the rest of the family and close friends as Mrs. Howe discovered.

Phone calls are wonderful, you know with their mobile phones now he (son) might be travelling back from a trip interstate and he'll ring me on his way home, so that's always a pleasant surprise. (Daughter) works over at Blacktown twice a week and she calls in on her way home that's always pleasant in the afternoon. My sister whom I'm very close to who lives at Forbes, and we keep in touch once a week. We have a good old chat on the phone we don't worry about the cost of the call now we just relax and have a nice chat.

Other people tried to visit the resident in order to provide support for the wife, the children tended to try and support their mother and father by visiting regularly. *They'd come in, one son used to come in every day there for a while, forgo his lunch you know, come in to see his father and now he comes once or twice a week.*

Other friends and relatives were also elderly and some had their own health problems which meant that their visiting was more spasmodic.
when his sister and them comes up here they're the same, they like it very much... They were up here on Monday... she's very sick Jane. she's got something wrong with her stomach and she gets up here, well Amie's got another sister in another nursing home, she's only got one leg and they have to go and see her too.

All of the wives in this study had children and other relatives and friends who were willing and able to provide support for them, such as visiting their husbands and to talk to. Sometimes our son comes in, he'll look up at him, Jack doesn't look up much does he? And he'll look up at Barry and he puts his hands out to hold it and Barry sits there and holds his hand all the time. One can only wonder what happens in circumstances where there are no children, or the children are unwilling to help and there are no other relatives or friends to help out.

6.4.3. The Result of the Experience.

This experience then had been a difficult period for the wife, the husband, the children and many other associates. The wife, however, was the focus of this paper and it was to her that we looked for her ability to cope with this experience. There was an acceptance of the situation of having to place their husbands in a nursing home, health issues for themselves, coping strategies, changes in accommodation and informal support that become important in this part of the experience.
6.4.3.1. Acceptance

There was a general acceptance by all of the wives that the placement of their husbands in a nursing home was the only option that they had. No one felt that the decision had been taken without their consent.

Most wives wanted to care for their husbands at home as long as they could. When the time came to place their husbands in a nursing home each wife realised that they could not cope any longer, *but then, you know, I kept him at home as long as I could*, and accepted this placement as somewhat inevitable, *it was just that ah, you know it just got a bit much and then of course I was still, you know, trying to think that I could look after him but I realise now that I couldn't.*

Generally, wives were quite reassured within themselves that they had taken their only option available to them, even though they would have liked to have kept their husbands at home longer. For some of the wives, the acceptance of the situation and the ongoing satisfactory experience encouraged the notion that the original decision had been a correct one. Mrs. Kaye, for example, recognised that Mr Kaye was better off at the nursing home, *oh well I just know that I couldn't have him back because even to have him at my daughter's 3 weeks ago and there we were standing you know 3 feet away from him and he had a fall, you see, and that can happen any time.*

The husband was reasonably happy at the nursing home and this reassured his wife again that she had done the right thing by placing him
in the nursing home, well I think he'd be more happier than he would be at home because they do everything for him I mean I couldn't be sitting alongside of him all day. The wife was happy about the care that her husband was receiving and that also reassured her that she had done the right thing, at least we can be grateful that they're well cared for. There was a reassurance that each husband was well cared for which led to a general acceptance of the entire situation.

The wives undoubtedly feel very sad that their husbands had to be admitted to a nursing home but they feel that there was no more that they could do. It is important to them that their husbands are well cared for and for that they are extremely grateful. The general health of the wives improved after the admission of their husbands to the nursing home as each wife now did not have to cope with the intense physical exertion required by a carer looking after a chronically ill person at home.

6.4.3.2. Health Issues.

Wives also mentioned that they had noticed an improvement in their own health since their husbands had been in the nursing home - I felt myself getting a little bit stronger. For some the health improvement was a direct result of a relief in care burden. Since Mr Kaye had been admitted:

I haven't been lifting him up and trying to get him off the floor occasionally, but even trying to lift him up out of his, he had the Don recliner but ah!, I used to be having physio all the time on my back. I had these sciatic pains going down my legs and everything and my back and ah! since he's been in here I haven't had to take one tablet or have any physio. You know because there's no strain on
my back from lifting him because even though he's a tiny man, he was a dead weight.

For Mrs. Howe, who had a major illness, it took a period of time and some considerable professional assistance before her health improved. I had my meals made for me and even the washing was done so all I did was get back my strength, I was terribly thin, everybody said I looked dreadful, and gradually after nine weeks I think it was there, I was moved over to here.

These wives had an illness that was probably directly related to their caring role. They needed relief from that caring role until they recovered from their illness. The children however, saw the chance to relieve their mother from the role of caring for their father at home and placed their father in a nursing home.

6.4.3.3. Coping or not coping?

There were comments from the wives about how they could have coped better with the whole experience, when John was at home I used to say I'm not really coping with this I really should be able to cope with this better.

One of the major issues in the perception of coping was a lack of knowledge on caring:
things like holidays and going away and visiting and all that I didn’t understand what was going on and I think that’s the problem with a lot of people who are in this situation they really don’t understand and they’ve had no training so they don’t know how to cope and they don’t know what to do so they learn by if they do it this way it doesn’t work so they do it another way...but um finally you find out how to help.

Mrs. Keegan would have really liked some information from the professionals in regards to caring strategies: *I just really would like to know how to cope better than I am coping it’s sad sad...I try to do all the normal things and ahh having John in the nursing home I’m a bit freer now than I was and I do go to town occasionally but I really would like to have a pattern of knowing how...I find that very difficult to cope with and I just don’t quite know how to cope with that so that it’s not going to wear me down.*

It seems these wives are expressing a lack of knowledge about how to cope with the difficult situation that they find themselves in and a desire to have someone whom they could talk to, in a professional way. The wives are coping admirably, but perhaps, some professional assistance would be of great value to wives who find themselves in this situation.

**6.4.3.4. Accommodation choices for the wife.**

One of the major adjustments prior to or following admission of the husband to the nursing home had to do with accommodation adjustments. Some who were living in their own houses with their husbands prior to his illness or hospitalisation had moved recently into a smaller house or unit: *in the meantime we sold the house we were in and*
moved into a unit because we thought it would be easier to manage in a
unit and um...that was quite a trauma because looking back I realise now
that he didn't quite understand what was going on. For some, bigger
houses had proved difficult to maintain by the wife on her own - I have a
lovely, very small unit. We've had to condense you know with each move
we've made, this one was worst of all, I had to go through all my
husband's paper and old records that he'd kept stored up and I didn't
know what to do with them.

For some wives accommodation choices require additional coping
strategies at exactly the time she is coping with all of the other problems
surrounding the husband's admission: my biggest problem is looking after
the home and everything, it's a big house, 2 storey place you know, my
grandson mows the grass for me you know. Often this indicated moving
to smaller, supportive accommodation: living in a village was a solution
because it would have meant that I'd still be living at Mount Colah and
coping with a big house and garden and, it was all too...they, the family
could see it was all too much for me.

For Mrs. Pearce the selling of the family home upset her husband and
she had to be careful about how she approached the subject with him:

when, I sold the house...we were so pleased that we had sold it and
when I went into the nursing home I was telling them there and then
I told Bill and I thought drat, I shouldn't have done that, I shouldn't
have told him...I shouldn't have done it...because I said he's
thinking of home. In his mind this is home. So I thought oh right, I
said look, immediately we move into our new home I said I'll take
you home.
Of those interviewed, only one - Mrs. Kaye - had not found her living arrangements difficult since her husband had become ill. She enjoyed living in her house with its big garden:

"he hasn't been able to do anything for about oh, 9 or 10 years I suppose, and people say to me - oh are you going to stop in your home? You know you've got a big garden and this, that and the other and - I said well I think that's what keeps me healthy, if I, if I feel a little bit down I just go outside. See I came from an orchard, I think it's in my bones, the soil, and I, I love to get outside. I do have a nice garden so it doesn't make any difference."

So, each wife has had to make choices regarding her own future and, in most cases this has meant selling the family home, just prior to or after she has placed her husband in the nursing home. This, again has had a tremendous effect on the wife and has created just another problem for her to cope with.

6.4.3.5. Informal support

Some of the wives found support from other spouses in the nursing home quite satisfying: we talk things over and perhaps if we had something that...or feel worried about...it does help doesn't it, knowing what others are going through.

One wife mentioned the meetings that they have at the nursing home for relatives, they do have a meeting from time to time for um residents and relatives and you can raise matters that err your not happy about at the meeting and err in between times if your not happy about something you can raise it with the staff or the Director of Nursing.
This reality stage\(^3\) includes the torn-apart phase where devastation, loneliness, guilt, sadness, grief and changes in the husband/wife relationship occur. The becoming family phase is where the wives began to develop relationships with other visitors and staff in the nursing home and finally, the adaptation phase, where there was a general acceptance of the situation and the problems associated with it were addressed. This stage is demonstrated in the following diagram:

\[\text{Reality Stage}\]

6.5 Summary

The wives, in this study, have been through a difficult period of caring for their husbands on a daily basis. They have also made a difficult decision to place their husbands in a nursing home. The stage addressed, in this chapter, follows these pre-admission and admission periods and is called the post-admission period. The post-admission period includes the Reality Stage incorporating the 'Torn Apart' Phase, the Becoming Family Phase and the Adaptation Phase. This Reality Stage is where the wife

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\(^3\) The reality stage is a recognition that there is a new reality about the situation in which the wife finds herself. Each stage could be classed as a reality in its own way but this stage signifies a realism about the husband’s illness and the pathway that the whole situation is taking.
copes with the finality of her husband being placed in a nursing home, there is the wrench of the separation, relationships that are developed and adaptation to the new circumstances.

The feelings associated with the separation of husband and wife are aptly described by one wife as being 'torn apart'. Being 'torn-apart' led to other feelings such as devastation, loneliness, guilt, sadness, grief and changes in the husband/wife relationship.

The becoming family phase had some positive benefits for the wives as they developed relationships with the staff, other visitors and other spouses. In almost every instance this was extremely helpful to the wives in this study. The wives coping with the adaptation phase were assisted by family and friends. There was a general acceptance of the situation by the wives as they, without exception, realised that they could no longer cope at home caring for their husbands, the wives felt that their decision to institutionalise their husbands was confirmed by the husbands' contentment at the nursing home and their improved health since the admission. whole experience can be summed up by the following diagram:
The Experience of Wives Following Admission Of Their Husband In A Nursing Home.

The Role Change Stage

Busy phase

Early phase

Effects of change phase

Becoming single phase

Transition Stage

Initial contact phase

Critical event phase

Introductory phase

Reality Stage

Becoming family phase

Torn apart phase

Adaptation phase
CHAPTER 7 - SUMMARY AND CONCLUSIONS

This chapter overviews the important issues developed as an emergent theory in this study. It also considers the importance of the study as an addition to the literature of the significance of the experience of placing one's husband in a nursing home. The relationship of the study to nursing practice is also explicated.

This thesis has reported on wives who have experienced their husbands' illness and eventual nursing home placement. These wives were looked to as a means of understanding what it is like to care for an ill spouse and eventually have to place him in a nursing home. The perceived benefit of investigating this experience was to increase nurses' knowledge in order to provide an understanding of the whole family situation when caring for the husband in a nursing home.

This thesis would be important even if only to be experienced by one couple, however, it is indisputable that the number of older people in Australia will increase substantially over the next few years, to a total percentage of the population of approximately 22% in the year 2028 (Australian Bureau of Statistics 1997). Many of these older people will be married and most married couples will have the support of one or more child (Australian Bureau of Statistics, 1997), the majority of these older people live quite happily in their own homes.

This study involved a group of people, increasing in number, who were aged 65 years or older who, within the demographics above needed to face an increasingly common experience - namely that of placing their husbands in a nursing home. Understanding of this experience was
sought by the method of qualitative research using a modified grounded theory from a symbolic interactionist perspective. Interviews were conducted with wives who had placed their husbands in nursing homes in the preceding twelve months.

7.1. Overview

This chapter will not repeat the findings reported in the previous chapters. Rather a number of themes and issues which have surfaced will be discussed. The potential number of issues is large and previously outlined in the form of stages. The Role Changing Stage has been described as that where wives have to deal with problems associated with their husbands’ illness - memory loss, personal hygiene needs, incontinence, falls, confusion and wandering among other problems. It is in this stage too that wives take over the day to day activities that the husband used to look after, find time for her own social activities, become a carer and take on the associated problems of increasing burden and negotiating the use of support services.

The Transition Stage follows. Here a critical event occurs and the couple finds themselves separated, with the husband in a nursing home and the wife living alone (typically) in the family home. The subsequent issues surrounding nursing home placement - the first impressions of the nursing home, changing the wife’s role again, from that of care provider to that of care co-ordinator and the effect that this placement had on the husband - are also part of this transition period.
Wives described the feelings of devastation, loneliness, guilt, sadness, grief and changes in the husband/wife relationship following admission. I have conceptualised this stage as the Reality Stage. There were many hours spent visiting their husbands in the nursing home which also had some benefits in developing relationships with the staff and other visitors at the nursing home. Confronting reality led over time to the Adaptation Stage where the wife became somewhat resigned to the situation that she found herself in. With the help of family and friends, wives began to adjust their lifestyles to accommodate new circumstances. Some wives made alternative accommodation choices as a significant act in this Adaptation Stage.

These issues and themes will be discussed under the natural progression of wives' experiences: pre-admission, nursing home placement and after placement adjustment. In doing so the issues of family help and nursing care will be highlighted.

7.2. The Findings of the Study.

As has been documented in this thesis, the institutionalisation of a husband is a devastating experience and its effects are quite exhausting for wives. The whole episode can be divided into the pre-admission experience, the actual placement, and the after placement feelings of loneliness, guilt, sadness and grief.
7.2.1. Pre-admission.

The women in this study managed quite a variety of problems before the decision was reached to place their husbands in a nursing home. Many of these problems, related to the husband’s illness, parallel those reported by Isaacs (1971) - memory loss, minor difficulties (for example, shuffling feet, being unable to clean teeth), failing mental abilities, incontinence, immobility, confusion and wandering. The pre-admission experience was more than this however and, if these problems had been isolated ones wives could have continued to manage.

Other difficulties tended to add to the situation of the husband’s illness at this stage. These difficulties related to taking over responsibilities that the husband once dealt with himself (such as financial matters); finding time to relax and attend social activities, protective and monitoring activities (such as having the husband’s driver’s licence revoked) and taking him to numerous doctors appointments.

Whilst these difficulties were being experienced, coped with and worked through, the husband’s illness was deteriorating which increased the husband’s dependency on the wife who is now becoming more like a carer than a wife. An increase in the sense of burden and an increase in the need for support services - both professional and family support - result.

The pre-admission stage can thus be characterised by the phenomenon which can be termed ‘absolute and utter exhaustion’. This
phenomenon is a combination of a number of different problems, not all of which were related to the husband's illness.

In support of these findings, a range of studies that have previously been conducted with carers include many different and varied effects. Isaacs (1971), for instance, reports that the elderly were generally looked after at home until the patient's disabilities became so overwhelming, that they (the carer) could no longer manage. Isaacs (1971) also stated that there were three main reasons for admission to a nursing home - factors in the patient (for example, incontinence), factors in the carer (such as their age and physical condition), and factors in the carers' life space such as other sick relatives and the surrender of employment.

In this study the wives/carers were in a situation where they could spend as much time as was needed with their husbands and it was the problems within the husband's and the wife's own age and physical condition that seemed most important. Overwhelmingly, it was a combination of these two factors, and not one exclusively, that became the central issue leading to nursing home placement.

Interestingly, Barber and Pasley (1995) found that unlike caring daughters who had problems with family relationships, the wives' main problems were restrictions in social activities. This finding is not strongly reflected in this study. The restriction of social activity was only reported by one particular wife who couldn't go and have a game of golf or entertain guests or go out to dinner.
Chapter Seven – Summary and Conclusion

The difficulties in the Role Changing Stage of pre-admission experience are not singular or isolated and sometimes not even identifiable. Rather, it is a combination of many factors which range from the physical aspects of caring for an ill spouse, the age and health of the carer and the past experiences of the carer with nursing homes which are the basis of experienced difficulties. Wives have considered, interpreted and synthesised information available to them, they have attached meaning to the situation that they are in and based on this information, as well as the physical and emotional exhaustion that they are suffering from, made a decision to place their husbands in nursing homes. This decision as has been shown was often at the urging and with the encouragement of their children and other family members.

7.2.2. Nursing Home Placement.

It is clear that all of the wives in this study experienced great personal stress at the time of placement - described as feeling torn apart, being terribly depressed and feeling devastated. There is no doubt that the strength of these feelings made the placement of their husbands in nursing homes one of the most traumatic times of wives' lives.

The trauma associated with placing a spouse in a nursing home is a well documented theme in the few studies that have also been carried out in this area. Grau et al. (1983), for example, examined the aspect of demoralisation and depression in relation to family members and noted that all experienced significant burden and other stresses. Wives,
according to Rosenthal and Dawson (1991), experience depression, low morale, poor health, sadness, loneliness and guilt and Kaplan and Ade-Ridder (1991), focussing on the impact on the relationship when one spouse has to move into a nursing home, found that the spouse, in this situation, has problems that are unique to them. Changes in the husband/wife relationship, how the decision was made to place their spouse in a nursing home, support systems and adjustment to living alone, are such instances.

7.2.3. After Placement Feelings

In this study, women are older (average age 74.5 years) and mostly living only with their husbands up to this point. The dramatic changes in circumstances may serve to increase the devastation of the experience of placing their husbands in nursing homes.

After placement, the initial response of women in this study was emotional - loneliness, sadness, grief, and less obviously guilt. This is in line with Rosenthal and Dawson (1991) who, when considering wives of institutionalised elderly men, found that guilt, anger, sadness, resentment and loneliness were common in the early stages after the admission of their spouses to nursing homes.
7.2.3.1. Loneliness

The one emotion felt and experiential that was experienced by the wives in this study, more than any other, was the feeling of loneliness. Given that Mr. and Mrs. Rigby had been married for 39 years, it is not surprising that loneliness, experienced as looking at the empty bed at night when I was going to bed, was a dominant response.

Some of the literature, for example Davis and George (1993), mention that loneliness is one of the major problems associated with placing a loved one in a nursing home. Rollins, Waterman and Esmay (1985) also mention that aloneness was a characteristic of 'married widowhood', with an emphasis on the emptiness of the home.

7.2.3.2. Sadness and Grief

The after placement emotions of sadness and grief were best described as an ongoing funeral where the husband is not physically dead but he his not the same person that he used to be, he is not the husband that she married, he has changed. Wives also expressed the feeling of ongoing grieving in that if their husband had died, they would have been able to grieve and complete the process, but the grieving associated with nursing home placement is not able to be expressed in the same way.

The grieving is unresolved because the wife continually sees this person who is still her husband, but is no longer the same person. She is not
able to have a husband/wife relationship with this person who is still legally her husband. Not surprisingly the sense of loss and related grief processed lead to ongoing sadness that cannot be resolved. Kaplan and Ade-Ridder (1991) described the situation for three non-institutionalised spouses and found that “having a spouse in a nursing home is like having a husband, and at the same time, not having a husband” (P.93).

As a relationship develops over time there is, according to Wade and Waters (1996), a mutual exploration, disclosure, acceptance and adaptation in a couple relationships, and that the couple develop meaning and identity from this relationship. As the relationship ends - one partner moves to a nursing home - there is a loss of that meaning and identity which is part of the person. This leads to a sense of losing the partner and also losing a part of oneself.

7.2.3.3. Guilt

In most instances there appeared to be some guilt emerging post-admission, sometimes explicitly expressed, sometimes not. Many expressed some guilt in the reasons they gave for visiting their husband on a daily basis. Guilt was expressed when the timing of the decision to place their husband in a nursing home was referred to, with many saying that they wanted to be able to cope longer, or thought that they should have been able to cope more effectively.
7.2.3.4. Changes in the Husband/Wife relationship

It is no wonder that women find great difficulty in new situations such as nursing home placement of their husband, as traditionally men have been the breadwinner and provider and women have fulfilled the social, emotional and nurturer roles (Anderson, Earle and Longino 1997). Ageing itself has brought new roles. If one considers disengagement theory where older people decrease their interaction with others and withdraw from society (Fennel, Phillipson and Evers, 1988), the wives in this study have been required to do the opposite to this by increasing their contact with many members of society with which they had no previous contact, for example doctors, hospitals, community services, social security.

Central to arriving at an understanding of the experience of wives in this study was the way in which relationships between the husband and the wife changed over time. Changes that stem from the illness itself, which in some cases, caused a change in the husband’s personality. Secondly, the disease process too caused a change of role from wife to carer to care co-ordinator. Finally, when the husband was admitted to the nursing home, the wife took on yet another set of different roles - she became visitor, patient advocate and in some cases, organiser of her husbands’ activity program. The wife also became the person who gave information to the rest of the family and sometimes helped in the day to day care of her husband.
7.2.4. The nursing care.

The standards of nursing care were important issues for wives in this study. Satisfaction with that care was extremely high and in part this was due to the relationship that each wife developed with the staff.

7.2.4.1. The care received

Each wife had managed, in some cases, for many years with the day to day care of her husband. It comes as no surprise that the care that the husband received was of great importance to the wife. Over the years the wife had developed a good routine and, in most cases, became an expert in the handling her husband’s particular needs. This care has now had to be ‘handed over’ to others and the wife has become the ‘care co-ordinator’, informing the staff about her husband’s likes and dislikes, peculiarities with care routines and his abilities and disabilities. This care co-ordinator role is vital if the transition from home to nursing home is to be smooth.

The care of the husband in the nursing home has become a partnership between the nurse, the resident and the wife. Christensen (1993) described her model for nursing practice as a nursing partnership which is a relationship that develops between nurses and their clients. The situation within the nursing home setting involves one additional person - the carer - in this instance
7.2.4.2. Satisfaction with the care

All of the wives were generally very satisfied with the nursing home environment, the staff and the care that their husbands received. This satisfaction was expressed in familiar relational terms, for example - one wife described the staff as being like additional family, they just accepted (us) as a member of a big family, they’re all my friends and they’re really lovely people.

This research would agree with that of Rosenthal and Dawson (1991) who found that the wives reported feelings of satisfaction with the arrangements for their husbands’ care, there was overwhelming support for the staff being caring and trustworthy, doing a good job, making the patient happy and comfortable and knowing who to contact.

Satisfaction with the care received by the resident should not surprise us, investigations of satisfaction with health care (Rosenthal & Dawson, 1991; Hill, 1997) traditionally report high levels of satisfaction.

7.2.5. Family Help

Garrett (1983) reports that even though the contact between family members is less intimate in old age there is still a lot of it. Kendig and McCallum (1988) also state that the vast majority of older people have close ties with their children and grandchildren. These findings are supported in this study where many people were mentioned - sisters,
brothers, cousins, friends - as being supportive to the wife during this whole experience of admitting her husband to nursing home care. In particular, the couple's children were extremely supportive, with both sons and daughters providing encouragement to their mother and physical and emotional support in selecting and moving their father to the nursing home.

There is support in this thesis for the argument by Kendig et al (1983) that the generations are mutually supportive.

7.3. Application of the findings

Nursing homes are considered the resident's home and as such nurses working in them are concerned about their elderly residents and their immediate family. The family have previously lived with the resident and therefore, close to them. Many of the residents of nursing homes are unable to communicate their needs adequately and it is the information from the close relatives that helps to create a homelike environment and normal routine for the resident.

7.3.1. The link between home and nursing home.

The family, the wife in particular, becomes a vital link between the previous living situation and the current nursing home environment, their information is often required to determine the resident's food
requirements, normal activities of living needs and to create a history for the resident in terms of health problems and family and individual identity. It therefore becomes obvious, that the role of the wife of the resident in the nursing home is a critical component of nursing care. This relationship between the previous carer (in this situation the wife) and the nursing staff therefore, becomes an important aspect of planning care for the resident.

In the development of this link between the resident’s past and current situation, the wife and the nurse develop an alliance in order to provide the best possible care for the resident. It is within this alliance that the needs of the wife become well known, and therefore a concern for the nurse as a source of information about the resident, and the nurse can act as a support for the wife.

7.3.2. The Staff/Wife Relationship

The relationship between the family and the nurses in a nursing home situation becomes somewhat more intense than relationships in other areas of nursing as the family is in contact with this staff who are relatively stable and the family who are often involved in the nursing home for many months or years. The staff and family are involved in outings, celebrations like birthdays, Christmas and other important occasions, even attending the resident’s funeral when the time comes. This relationship therefore is an emotional one as well as a needed one for the health and welfare of the resident.
As the care of the resident then should be ‘holistic’, that is encompassing the physical, spiritual and intellectual, emotional, environmental and sociocultural dimensions of the person (Taylor, Lillis, & LeMone, 1997), information regarding the past experiences of both the resident and their wife leading up to the placement of the husband in a nursing home helps to fill the gaps in knowledge that the nursing home staff may have and the wife could and should be used as a consultant in that way. This knowledge is not able to be gained easily and it takes research such as this and others, to gain an appreciation of the problems and experiences that the wife may have had to endure previous to the admission.

The idea that the wife may be suffering from the effects of the past few months or years, needs to be taken into consideration when discussing the needs of the husband. Reassurance about various aspects of his care and the availability of the staff to discuss aspects of the husband’s care is also important at this stage and it is obvious from the results of this research that this is occurring in the nursing homes that are included in this study.

7.4. Limitations of the Study - Need for Further Research

It is important to note that there are a number of limitations on this particular study, one is the selection of respondents. Wives were selected by the Director of Nursing of the nursing home and it would be obvious that the Director of Nursing would ask the wives that she would
see most often, these are the wives that spend a considerable amount of time at the nursing home.

Secondly, the type of nursing home selected may affect the results of the study. Nursing homes that were approached came from a particular type of nursing home, that is, private not-for-profit in the north western area of Sydney, this may also affect the results of the study.

It would be interesting to conduct a further study specifically targeting the private for profit nursing homes to see if the results are similar, one would envisage that the experience prior to placement would be similar, but from admission the actual experience of the nursing home and staff may be different.

Groups of people that were not included in this study are the men, daughters, sisters, brothers and friends who have cared for the new nursing home resident up to and including the admission, and who have difficulties that need to be identified. The indigenous and ethnic groups are also a significant section of the Australian community who could benefit from research such as this. There were unfortunately, limitations on this research that leaves gaps in the knowledge that has been gained from this research.

Further research is required in the area of aged care, and it is hoped that further research based on the needs of people in nursing homes and their families is conducted in the near future as older people are increasing in number and their problems are also increasing. This research should
also take into account the experience of the carer prior to and during the placement.

7.6. Conclusion

The elderly population in the Western Countries of the world is increasing rapidly and the problems associated with caring for the elderly in such great numbers has not been addressed. Very little research has been attempted in the specialty area of Gerontological Nursing and, with increasing numbers, much has yet to be achieved. This research was conducted in order to contribute to the scarce knowledge that nurses have of elderly people and their families.

This thesis has identified some of the factors that contribute to the difficulties that wives may have in placing their husbands in nursing homes. The basic stages of Role Change, Transition and Adaptation gave the researcher some understanding of the changes that take place in the life of a wife when she has to face the problem of placing her husband in a nursing home.

The phenomenon of 'absolute and utter exhaustion' has been identified as the contributing factor to all nursing home admissions in this study. It is not a single identifiable factor, but a combination of many circumstances, not the least of which is the physical exhaustion that the wives found in caring for their husband for as long as 35 years. The critical event was also an important factor in the process as it indicated a
breakdown in the everyday routine in the care of a husband with a chronic illness.

The words of the wives themselves are seen as a fitting conclusion to the study.

*torn apart, on going funeral, absolutely devastated, terribly depressing...it’s just so depressing, lonely of a night...so lonely isn’t it?, it’s so hard now without them, it is...it’s just so sad*
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References


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References


Sheldon, F. (1982). Supporting the supporters: working with the relatives of patients with dementia. Age and Aging, 11, 184-188.


Appendix 1

PARTICIPANTS' CHARACTERISTICS
<table>
<thead>
<tr>
<th>Wife's age</th>
<th>Husband's age</th>
<th>Illness</th>
<th>length of illness</th>
<th>number of children</th>
<th>length of marriage</th>
<th>Name given to couple</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) 68</td>
<td>75</td>
<td>Cancer of the bowel</td>
<td>3 months</td>
<td>3</td>
<td>44 years</td>
<td>Mr &amp; Mrs James</td>
</tr>
<tr>
<td>b) 77</td>
<td>88</td>
<td>Parkinson's Disease</td>
<td>20 years</td>
<td>1</td>
<td>53 years</td>
<td>Mr &amp; Mrs McDonald</td>
</tr>
<tr>
<td>c) 73</td>
<td>67</td>
<td>Parkinson's Disease</td>
<td>8 years</td>
<td>2</td>
<td>30 years</td>
<td>Mr &amp; Mrs Pearce</td>
</tr>
<tr>
<td>d) 82</td>
<td>76</td>
<td>CVA</td>
<td>12 months</td>
<td>1</td>
<td>39 years</td>
<td>Mr &amp; Mrs Rigby</td>
</tr>
<tr>
<td>e) 79</td>
<td>83</td>
<td>Alzheimer's Disease</td>
<td>18 months</td>
<td>2</td>
<td>53 years</td>
<td>Mr &amp; Mrs Fraser</td>
</tr>
<tr>
<td>f) 74</td>
<td>76</td>
<td>Alzheimer's Disease</td>
<td>3 years</td>
<td>2</td>
<td>53 years</td>
<td>Mr &amp; Mrs Smith</td>
</tr>
<tr>
<td>g) 71</td>
<td>70</td>
<td>Parkinson's Disease</td>
<td>20 years</td>
<td>4</td>
<td>49 years</td>
<td>Mr &amp; Mrs Keegan</td>
</tr>
<tr>
<td>h) 76</td>
<td>85</td>
<td>Pagett's Disease</td>
<td>35 years</td>
<td>4</td>
<td>57 years</td>
<td>Mr &amp; Mrs Kaye</td>
</tr>
<tr>
<td>i) 71</td>
<td>73</td>
<td>Parkinson's disease</td>
<td>12 years</td>
<td>3</td>
<td>45 years</td>
<td>Mr &amp; Mrs Howe</td>
</tr>
</tbody>
</table>
Appendix 2

INFORMATION SHEET
My name is Lynne Brown and I am a nurse and a mature age student at the University of Western Sydney, Nepean undertaking research at the Masters level.

I am interested in older people and their life experiences. Your experience, at this time, is important to understand so that nurses working in nursing homes can provide care for your husband and others like him in the best possible way.

I am conducting interviews with wives of men who have recently been admitted to a nursing home. The interview will take about one hour and can be held at the nursing home or in your own home depending on where you feel most comfortable, this choice will be discussed with you when the appointment is made. The interview will consist of a discussion of your experience and although it is possible that this may cause some stress most people find it a helpful experience.

Any information obtained will be confidential and kept in a secure place. I will be the only person who will have access to the information you provide. When the research is written up no individual participants will be able to be identified as your name and address will not be attached to the interview material.

When I have spoken to you and given you more details about the interview, if you decide to participate I want to assure you that you may discontinue at any time. This research is not connected in any way to the nursing home in which your husband is now residing. The Director of Nursing has given you this Information Sheet and will notify me if you decide to participate. This is the extent of the Director of Nursing’s involvement in the research project.

I can assure you that whether you decide to participate or not, or whether you change your mind later it will make no difference to the care that your husband receives.

If you are interested in finding out more about this project I would like you to tell the Director of Nursing who will pass on your name, address and telephone number to me and I will contact you soon after receiving this information.

Thank you, I look forward to meeting you soon.

Lynne Brown

Telephone number: 896 4171 (home)
Appendix 3

CONSENT FORM
FACULTY OF HEALTH STUDIES

Phone: (02) 685 9020
Fax: (02) 685 9023

I, ................................................................. (name) agree to take part in the research being conducted by Lynne Brown through The University of Western Sydney, Nepean.

I understand that my involvement will include an interview of about one hour. This interview will take place within six months of my husband's admission to the nursing home.

I understand that I may discontinue my involvement at any time and that this will in no way affect the care of my husband in the nursing home.

I have read the information sheet and understand what is required of me in the research project.

Signed

.................................................................

(Date)..........................................................