My spouse is a "stranger": a journey unravelling the nature of the intimate marital relationships of spousal caregivers of dementia sufferers from a personal construct perspective

Marilyn Georgina Rudd

University of Wollongong

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MY SPOUSE IS A "STRANGER": A JOURNEY UNRAVELLING THE NATURE OF THE INTIMATE MARITAL RELATIONSHIPS OF SPOUSAL CAREGIVERS OF DEMENTIA SUFFERERS FROM A PERSONAL CONSTRUCT PERSPECTIVE

A thesis submitted in fulfilment of the requirements for the award of the degree

DOCTOR OF PHILOSOPHY

from

UNIVERSITY OF WOLLONGONG

by

MARILYN GEORGINA RUDD, BSc.(Hons)

Department of Psychology
2003
In memory of my mother, Kathleen Mary Turnbull
whose loss from Alzheimer's disease
started me on this journey ...
ACKNOWLEDGMENTS

My heartfelt thanks must first go to my supervisor, Associate Professor Beverly Walker, without whom I would not have completed this research. I truly appreciate her unwavering encouragement, support, and guidance during some very difficult times. Her interest in this study has inspired my efforts to the end.

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I am indebted to Ros Hodgkins for her expertise and help with my current "loss". This experience has enabled me to understand the unique type of relationship unravelled in this study. My thanks also go to the members of the Wollongong Personal Construct Group for their invaluable suggestions. I am also indebted to many wonderful friends who have encouraged, supported, and prayed for me during this journey.

Finally, I would like to extend my sincere appreciation to the 124 men and women who willingly shared their experiences and deepest feelings with me. Some have passed away since I interviewed them, but their words linger on in this thesis.
I, Marilyn Georgina Rudd, declare that this thesis entitled, *My Spouse is a “Stranger”: A Journey Unravelling the Nature of the Intimate Marital Relationships of Spousal Caregivers of Dementia Sufferers from a Personal Construct Perspective*, submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Department of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Marilyn Georgina Rudd

6 June 2003
ABSTRACT

This study unravelled the nature of the intimate marital relationships of spousal caregivers of dementia sufferers from a personal construct perspective. One hundred and twenty four long-term married men and women were interviewed: 61 spousal caregivers (30 husbands and 31 wives) aged between 48 and 88 years, and 63 spouses (30 husbands and 33 wives), of similar age, whose partners did not have dementia. A constructivist model was developed, hypotheses formulated, and both quantitative and qualitative methodologies were used to collect the data. However, during the in-depth interviews, many spousal caregivers denied that they were in a “marital relationship” and refused to complete some of the standardised measures. Due to this unexpected issue, the model and hypotheses became redundant and the study was amended. The complex nature of the intimate marital relationships of the spousal caregivers was then compared to the intimate marital relationships of the spouses in the comparison group. Gender differences were also examined. The study then attempted to explain the type of relationship the spousal caregivers were experiencing using personal construct psychology (Kelly, 1955). The findings of the amended study revealed very few gender differences. The comparison group reported significantly higher marital and life satisfaction, reciprocity, intimacy, passion, and commitment than the caregiver group. The spouses in the comparison group were experiencing a “companionate” kind of love, with increased marital satisfaction in the later years of marriage. Due to personality changes, the dementia sufferers had become strangers to the spousal caregivers, who expressed profound sadness, anger, guilt and anxiety over the loss of their marital intimacy. Although the spousal caregivers were experiencing an “empty” kind of love, they were highly committed to their demented spouses. The type of relationship the spousal caregivers were experiencing was explained in terms of nonvalidation, re-writing identities, and lack of sociality.
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CHAPTER ONE

MY JOURNEY WITH DEMENTIA BEGINS
JOURNEY BEGINS . . .

All our understanding of people and things comes to us in the form of a story.  
(Rowe, 1988, p. 32)

Before launching into this doctoral study, I think it is important to relate a little of my personal experience with dementia. It is because of the loss of my mother from Alzheimer’s disease that I am now a Ph.D candidate and a registered psychologist. That tragic experience changed the direction of my life and started me on this journey. The following is a brief outline of my experience with this devastating disease and I begin with the story of my mother, Kathleen.

The Story of Kathleen

My journey with dementia began in 1988 when my beloved mother, Kathleen (or Kathy as she was known), was diagnosed with Alzheimer’s disease and I became her primary caregiver. She was 70 years old and had been a widow for 15 years. Up until that time, she was a vital woman who looked much younger than her years. She was blessed with a beautiful face and a lovely nature (in fact, she had been described as a classic “English Rose”). Mum was also a woman of high principles. As well as being kind, caring and loving; she was strong and independent. She had suffered many tragic losses throughout her life, as well as financial hardship, but remained happy and cheerful, and always “counted her blessings”.

My mother, father and I immigrated to Australia from England when I was four and so I grew up without any extended family. Dad was a compulsive gambler and made life very difficult for Mum. He was her second husband. Her first husband,
the “love of her life”, was killed during World War II, when he was only 26 years old and they had been married for only two years. Mum married a third time, but he died only nine months after the wedding.

Mum and dad divorced when I was 20 years old, following my first marriage. As an only child, and without other relatives around, I developed a very close relationship with my mother. As the years went by, we also became close friends. She was always there for me to talk with, to cry with, and to laugh with. I could not have coped with the trauma associated with the breakdown of my first marriage without my mother's help, support and unconditional love.

Seven years prior to the diagnosis of dementia, Mum was forced to relinquish her independence, because of financial difficulties, and she came to live with me and my family. As well as being a wonderful mother, she was a good friend to my second husband, Terry, and a devoted Nanna to my two children, Natalie and Stuart. We loved having her live with us - that is until Alzheimer's disease struck. Then madness and mayhem reigned! We all became victims of this terrifying disease.

I had never really imagined life without my mother but naively thought she would always be there for me. I took it for granted that our mother-daughter relationship would never change. Sadly, it not only changed, but “died”, and that was several years before her physical death.

It has been reported that Alzheimer's disease has a slow, insidious onset (Naughtin & Laidler, 1991); however, from the start, Mum's deterioration was rapid.
We initially noticed profound changes in her personality - she went from being loving and kind, to difficult and demanding. She was critical and suspicious, especially of me. The beautiful “English Rose” became a thorn in our side! I was giving more to the relationship and getting less from it. She was forgetful, disoriented and confused. She forgot how to write her name. We also noticed that she was hiding her stockings - under carpets, under lounges, under the mattress! Stockings were obviously precious to her - probably because of their scarcity during the War. All these changes occurred within a couple of months and so, initially, we attributed them to her being upset about turning 70. We were definitely in denial!

Mum’s doctor was alarmed at her dramatic weight loss and ordered multiple medical tests, which included nine days in a Sydney Hospital. On her departure from hospital, the neurologist bluntly told her: “Mrs Turnbull you’ve got Alzheimer’s disease and there is nothing that can be done about it”! He did recommend to me that I have an autopsy carried out when she died, to make sure it was Alzheimer’s and not some other cause. Although she was in the early stages of dementia, Mum did not really understand what he was telling her. Needless to say, we were devastated and heartbroken, and angry that a neurologist could be so insensitive.

However, the situation became a lot worse. Mum started having catastrophic reactions, where she would have emotional outbursts over the smallest things, at the most inappropriate times. She became excessively upset, stubborn, nasty, critical, and even physically abusive on occasions (Mace & Rabins, 1991). Her behaviour and moods were very unpredictable, which was disconcerting for my children who, by this
time, were in High School. My daughter was working towards her Higher School Certificate. I recall that my son's 13th birthday was a complete disaster because of Nanna's "acting-up". Hallucinations and delusions followed. She mistook ceramic dogs for people and thought she lived in a den of thieves! There was always the uncertainty of when and where we were going to be accused of stealing her money, which she hid along with the stockings. The accusations came when she forgot that she had hidden them.

Then, to my horror, within a couple of weeks of diagnosis, she no longer recognised me. The woman I called "Mum" denied I was her daughter. Instead, she accused me of being "that wicked woman who kidnapped her"; "the thief who stole her money"; or, worse still, "that woman who was having an affair with Marilyn's husband"! How could she remember my name but not recognise my face? How could she recognise others and not me? I realised that she had agnosia (explained in Chapter 3), but having that awareness was little comfort. I was in a state of total despair; my identity and existence were being threatened and invalidated.

I watched helplessly as Alzheimer's disease transformed my loving, caring mother into a complete stranger. My mother had "died", and this happened within a few short months of diagnosis. However, it was a death without a funeral. We could not mourn decently - it was a long painful bereavement (Forsythe, 1990).

Not only had I lost my mother, and friend, but I had also lost my role as a daughter. One of the most important relationships in my life had died, and this
happened several years before her physical death. I was now only a caregiver, a 24-hour-a-day caregiver, to a person I no longer knew, and who did not know me. I certainly did not understand this hideous disease that robbed me of my relationship with my mother, and I experienced a myriad of mixed emotions from anxiety, fear and profound sadness, to anger, guilt and hope.

My life became a living nightmare after Mum thought I was an imposter, who had “done away” with her daughter. I could not relate to her on any level, and the day came when I could no longer look after her. The anguish I felt was indescribable. I cried out for help. Within a few days she was gone. I shall never forget the torment of having to place my beloved mother in a nursing home - the residue of her life in one small suitcase. Although she was ravaged by Alzheimer’s disease, she was still able to convince some nursing home staff that we had stolen all her money and had now gotten rid of her. Within a day, she was accusing them of being the thieves!

For the next three years, I visited Mum in the nursing home every day, sometimes twice a day. She was put on anti-psychotic medication and the catastrophic reactions, hallucinations and delusions subsided. She was calm at last. We brought her home for the last time on Christmas Day, 1989. Soon thereafter she became bedridden and had regressed to her girlhood. Each day I would feed her and hug her. She did not know me but must have sensed I was someone who cared. She rewarded me with sweet smiles.
For the last two years of her life she was reduced to a vegetative state. Emaciated and laying in a foetal position, she came close to death a number of times, only to be revived by well-meaning nurses who pumped her with antibiotics! She succumbed to pneumonia on the 5 October, 1992. Indeed, it was not until her physical death that I was able to grieve for the mother that I knew - the beautiful "English Rose". At her funeral service we played her favourite song: "Take me home again, Kathleen". In time, I was able to accept my loss.

Rationale for the Original Study

This traumatic experience changed the direction of my life and for over a decade I have supported, counselled and studied dementia sufferers and their caregivers. I was particularly interested to explore the impact of dementia on other caregivers, in particular spousal caregivers, whose experiences would be similar and yet different to mine. This doctoral study, commenced in 1995, is a continuation of my journey.

In an effort to make sense of my experiences, after I had placed my mother in the nursing home, I completed an undergraduate degree in psychology. I commenced this degree in 1990 and Mum died five weeks before my final third year exams. Then, during my Honours year in 1993, I investigated the grief experienced by spousal caregivers prior to the death of their demented partners, using Kelly's (1955) personal construct theory (PCT) as a theoretical base (Rudd, 1993; Rudd, Viney & Preston, 1999). Triggered by the intense grief I experienced after I placed my mother in the nursing home, I wanted to compare the grief reactions of spousal caregivers who
cared for their demented partners at home with those who provided ongoing nursing home care. I also thought it would be interesting to examine gender differences. As this research is referred to many times throughout this thesis, set out hereunder is a brief overview of this study.

* * * * * * *

A constructivist model of spousal caregivers' bereavement, focusing on four psychological states of grief (anxiety, sadness, anger and guilt) was developed and empirically tested. Two hypotheses were formulated from this model. First, that spousal caregivers of dementia sufferers would experience significantly more anxiety, sadness, anger and guilt if they were providing ongoing nursing home care than if they were providing home care; and secondly, that wives of dementia sufferers would experience significantly higher levels of those states than husbands of dementia sufferers.

Sixty spousal caregivers participated in the study (30 husbands and 30 wives). There were equal numbers of home and nursing home caregivers. Content analysis of the participants' verbalisations was performed and content analysis scales scored for the four psychological states. A self-rating, adjective mood scale was used as a secondary measure. Giving support to the first hypothesis, nursing home caregivers expressed significantly higher levels of sadness and guilt than home caregivers; but home caregiving wives expressed the most anger. Caregiving wives expressed significantly higher levels of anxiety, sadness and anger than caregiving husbands, giving support to the second hypothesis.

The results of the content analysis scales were confirmed by the secondary measure, but the former measure proved more powerful for detecting statistically significant differences. The inclusion of severity of dementia, importance of spirituality
and age of caregivers as covariates made little difference to the results of the analyses (Rudd, 1993, p. ii).

* * * * * *

The caregivers in the above study reported that they had experienced many losses as they helplessly watched the slow death of their demented spouses, however, it was the loss of their intimate marital relationships that overwhelmed them with grief, loneliness and isolation. Being neither widowed nor really married, many of these spousal caregivers felt so devastated and lonely that they sought intimate relationships with other men or women, even though their demented partners were still alive. This often caused a great deal of conflict for the people concerned.

Having lost a close relationship to Alzheimer's disease, I felt I could understand a little of what these spousal caregivers were experiencing, but I realised that their losses were different to mine in many ways. I was fortunate to have had other close relationships to cushion my grief. During that time my husband and children were great sources of comfort and support to me, and I was able to discuss my feelings with them. Indeed, they were also experiencing their own grief over the loss of a beloved mother-in-law and Nanna.

Furthermore, the marital relationship is quite different from the parent-child relationship because marital intimacy, and in particular sexual intimacy, is a very private issue and often a taboo subject for older people. Therefore, spousal caregivers of dementia sufferers often feel embarrassed or ashamed to discuss the changes taking place in their marriages. However, many of these caregivers are giving love and care
to spouses who reject them. They sometimes have sexual relations with spouses who are strangers to them. They have lost every facet of intimacy with their spouses but cannot get on with their lives.

In this doctoral study I originally set out to examine the impact of a dementing illness on the intimate marital relationship. What does it mean to be a “married widow or widower”? How do these heterosexual spousal caregivers cope with the loss of their marital intimacy? How do their relationships differ from those of heterosexual men and women not married to dementia sufferers? Indeed, this research is needed in order to increase awareness and understanding about the emotional and sexual problems and losses faced by spousal caregivers of dementia sufferers, and to highlight the need for counsellors and other health professionals to become competent and comfortable in raising and addressing the intimacy-related concerns of these caregivers.

The Researcher

Following Kelly (1955), I thought of myself as a co-investigator with each of the research participants as both of us explored their experiences of marital intimacy. Data were collected for this doctoral study between mid-1996 and mid-1998. Although my experiences with dementia were different from the spousal caregivers (and I acknowledged the differences to them), the fact that my own construct system included understandings of what it is like to be a primary caregiver, and to lose a loved one to a dementing illness, helped build rapport with the spousal caregivers. It also helped them to freely share their most private experiences with me. In fact, most caregivers
said: “You can’t really understand unless you have cared for a loved one with
dementia”.

There has been very little research carried out in the area of dementia and
marital intimacy; however, I did have expectations of what the findings of my research
would be and carefully planned the study in advance. My expectations were based on
my own past research as discussed above (Rudd, 1993; Rudd, Viney & Preston, 1999),
the work of Wright (1991; 1993) (outlined in the next chapter) and past studies on
marriage in general, particularly Neimeyer and Hudson (1985).

I discovered from the literature that most research on marriage focuses on
either “satisfactory” or “unsatisfactory” marital relationships, and Neimeyer and
Hudson (1985) translated this into personal construct psychology (PCP) terms when
they devised and tested their model of marital relationships. In turn, I tried to follow
these researchers. However, during my in-depth interviews with the spousal
caregivers I was faced with some unexpected issues which totally invalidated my
expectations and dramatically changed the focus of this study (Rudd & Walker, 2002).
I shall elaborate on these unexpected issues in Chapter 8.

**Consequences of Unexpected Problems**

This exploratory study of the impact of dementia on the intimate marital
relationship has ended up being different, and somewhat broader, than I originally
intended. The findings will still give us greater understanding about the nature of the
intimate marital relationships of caregivers of dementia sufferers and further our
understanding of the intimate marital relationships of older men and women in general. However, by examining the problems encountered during the data collection process, and evaluating the differences between these cohorts, I hope to make a valuable addition to the research literature by revealing a type of relationship that, to my knowledge, has never before been studied. By doing this, in line with other authors (e.g., Walker, 2002), I shall also be extending Kelly's (1955) theory.

Due to my unexpected findings, I have taken an unorthodox approach to writing this dissertation. I have written it, somewhat informally, as a journey of my work. Hence, throughout the thesis, I have included short chapters (such as this one) setting out my findings and experiences along the way. These short chapters will be written in a distinctive font. In the first half of the thesis, I have presented my reasons for conducting the original study the way I did, including details of the conceptual models from which I formulated my original research questions and hypotheses, and listing all the research instruments and methods used to collect the data.

However, after the Method section (Chapter 7) the journey takes another path. The conceptual models and hypotheses became redundant and new aims are presented. My conclusions are supported by the results of both quantitative and qualitative data and, more importantly, the research participants' own words.

Another reason for presenting this thesis in the form of "the journey" is that researchers rarely write about the problems they encounter along the way but, instead, write up their theses or papers as if the problems had not occurred. At the end of her
paper presented at the 6th Congress of the European Personal Construct Association held in Italy in March, 2002, Pam Denicolo asked the question: "Would it be possible and productive to share distress/disaster stories as well as success stories at conferences and through publications, or are we yet too vulnerable?" (Denicolo, 2002, p. 10). Denicolo's paper struck a cord with me and I felt compelled to reveal the "warts and all" of this research. As well as being cathartic for me, I hope it may be useful for other researchers, particularly doctoral students, whose aims and hypotheses are similarly invalidated by the research participants they work with.

* * * * * * *

Although I gathered data on coping with changes to marital intimacy, I found that the volume of information collected was beyond the scope of this thesis. Therefore, from the Method section (Chapter 7) onwards, I have reluctantly omitted coping from this doctoral study and will endeavour to analyse the data and publish the findings at another time. Furthermore, as it seemed unnecessary, and would perhaps be confusing when discussing the results, I also decided not to include a review of the literature on coping.

This chapter began with the story of my mother, Kathleen, whose loss from Alzheimer's disease started me on this journey. The rationale for the original study was also presented, with mention of the unforeseen problems which led to my journey taking an unexpected detour. These problems eventually resulted in the unravelling of a type of relationship that, as far as I am aware, has never before been reported in the literature, and therefore has broken new ground in the area of relationships as well as in the area of dementia.
Chapter Two provides a brief overview of the topic that was the focus of the original study; that is, the impact of dementia on the intimate marital relationship. Chapter Three reviews the literature on the caregiving of dementia sufferers, focusing on spousal caregivers; while Chapter Four includes a brief overview of the general literature on marital intimacy, including gender differences, and a review of Sternberg's (1986) Triangular Theory of Love. Chapter Five focuses on marital and life satisfaction, sexual relations and commitment in long-term marriages, including a review of studies involving spousal caregivers of dementia sufferers, and gender differences. In Chapter Six, concepts from Kelly's (1955) PCT are provided and the conceptual models and hypotheses, which I attempted to test, are discussed. The methodology which was used for this purpose is described in Chapter Seven. Chapter Eight describes how my journey was interrupted. The results of the analyses, that were able to be carried out, are presented in Chapter Nine, and discussed in Chapter Ten. In Chapter Eleven the journey progresses as I begin to unravel the conundrum; while Chapter Twelve presents an evaluation of the findings of the amended study, concluding with a discussion about the new type of relationship that has emerged. In Chapter Thirteen, the implications and limitations of this study are presented, including a critique of the standardised instruments, and recommendations for future research are made. Finally, in Chapter Fourteen, I conclude my journey with spousal caregivers of dementia sufferers.
CHAPTER TWO

INTRODUCTION TO THE ORIGINAL TOPIC: THE IMPACT OF DEMENTIA ON THE INTIMATE MARITAL RELATIONSHIP
**Overview of the Original Topic**

Marital intimacy, especially sexual intimacy, is a sensitive and private issue which many heterosexual middle-aged and elderly people prefer not to discuss; hence, it is a neglected area of research. However, research on long-term marriage in general has been undertaken. The focus of such research has generally been on marital satisfaction, with the studies reporting contradictory findings. Studies reported in the 1960s (e.g., Blood & Wolfe, 1960; Pineo, 1961) described a continuous decline in marital satisfaction as time goes by, whereas more recent studies indicated that some couples experience increased marital happiness and satisfaction during the later years of life (Roberts, 1979; Gilford, 1984; Weishaus & Field, 1988).

Although two of these latter studies could be criticised for having some methodological problems (e.g., Roberts, 1979 was cross-sectional; and Gilford, 1984 was described as quasilongitudinal), the study by Weishaus and Field (1988) was longitudinal and showed the progression of 17 marriages that lasted 50 to 69 years. Although the sample was relatively small, no continuous decline (or continuous increase) in affect was observed. Furthermore, Weishaus and Field (1988) believe that the results from studies reported in the 1960s were due to the fact that the marriages described in these studies were of shorter duration. For example, Pineo (1961) reported on the changes that occurred to marriages between the early and middle years, that is, up to 20 years. Hence, the decline in satisfaction reported by Pineo could be explained by research that has indicated that marriages can start at a high level of happiness and satisfaction; dip in the middle years, especially after the arrival of children (as found by Pineo's research); and increase in later years, particular after children leave home. The pattern of these marriages is often described as curvilinear or "U"-shaped (Coleman, 1988; Weishaus & Field, 1988; Brubaker, 1990).
In line with the above, the most common pattern found in Weishaus and Field’s (1988) study was the curvilinear marriage, with seven out of the 17 couples reporting high satisfaction in the early years, with a decline in the middle years, and an increase in later years. However, in all of the 17 marriages, the spouses expressed acceptance of one another (occasionally grudgingly) and were committed to the marriage. They also had shared and separate interests. Many couples also expressed tolerance, respect, understanding, affection and love for each other. The authors described the marriages as “evolving and developing ... changing with life stage, circumstances, and time itself” (p. 770). A more detailed review of the literature on marital satisfaction can be found in Chapters 4 and 5.

When one partner has a dementing illness, such as Alzheimer’s disease, many additional changes occur to the marital relationship, especially to marital intimacy, and spousal caregivers need to make sense of their new experiences. Almost no information exists about how dementia affects marital intimacy. In fact, it appears that only one empirical study (Wright, 1991; 1993) has specifically investigated the impact of Alzheimer’s disease on marriage, comparing couples where one spouse has dementia to couples with no dementia.

This valuable study explored five specific dimensions of marriage: household tasks, tension, companionship, affection and sexuality, and commitment. These dimensions were based on the Dyadic Adjustment Rating Scale (Spanier, 1976; Spanier & Thompson, 1982). As well as this standardised measure of marital satisfaction, Wright’s semi-structured interview questionnaire contained “investigator-designed, pretested, open-ended questions which related to marital quality and coping” (Wright, 1991, p. 226). Furthermore, she included Swensen and Trahaug’s (1985) two “Commitment to the Spouse” questions as an additional marital quality measure; a depression rating scale (viz., Short Zung I.D.S. - Tucker et al., 1986; 1987); a scale which assessed aspects of physical health (viz., Multiple Assessment Instrument -
Lawton et al., 1982); and a coping scale (viz., Jalowiec Coping Scale - Jalowiec, 1988). (A description of all these measures can be found in Wright, 1993). Both quantitative and qualitative analyses were carried out. It was found that dementia in one partner affected all these marital dimensions. Any findings from Wright’s research that are relevant to my study will be discussed in later chapters.

Most studies of marital relationships focus on the couple, and therefore include both partners in the dyad in order to make within-couple comparisons. Wright (1991; 1993) followed this practice, and her two groups consisted of caregiver-dementia sufferer couples (AD group) and relatively healthy couples (well group). In fact, she stated that it was “arrogant” for researchers to ignore the perceptions of people with dementia (Wright, 1993). Nevertheless, when it came to testing differences between the two groups, the questionable reliability and validity of the demented spouses’ responses were considered, and only the caregiver spouses’ scores were used to represent the AD group. Wright’s AD group consisted of 30 couples of mean age 67.5 years, with the demented spouse in the early to middle stages of Alzheimer’s disease. Her well group consisted of 17 couples, with a mean age of 70 years. Her sample was selected purposively through ten organisations located in two south-eastern states of America.

Although I respect Wright for including the dementia sufferers in her study, due to my concern about the validity and reliability of their responses, as well as the belief that it is the individual’s perception of the relationship that is important (Spanier & Filsinger, 1983), I decided to leave the dementia sufferers out of this study and (as I had originally intended) focused on the experiences of the spousal caregivers. In order that differences in marital intimacy could be assessed, the focus was also on individuals rather than couples in the comparison group (that is, long-term married men and long-term married women whose spouses did not have dementia). My decision to interview individuals, rather than couples, was further supported by the belief that in every
marriage there are two relationships - his and hers - which are experienced differently (Bernard, 1972). As I was also interested in looking at gender differences generally, in relation to the experience of marital intimacy, it was not necessary to focus on couples.

Whilst conducting a final literature search before completing this thesis, I found an article by Baikie (2002), reviewing some of the literature in relation to dementia caregivers and marriage, which formed the basis of a doctoral dissertation being carried out by that author. Baikie’s study in progress is examining the impact on intimacy and marital relationships of caring for a spouse with either dementia or physical illness. Although no results were given, she provided some qualitative information emerging from the interviews with her research participants, and I shall include themes arising from this study when relevant.

This thesis used Kelly’s (1955) PCT, which provided a useful conceptual framework, and the original study followed (in part) Neimeyer and Hudson’s (1985) PCP model of marital relationships, to empirically examine the intimate marital relationships of spousal caregivers of dementia sufferers compared to long-term married men and women not married to such sufferers. It also examined gender differences. It will be noted that my focus was on heterosexual relationships.

To conclude, in this chapter a brief introduction to the original topic was presented, together with a brief discussion of the only other empirical study that, as far as I am aware, has published findings in this area (Wright, 1991; 1993). Although Wright interviewed married couples in both her AD and well groups, I argued that the issues of reliability and validity needed to be considered if dementia sufferers’ scores were included. Hence, the reasons were given for using individuals, rather than couples, in this study. In the next chapter, a review of the literature on the caregiving of dementia sufferers, focusing on spousal caregivers, will be presented.
CHAPTER THREE

A REVIEW OF THE LITERATURE ON THE CAREGIVING OF DEMENTIA SUFFERERS
In this chapter the literature reviewing the nature of dementia and the implications for caregiving is presented. This will be carried out under three main headings. First, the meaning of dementia and its symptoms and causes will be discussed. Second, the dementia caregivers will be presented, focusing on spousal caregivers. In this section, the spousal caregivers’ place of care (i.e., home or nursing home), the differences between spousal caregivers of late and early on-set dementia sufferers, and gender differences will also be addressed. Third, two early changes to the marital relationship: that is, changes in roles and responsibilities, and changes brought about by the “death” of the dementia sufferer’s personality, will be presented.

**What is Dementia?**

_Last scene of all,_  
_That ends this strange eventful history,_  
_Is second childishness, and mere oblivion,_  
_Sans teeth, sans eyes, sans taste, sans everything._

Jaques’ Soliloquy on the Seven Ages of Man, Shakespeare’s As You Like It, II, vii.

Dementia is derived from two Latin words which mean *away* and *mind* (Mace & Rabins, 1991). It is the name given to a group of symptoms which result from failing brain functions, with the major signs being persistent and progressive memory loss, deterioration in intellectual functioning and personality changes. Symptoms can also include mood changes, failure to recognise people or things (agnosia), disorientation, confusion, delusions and hallucinations. During the disease process, afflicted individuals progress from a mild state of confusion to disintegration of the whole person (Forsythe, 1990; Alzheimer’s Australia NSW, 2002). In Australia, dementia ranks as the fourth leading cause of death for those aged 65 years and over (Australian Bureau of Statistics, 1996).
The most common cause of irreversible dementia is Alzheimer's disease, accounting for approximately 70 percent of all cases. Some other causes are Vascular disease, Frontal Lobe dementia, Lewy Body disease and AIDS. Although dementing illnesses know no racial or socioeconomic boundaries, some ethnic groups appear to have a lower prevalence of dementia (Alzheimer's Australia NSW, 2002). Dementia also affects both sexes but, as women live longer than men, these illnesses are noticeably more common in older women (Gruetzner, 1992).

According to Alzheimer's Australia NSW (2002), approximately one in 15 Australians over the age of 65 years have moderate to severe dementia, with the rate jumping to one in four for those over the age of 85 years. Furthermore, in 1998 it was estimated that approximately 2000 people in Australia under the age of 60 years had dementia.

In Australia in 2001, there were an estimated 160,000 people, 60 years or over, diagnosed with moderate to severe dementia, with New South Wales having around one third of these cases (Alzheimer's Association NSW & NSW Health, 2001). At least as many people again would have early stage (that is, mild) dementia. With the continuing growth of our older population, it is anticipated that by 2011 the number of people with moderate to severe dementia will rise to approximately 210,000 (Alzheimer's Australia NSW, 2002).

Alzheimer's disease is particularly devastating because there is no identifiable cause and, to date, no prevention or cure. The progressive course of the disease renders its victims totally incapable of caring for themselves. Although there is no definitive treatment, there are now drugs available to help treat people in the early stages of Alzheimer's disease. As the population ages, and the incidence of Alzheimer’s disease and other dementing illnesses increases, not only is dementia going to be one of the top public health issues of the 21st century (Alzheimer's Australia NSW, 2002), but
caring for people with dementia will also remain a complex personal and public policy issue (Corcoran, 1992).

**Who are the Dementia Caregivers?**

A caregiver is defined as one who attempts to meet the physiological and psychosocial needs of another individual (Hirst & Metcalf, 1986). The vast majority of caregivers, both paid and unpaid, are female. Traditionally, all caregiving has been viewed as the responsibility of women, particularly wives and daughters (Johnson & Catalano, 1983; Brody, 1985). Supporting this notion is Stone, Cafferata and Sangl’s (1987) report, based on an American National Long-Term Care Survey, which found that 72 percent of all unpaid caregivers of the disabled elderly were women, with adult daughters comprising 29 percent and wives comprising 23 percent of this population. A report from the Australian Bureau of Statistics (1988) indicated that, in Australia, women (64 percent) also predominated in the caregiving role. This finding was again supported by the Australian Bureau of Statistics (1993).

However, according to the Australian Bureau of Statistics’ (1988) report, the predominance of women as caregivers was reversed for those aged 70 years and over, where there were more male caregivers (53 percent) than female caregivers (47 percent). This is because, in the Australian population, there are more married men in this age group than married women (the majority of women being widowed), and, according to this 1988 report, 87 percent of caregivers in this group were caring for their spouses.

Caring for a spouse with a dementing illness is one of the most stressful experiences an elderly person can have. Davies, Zeiss and Tinklenberg (1992) observed that “spousal caregivers have one of the world’s toughest jobs, if not the toughest” (p. 5). It is a role that Pruchno, Kleban, Michaels and Dempsey (1990) state
is "devoid of formal training, choice, and compensation" (p. 193). This care is often provided at great cost to the spousal caregiver's physical and psychological well-being.

The results of a study by Pruchno and Potashnik (1989), comparing dementia spousal caregivers with general population norms matched for age and gender, suggested that spousal caregivers were more depressed, expressed more negative affect, were more likely to use psychotropic drugs, and reported more symptoms of psychological distress than the general population. Furthermore, spousal caregivers reported higher rates of diabetes, arthritis, ulcers and anaemia. However, according to Pruchno and Potashnik (1989), the most surprising finding was the frequency that spousal caregivers reported their own health as being the same as, or worse than, the health of their demented partners.

**Spousal Caregivers: Place of Care?**

Most spousal caregivers either care for their demented partners at home or provide ongoing care once their partners have been placed in nursing homes. Alzheimer's Australia NSW (2002) reported that in 1998 nearly half of the people with moderate to severe dementia lived in a nursing home, hostel or similar facility. However, Gilhooly (1986) stated that, despite the increased burden, spousal caregivers were less willing to consider institutional care, but more likely to continue caring for their demented partners at home. Many spouses took their marriage vows quite literally and said they would continue with home care 'until death do us part'.

Moreover, Motenko (1989) found that home caregiving wives, who viewed their caregiving as the continuation of an enduring, meaningful marital relationship, derived gratification out of caring for their demented husbands; whereas those wives, who provided home care out of a sense of responsibility and duty, perceived caregiving as the end of their marital relationship. Motenko (1989) stated:
There are many reasons to feel this way about an Alzheimer’s patient who often cannot even remember who his wife is, cannot reciprocate affection or show appreciation, and now needs his wife as a small child needs a mother. A caregiving relationship characterised by responsibility connotes a break in the marital relationship and can contribute to the burdens rather than the gratifications of caregiving (p. 171).

It is frequently assumed that the caregiver’s burden is strongly related to the severity of the patient’s impairment, so that when the burden becomes too great, nursing home placement will occur. However, Colerick and George (1986) found that neither the severity of the dementia nor the length of the illness were significant predictors of institutionalisation. In fact, dementia sufferers who are cared for at home often have impairments as severe as those who are placed in nursing homes, and institutionalisation is more strongly associated with the caregiver’s perceived burden rather than the severity of the dementia (Zarit, Todd & Zarit, 1986). Although there appears to be little consensus among researchers as to the predictors of institutionalisation, it has been suggested (Pruchno, Michaels & Potashnik, 1990) that the decision to institutionalise is not one that is taken lightly but, rather, is the product of years of consideration.

Brown, Williams, Mitchell and Brown (1992) found that caregivers who provided ongoing nursing home care reported deteriorating changes in health status and experienced significantly greater burden and depression than those caregivers who provided home care. This finding was supported by Rudd (1993; Rudd, Viney & Preston, 1999) who found that spousal caregivers who provided ongoing nursing home care experienced more profound grief reactions, in the form of overwhelming sadness and intense guilt, than spouses who provided home care.
Spousal Caregivers: Late or Early Onset?

Alzheimer's disease and other dementing illnesses usually strike people over the age of 65 years. This is called "late onset" dementia. This is more common because aging increases the risk of developing dementia (Mace & Rabins, 1991). In turn, it is more likely that the spousal caregivers of late onset sufferers will also be elderly.

However, dementing illnesses can also strike people in their 30s, 40s and 50s. These (under the age of 65 years) cases are called "early onset" dementia. Some researchers believe that such cases are more likely to have a family history and it is generally thought that younger sufferers deteriorate more rapidly than older people with dementia (Alzheimer's Association NSW, 1998). As there is a preconceived notion that only older people get dementia, the changes in the behaviours and personalities of early onset sufferers might be confused with psychiatric disorders, such as depression, or mid-life issues, such as menopause.

The spousal caregivers of early onset sufferers will generally be younger, probably middle-aged. Although they may experience many of the same problems as those faced by older spousal caregivers, the younger spouses may also have to deal with additional issues. For example, they may still have dependent children at home, be caring for aged parents, or be in the workforce. There is also an increased likelihood that the early onset dementia sufferer will still be in the workforce, and having to cease work may cause severe financial hardship for the family, especially if the spousal caregiver has to leave a job as well (Alzheimer's Association NSW, 1998). In a study carried out by the Alzheimer's Association Australia (1994) it was reported:

In discussion many people highlighted the devastating legacy of dementia on their marriage/relationship. This ranged from conflict and aggression in the early stages, where personality changes are occurring, to the lingering feelings of loss, loneliness, guilt, sexual frustration and grief, to name only a few, as the affected partner moves from mild to profound dementia. While older people will also experience many of these same feelings, their impact at a younger age,
combined with child and work responsibilities, can only be more heightened (p. 27).

Spousal Caregivers: Gender Differences?

Due to different socialisation patterns and life experiences, it would be expected that men and women may react differently to the caregiving role. Some authors (Fitting, Rabins, Lucas & Eastham, 1986; Corcoran, 1992) suggest that female caregivers use a parent-child approach; whereas male caregivers adopt a task-oriented approach, derived from the workplace. Although many older women were socialised to be family-oriented and nurturant, they often look to their later years (after children leave home) as a time for personal opportunity and growth. Hence, these women may resent becoming caregivers to their demented husbands as it conflicts with their desire for autonomy (Zarit et al., 1986; Fitting et al., 1986; Rudd, 1993). Surely after so many years of nurturing, now it is their turn.

Conversely, caregiving husbands of the same generation were socialised to focus on the outside world and, although the caregiving role may be foreign to them, Pruchno and Resch (1989) found that they reported being more emotionally invested in the caregiving-marital relationship than the caregiving wives. Reciprocity was critical to these men. They believed that the care they were currently providing to their demented spouses was their due, and they were likely to make comments such as, “She took care of me when I was ill - now it’s my turn to take care of her” (p. 163). However, these investigators found that caregiving wives, who reported that they were not as emotionally invested in the caregiving relationship, felt more depressed and more burdened. In fact, many researchers (Cantor, 1983; Fitting et al., 1986; Pruchno & Resch, 1989), who have examined gender differences among caregivers, state that women report experiencing more psychological distress and depression than do men.
In view of the above discussion regarding the nature of spousal caregivers, it seems that the three variables (i.e., place of care, early or late onset, and gender of spousal caregiver) have potential importance to changes in marital intimacy. Indeed, in my earlier study on grief over pre-death losses (Rudd, 1993; Rudd, Viney & Preston, 1999), significant differences were found between home and nursing home caregivers and males and females. However, only spousal caregivers of late onset sufferers were interviewed in that study.

**Early Changes in the Marital Relationship**

**Roles and Responsibilities**

Spousal roles and responsibilities change when one partner has a dementing illness (Mace & Rabins, 1991). Responsibilities are the jobs or tasks that each spouse contributes to the relationship (for example, the wife might do the cooking and cleaning, while the husband mows the lawn and pays the bills). Roles, on the other hand, include who a person is, how they are seen, and what is expected of them. In a marital dyad the roles may not simply be “husband” or “wife”, but may also be “head of household”, “money manager”, “homemaker”, “car driver” and so on (Mace & Rabins, 1991).

Learning a new responsibility or task, such as washing or cooking, can be stressful, especially when dealing with the needs of a demented spouse. However, adjusting to, and coping with, changes of roles is generally much more difficult (Mace & Rabins, 1991). In a prior study (Rudd, 1993), it was reported by many older caregiving wives that one of their demented husband’s prior roles was “driver of the family car”. Most of these elderly women did not hold a driver’s licence and therefore they either found themselves housebound, which exacerbated their feelings of isolation, loneliness and depression; or they relied on public transport, which caused stress and anxiety, especially when trying to also manage a demented spouse.
An interesting grounded theory study by Perry (2002) described a process which allowed for positive aspects of caregiving to be considered along with the frustration and grief. This researcher examined the experiences of 20 wives (aged 57-82 years) caring for husbands with dementia. Their experiences were explained as “a process of interpretive caring” (p. 307). In line with Kelly (1955), “interpret” here means to “try to make sense of something” or “construe or understand in a particular way” (p. 309). In brief, the wives began the process by recognising changes in their demented spouses’ behaviour, which they construed as problematic. This led to them taking over their husbands’ roles and responsibilities. These new roles and tasks prompted the wives to re-write identities for both their husbands and themselves. Perry (2002) explained:

Many described a time of reflection during which they found new understandings of their current situations and a perspective on what was to come, for themselves and for their spouses. From this they developed new identities for their spouses and for themselves. For the husbands these new identities incorporated the changes that could be attributed to the disease and whatever parts of the husbands’ personality or character that the wives could still see ... The message here was that the husbands were the same but different ... As the wives redefined their husbands, they also needed to redefine themselves and to align, establish congruence, or create some balance between the identities they assigned to their spouses and the identities they constructed for themselves. When a wife spoke of her husband as babyish and talked of changing his diapers, she described her own identity as that of a mother (p. 312).

Perry (2002) found that although a wife’s new identity incorporated her knowledge and skill as a caregiver, the history of the couple’s relationship, and the commitment the wife felt to her husband and to their relationship, had a powerful impact on the new identities of the spouses.

“Death” of the Personality

Because dementing illnesses generally have a slow, insidious onset, changes in the person’s personality and behaviour are subtle and early symptoms are often denied or put down to old age, depression, menopause or mid-life crisis. The person is still
there, but “often as a shell” of the one they used to be (Naughtin & Laidler, 1991, p. 1). In her study in progress, Baikie (2002) stated that her caregiving spouses reported personality changes in their demented partners but they also remarked that they occasionally saw glimpses of their spouse’s former self, which aroused a mix of emotions from pleasure to sadness. These personality changes can have a profound impact on the marital relationship and, in some cases, the marriage can completely break down even before diagnosis. Elizabeth Forsythe (1990) described her experience:

When we married he was forty-five and I was seventeen years younger. To me he remained extraordinarily remote and in many ways essentially a stranger ... It is not possible even with the benefit of hindsight to say that his dementia was now starting [but] ... The stranger with some sense of familiarity had gone and a stranger with a chilling feel of remoteness seemed to have arrived in his place. I found myself alone ... I became full of fear. At the time I saw him as an unreasonable tyrant, and I was afraid of him. He now believed that I was responsible for any problems he had ... he wanted a divorce ... It was a time of great confusion and it did not then occur to me that he might be mentally disturbed (pp. 3-8).

It is long before the dementia sufferer’s physical death that a psychological death occurs - the death of his or her personality, which is “that quality or assemblage of qualities that makes a person what he or she is” (Austrom & Hendrie, 1990, p. 16). These authors go on to say: “Once the patient’s personality and memory deteriorate considerably, the very qualities that made the patient a unique individual are gone” (p. 19). Because the caregiver has “lost” the spouse that they knew and loved, they may face some difficult and early changes to their marital relationship, especially in relation to their marital intimacy. However, as this aspect of marriage is so personal for most people, it is rarely discussed. One middle-aged spousal caregiver of an early onset sufferer was reported as saying:

Alzheimer’s slowly destroyed the intimacy we once shared. Shortly after diagnosis my husband’s personality began to change and the romantic part of our relationship was affected. I became less interested in continuing this aspect of our relationship, which made me feel extremely guilty (Alzheimer’s Association, 1995, p. 1)
The status of spouses providing continuing care for their demented partners has been described as 'married widowhood' (Brown et al., 1992). However, despite these caregivers mourning the loss of their demented spouses as surely as if they had died, society does not recognise their grief because the physical bodies of their demented partners are still there (Lezak, 1978). Furthermore, Doka (1989) suggested that these caregivers are experiencing, what he terms, “disenfranchised” grief, which occurs when their loss “is not or cannot be openly acknowledged, publicly mourned or socially supported” (p. 4). Additionally, because the spousal caregivers can no longer engage in reciprocal communication with their demented partners, nor rely on them for support and intimacy in the same ways, these spouses may become increasingly lonely, isolated and grief-stricken. Sometimes they will seek intimate relationships with other men and women, and some may even fall in love again. These spousal caregivers may then be faced with some difficult decisions and conflicting emotions (Mace & Rabins, 1991; Rudd, 1993). This rarely discussed area of marital intimacy is the focus of this thesis.

**Relationship between the Nature of Dementia Caregivers and Changes in Marital Intimacy**

As mentioned previously, in my earlier study (Rudd, 1993; Rudd, Viney & Preston, 1999), the focus was on grief over pre-death losses, and home and nursing home caregivers were compared. As explained in Chapter 1, it was found that, overall, the nursing home caregivers were experiencing more intense grief reactions than the home caregivers. However, in the current study, the focus was on changes to marital intimacy and, although spousal caregivers can either provide home care or on-going nursing home care, or be caregivers of either late onset or early onset dementia sufferers, there are unlikely to be differences between these groups. This is because personality changes generally occur in the dementia sufferer early in the disease process, which means an early impact on the intimate marital relationship, long before nursing home placement. Furthermore, once a person’s personality has changed, their
loved ones have to deal with a "new" person, and this can have a profound impact on
the marital relationship, no matter what the caregiver's age. Nevertheless, these
variables, as potentially relevant, were included as data within the current study.

In this chapter, the meaning of dementia and its symptoms and causes have been
explained, together with a review of the literature on dementia caregivers, focusing on
spousal caregivers. Place of care (home or nursing home), type of onset (late or early),
and gender differences were also addressed. Two early changes to the marital
relationship (changes in roles and responsibilities, and changes brought about by the
"death" of the dementia sufferer's personality) were also reviewed. In the next chapter,
an overview of the general issues and findings concerning marital intimacy will be
presented, while those relating specifically to older spouses, including spousal
caregivers of dementia sufferers, will be addressed in Chapter 5.
CHAPTER FOUR

WHAT IS MARITAL INTIMACY?
AN OVERVIEW OF THE LITERATURE
In this chapter an overview of the general literature on marital intimacy is presented. Various definitions of marital intimacy are first provided, in particular in relation to the terms "intimacy" and "love", as well as gender differences in regard to these terms. Following this, a review of an important relevant theoretical distinction, Sternberg's (1986) triangular theory of love, is presented together with the findings of recent studies which have utilised the associated Sternberg Triangular Love Scale. This theory of love is of particular relevance to the current study. A brief overview of the general literature on marital satisfaction, including gender differences, and the relationship between marital and life satisfaction is also included.

What is Marital Intimacy?

According to Giddens (1999) it has only been in the last 30 years or so that people have spoken of marital "relationships" or marital "intimacy". In the past, people did not need to speak in terms of "relationships" or "intimacy", or even "commitment" for that matter, as marriage was the commitment. In more recent times, however, the marital relationship has been increasingly seen as one where the partners share intimate experiences in several areas: emotional, social, sexual, intellectual and recreational (Schaefer & Olson, 1981). Individuals desire each kind of intimacy in differing degrees. This view is supported by Neimeyer and Hudson (1985) who state that "marriage involves the development of many different subsystems at varying levels of intimacy. The elaboration of sexual, emotional, recreational and social frontiers, among others, says something about the comprehensive nature of marital relationships" (p. 128).

Furthermore, it appears that intimacy has been viewed as an integral part of love in marriage. Sternberg (1986) believes that love can be understood in terms of three components: intimacy, passion and commitment. In his view, intimacy is "a foundation of love" (Sternberg, 1988b, p. 41). Beach and Tesser (1988), on the other hand,
discuss four components of the marital relationship that relate to love: commitment, intimacy, cohesion (closeness and sharing), and sexual interaction. These authors believe that intimacy is typically related to “hot” emotions ranging from “deep caring and passion to intense anger and depression” (p. 336). In a study investigating the dimensions of emotional intimacy in marriage, Parelman (1983) found that the item “love my spouse” received a high loading for both married men and married women. Hence, Parelman concluded that love was one of the variables typically associated with emotional intimacy in marriage. It therefore seems that both intimacy and love are intertwined when we refer to marital intimacy. But what do we really mean by the terms “intimacy” and “love”?

**Intimacy**

Although these concepts are widely used by researchers of interpersonal relationships, there does not seem to be any generally accepted definitions. The word “intimacy” comes from the Latin word *intimus*, meaning innermost (Brown, 1993). According to Sternberg (1988b), intimacy involves feelings that promote closeness, bondedness, and connectedness, such as mutual understanding, communication, mutual emotional support and sharing (fully discussed later in this chapter). Parelman (1983) referred to intimacy as emotional closeness, which is most commonly associated with mutual feelings of love, caring, emotional support, trust, and acceptance. Giddens (1999), on the other hand, equates intimacy with emotional communication which involves self-disclosure, mutual trust, and understanding the other person’s point of view. Schaefer and Olson (1981) noted that it is often defined in terms of sexual relations, whereas Reis and Shaver (1988) propose that intimacy involves feeling “understood, validated, and cared for” (p. 367).

In their work on developing the Sociality Scale, which measures satisfying interpersonal relationships, Viney and Westbrook (1979) included the category intimacy
to mean a type of relationship where people are construed as sources of personal satisfaction. Here intimacy also implies “empathy, fellowship, affection, friendliness, sociality or efforts to maintain a close interpersonal relationship” (p. 131).

Love

Noller (1996) argued that love is socially constructed, and can be affected by one’s social and cultural beliefs; while Hendrick and Hendrick (1992) described it as “a very elusive entity” (p. 62). However, these authors have agreed that it can be experienced as romantic, passionate, companionate, and even platonic. Two early researchers on love, Ellen Berscheid and Elaine Hatfield (formerly Walster) proposed two kinds of love: passionate and companionate. Passionate love includes sexual feelings and the “agony and ecstasy” of intense emotion; while companionate love is a warm and trusting affection between two people whose lives are deeply intertwined (Berscheid & Walster, 1978). According to these researchers passionate love peaks early in the relationship and then declines; while companionate love is more likely to continue growing. The distinction between passionate and companionate love (as well as other types of love) has been developed by Robert Sternberg (see later this chapter).

The loving relationship is considered the most intense form of happiness (Argyle, 1987). However, being in love entails both positive and negative affect. Furthermore, whereas sexuality may lie at the core of romantic or passionate love (Skolnick, 1983), commitment is the hallmark of companionate love, which often occurs in long-term marital relationships where passion has died down (Sternberg, 1986). For some people love is experienced as emotional feelings or sexual desire or a yearning to be with the other person, whereas for others it is caring, trust and companionship (Hendrick & Hendrick, 1992; Coleman, 1988). For most people, love seeks reciprocation (Skolnick, 1983).
Noller (1996) presented Beck’s (1988) list of characteristics of mature love. Beck’s emotional aspects of love included feelings of warmth; care and concern; empathy; sensitivity; and understanding, or being able to see things through the loved one’s eyes. His list of behavioural aspects of love included expressions of affection; acknowledging and accepting differences and weaknesses; companionship and closeness; friendliness; intimacy or sharing the everyday details of life; and pleasing and supporting one’s partner.

As well as viewing love as pleasurable, healthy or mature, some writers emphasised the negative aspects of love; the unhealthy or immature types of love (Noller, 1996). For example, Peele (1988, cited in Noller, 1996) focused on love addiction, which is defined as love:

characterised by an overwhelming dependency, which he [Peele] sees as leading to relationships that are not necessarily pleasurable and that seem to last despite (or perhaps even because of) the pain involved. These relationships seem to be driven by a deep need or deficiency in one or both of the individuals in the relationship and are characterised by possessiveness and jealousy (Noller, 1996, p. 103).

Tennov (1979) introduced the concept of “limerance”, which involves an intense dependency on, acute longing for, and intrusive thinking about, the loved one. Some authors (e.g., Sternberg, 1988b; Noller, 1996) believe Tennov is referring to an intense form of romantic love, and Sternberg (1988b) suggested that it may be similar to Peele’s addictive love. A third kind of immature love is infatuation, which Sternberg (1988b) described as generally obsessive, with a high degree of psychophysiological arousal. An infatuation can arise quickly and dissipate just as quickly. Sternberg also sees infatuation as being similar to Tennov’s “limerance”.

In her review of the literature that examined the emotional, behavioural and cognitive aspects of both mature and immature love (in an effort to define the love that supports marriage and family), Noller (1996) concluded that the cognitive aspect of
love, which includes commitment, is a very important factor. Sternberg’s (1986; 1988b) commitment component of love (discussed later this chapter) involves both the short-term decision that one loves another, and the long-term decision to maintain that love. Noller (1996) argued that the important point authors such as Sternberg make, is that “love is not just about feelings that can wax and wane, but involves a conscious decision to love” (p. 104). Nevertheless, Noller also pointed out that this commitment needs to involve more than simply a determination to stay together. It needs to involve a decision to work towards a satisfying and worthwhile relationship. In summary she said:

Although immature love is a reality in our world, mature love is possible and is sustained by beliefs that love involves acknowledging and accepting differences and weaknesses; that love involves an internal decision to love another person and a long-term commitment to maintain that love; and finally that love is controllable and needs to be nurtured and nourished by the lovers. This kind of love is the love that sustains marriage and family... (Noller, 1996, p. 112).

Meanings of Intimacy and Love: Gender Differences?

Gender differences have shown to be important in “intimacy” and “love”. According to Duck (1988) there is evidence that males and females differ in their meanings of “intimacy”. Men regard intimacy in terms of shared or joint activities, such as having sexual relations, whereas for women intimacy involves talking and disclosing personal information and sharing feelings. Riessman (1990) reported that although men and women both seek emotional closeness in marriage, women believe it is achieved by warmth, sharing and communicating with their spouse, while men want physical, not verbal, demonstrations of intimacy.

With regard to “love”, most research to date has involved college students and young married couples and therefore has focused on passionate or romantic love, which involves deep emotions and sexual feelings. Women have reported strong emotional reactions (Dion & Dion, 1973), whereas men’s attitude to love has been found to
encompass lower commitment and a strong sexual element (Hendrick, Hendrick, Foote & Slapion-Foote, 1984).

In conclusion, the terms “intimacy” and “love” are constructs that mean different things to different people at different times (Hendrick & Hendrick, 1992). As far as I am aware, no study has examined the meaning of these terms for middle-aged and elderly married men and women. As it was important to know how the research participants in this study construed these terms, I decided to ask them what “intimacy” and “love” meant to them (see Chapter 7 for open-ended questions, Chapter 9 for descriptive analyses, and Chapter 10 for research participants’ definitions).

**Triangular Theory of Love**

As noted above, there appears to be distinct individual differences in how people construe and experience the word “love”. Several different theories of love have also been proposed (e.g., Lee, 1977; Berscheid & Walster, 1978; Tennov, 1979). However, according to Beach and Tesser (1988), there seems to be some elements that remain constant across most of the work on love and these authors believe that Sternberg (1986) has “done an admirable job” of defining love in terms of these common elements (Beach & Tesser, 1988, p. 331).

As stated previously, Sternberg’s (1986) triangular theory of love proposes that love can best be construed in terms of three components: intimacy, passion and commitment. This perspective also tends to be consistent with data from Maxwell (1985) who found that people are more likely to use the term “love” to describe a relationship if (a) closeness (intimacy) is involved, (b) if commitment is present, or (c) if there is a sexual component. Furthermore, Hendrick, Hendrick and Adler (1988), believe that Sternberg’s view of love fits their finding that Eros (passion with intimacy and commitment) is a potent love style.
In the context of Sternberg’s (1986) triangular theory, intimacy is the emotional component of love. It refers to those feelings in a loving relationship that, as stated above, promote closeness, bondedness, and connectedness, which include feelings that give rise to the experience of warmth in the relationship. Furthermore, the research of Sternberg and Grajek (1984) indicated that intimacy in a loving relationship includes (among other things) happiness, high regard, mutual understanding, sharing, giving and receiving emotional support and communication. Sternberg suggested that the intimacy component is a common core in all loving relationships.

Passion is the motivational component of love and refers to the drives and desires that lead to physical attraction, romance, and sexual consummation. Whereas sexual needs may predominate, other needs such as those for affiliation, dominance, submission, self-esteem, nurturance, and self-actualisation may also contribute to the experience of passion. Of course, the strengths of these needs will vary according to individuals, situations, and the kinds of loving relationships. For example, the need for sexual fulfillment will be strong in a romantic relationship, but not in a filial one. Passion in a loving relationship tends to interact strongly with intimacy, and each will fuel the other (Sternberg, 1986).

Commitment is the cognitive component of love and encompasses, in the short term, the decision that a person loves another person and, in the long term, the decision to maintain that love. For example, with regard to marriage, Sternberg (1986) points out that “the institution of marriage represents a legalisation of the commitment to a decision to love another throughout one’s life” (p. 123). It is also the commitment component that keeps loving relationships together when couples experience hard times. In other words, an individual has considerable control over the commitment component of love, whereas it can be exceedingly difficult to control the emotion of intimacy or the arousal of passion (Sternberg, 1986).
Although intimacy, passion and commitment are all viewed as important components of loving relationships, their importance differs from one relationship to another. Furthermore, the emphasis on these components may vary over time within a relationship and thus change the nature of the loving relationship. Sternberg (1986; 1988b) listed eight kinds of love that are composed of differing proportions of the three components. Of course, it is unlikely that any component would be completely absent and therefore the kind of love experienced depends on the strength of each component relative to the other components. The kinds of love are as follows:

1. Nonlove - low scores on all three components
2. Liking - high score on intimacy, low scores on passion and commitment
3. Infatuated love - high score on passion, low scores on intimacy and commitment
4. Empty love - high score on commitment, low scores on intimacy and passion
5. Romantic love - high scores on intimacy and passion, low score on commitment
6. Companionate love - high scores on intimacy and commitment, low score on passion
7. Fatuous love - high scores on passion and commitment, low score on intimacy
8. Consummate love - high scores on all three components

Whereas the kind of love experienced by newly-weds might be described as consummate (high scores on all three components), as the couple gets to middle-age and older, their kind of love might change to companionate (higher scores on intimacy and commitment, lower score on passion) (Sternberg, 1986). In support of this decline in passion, Noller (1996) reported a study by Acker and Davis (1992), based on Sternberg’s triangular theory of love, which found that:

older respondents tended to want less passion in an ideal partner than did younger respondents, and that passion contributed less to satisfaction than did commitment and intimacy, especially in longer relationships (Noller, 1996, pp. 101-102).
Finally, Sternberg (1986) believed that it is paramount to be aware of the way individuals express their love. For example, intimacy might be expressed by communicating inner feelings; sharing one's possessions, time and self; offering emotional and material support; and expressing empathy for the other person. Passion might be expressed by hugging, kissing, touching, and making love. Commitment may be expressed by staying in a relationship through hard times, fidelity, becoming engaged, and getting married. As Sternberg (1986) stated: "Without expression, even the greatest of loves can die" (p. 132).

Noller (1996) noted that the strengths of Sternberg's theory included his recognition of the importance of the different aspects of love, especially the importance of commitment. However, she also commented that he did not really acknowledge the cultural aspects of love. Nevertheless, she stated that "Sternberg's triangular theory was an important milestone in terms of increased understanding of the concept of love" (p. 110).

Sternberg's Triangular Love Scale: Studies Reviewed

Sternberg developed an instrument to measure the three components of love, the Sternberg Triangular Love Scale (1988b) (see Chapter 7 for validation details). Several researchers have now successfully used this scale in their studies. For example:

* To examine the links between reciprocated love, satisfaction and psychological state, and to ascertain the differences between men and women admitted for treatment of addiction, Pepin and Nadeau (2001) administered Sternberg's Triangular Love Scale, the Dyadic Adjustment Scale, and the Addiction Severity Index to a sample of 26 men and 15 women from three substance abuse treatment centres in Montreal. The results revealed a significant correlation between reciprocated love and satisfaction, and confirmed that more women than men perceived themselves to be in an unreciprocated
love relationship. Furthermore, the results suggested that psychological state is not correlated with reciprocity and satisfaction; nor do women who perceive a relationship to be unreciprocated present a higher level of psychological distress than men in that position.

* In another study, investigating men’s and women’s preferences with respect to sex-related and nurturing qualities in dating partners, Fischer and Heesacker (1995) administered Sternberg’s Triangular Love Scale, as well as other measures, to 41 male and 57 female undergraduates. It was found that men preferred sex-related qualities and women preferred nurturing qualities.

* Using Sternberg’s Triangular Love Scale and other measures, Varga (1998) examined the similarities and differences between males and females in their reported feelings of intimacy, passion, commitment and sexual satisfaction. Participants were 303 students from two south-western universities in America, who were currently in a romantic relationship. The results showed that women reported stronger feelings of intimacy and commitment than men. For both women and men, sexual satisfaction was related to passion, but not to intimacy or commitment. For women, there was a negative correlation between age and passion as well as length of relationship and passion.

* In a study focusing on sexual satisfaction in women, Means (2001) administered Sternberg’s Triangular Love Scale and other instruments to 105 women aged 19 to 65 years. Among the many findings, the researcher’s projection that emotional intimacy would be the strongest predictor of sexual satisfaction for these women was supported.

* Finally, in a study examining the experience of love in abusive and non-abusive courtship relationships, Larry (1999) administered Sternberg’s Triangular Love Scale,
among a battery of instruments, to 224 university students. Among the interesting findings, it was reported that verbal abusers, or abusers who perpetrated acts of jealousy, obtained significantly higher scores on Passion than did non-abusers; and victims who were isolated and emotionally controlled by their partners obtained significantly higher scores on Intimacy, Passion, and Commitment than did non-victims. I found this latter finding particularly intriguing!

The above studies have demonstrated the usefulness of Sternberg’s Triangular Love Scale in a variety of research areas. Of course, it should be pointed out that this scale was administered to my research participants before many of these studies were completed, based on the results of Study 2 of Sternberg’s construct validation (outlined in Chapter 7). At that time, I believed it was a valid measure of love and thought it would be interesting to use it with the research participants in my study. The studies reviewed here substantiate my assumption. Furthermore, as this scale still does not seem to have been used with middle-aged or elderly spouses, nor with dementia spousal caregivers, my findings will be a valuable addition to the research literature.

**Marital Satisfaction**

In considering the psychology of marriage, the overwhelming focus has been on the dimension of satisfaction. In this section of the thesis, a brief overview of the literature will be presented that focuses on the nature of marital satisfaction and how it has been studied. This is a huge literature, so I shall only address some salient issues. Furthermore, in this section, the early years of marriage will be addressed. The literature on marital satisfaction in long-term marriages, including that on spousal caregivers, will be discussed in the next chapter.

What might be considered a satisfactory marriage to one person may be completely unsatisfactory to another. Although it is acknowledged (Coleman, 1988)
that the early years of marriage are generally characterised by happiness and satisfaction, young couples are not immune to marital dissatisfaction. According to Noller, Feeney and Peterson (2001) the significance of individual differences in marital satisfaction is emphasised by longitudinal data (Ruvolo, 1998), which show that the level of marital happiness reported by young adults predicts their sense of general well-being in later years. These authors also reported that studies of young married couples have consistently shown that differing levels of marital happiness can best be explained by two factors: couple communication and understanding.

Noller et al. (2001) cited longitudinal studies of newly-married couples in the United States, which linked marital satisfaction to spouses’ understanding and perceived similarity (Acitelli, Douvan & Veroff, 1993; 1997), and to problem-solving behaviours (Cohan & Bradbury, 1997). In addition, a two-year study of young Australian married couples (Feeney, Noller & Callan, 1994) found that marital satisfaction was linked to communication patterns. An interesting finding that emerged from these studies was that communication patterns during the early years of marriage were relatively stable (Noller et al., 2001).

With regard to the important issue of communication between couples, Duck (1998) reported evidence to suggest that satisfied couples talk more about their relationships, are more willing to compromise on difficult issues, and are able to agree, more often than disagree, when trying to solve problems. Duck also stated that couples with high satisfaction are the ones where husbands talk more about the relationship. Furthermore, satisfied couples support and validate (confirm) one another, whilst dissatisfied couples reject and invalidate (disconfirm) one another, even to the extent of threatening their very existence. This can happen when they make verbal statements that seem to imply “You are nothing to me”; “You do not exist for me”; “Your comments and opinions do not matter to me”; “I don’t care” (Duck, 1998, p. 107).
Duck (1979) argued that in order to have a relationship with anyone, it is necessary to share some form of communication, such as a common language or an agreed set of beliefs and ideas. In turn, the kind of relationship depends upon the kind of communication that is shared. For example, if two people share the same language but not the same beliefs and ideas, then their relationship is likely to be a formal, rather than an intimate, one. In order to change the nature of the relationship to an intimate one, Duck believes that it is necessary to change the level of sharing in this special area; for example, self-disclosure of thoughts and feelings, and expressions of affection. He stated: “personal relationships are nurtured not only by the sharing of ideas, language and so on, but by sharing of constructs, or ways of looking at or reacting to, the world” (p. 284).

Maxwell (1985) suggested that, as marriage involves a reciprocal role relationship, as well as sex and companionship, the behaviour necessary for marital satisfaction is likely to be different from that which is important in other relationships. In a study examining satisfaction among younger (aged 19 to 33 years) and older (aged 47 to 74 years) married couples, Maxwell found the best four predictors of marital satisfaction to be: (1) the extent to which the individual felt at ease and accepted by his or her spouse; (2) satisfaction with sharing tasks and decisions; (3) satisfaction with mutual understanding; and (4) the extent to which the individual felt appreciated by his or her spouse (Maxwell, 1985). Furthermore, there were no significant differences between the responses of the younger married couples compared to the older married couples, indicating that people report the same types of satisfactions after approximately 20 years of marriage that they found in the first couple of years (Maxwell, 1985). Interestingly, Maxwell reported that there was strong evidence from her study to suggest that the behaviour that was important for marital satisfaction was very similar to the behaviour that is related to the closeness of friendships and the closeness of young adult children and their mothers.
Furthermore, according to Argyle (1987), couples in happy marriages, in contrast to unhappy ones, tend to talk more to each other; make more use of nonverbal communication (such as a kiss, helpful behaviour, or giving a present); are more sensitive to each other’s needs and feelings; have a more enjoyable sex life; and spend quality time together. Couples who talk a lot build up a shared cognitive world, where each one’s world view is supported by the other (Argyle, 1987; Coleman, 1988). This understanding of their spouse’s world is in line with the view espoused by Kelly (see Chapter 6).

Although it has been emphasised (Maxwell, 1985) that reciprocity is vital to marital satisfaction, it must also be acknowledged that reciprocity occurs between dissatisfied couples. Billings (1979) found that dissatisfied couples reciprocated hostile-dominant comments more than satisfied couples. This author also concluded that dissatisfied couples were more likely to escalate conflicts. Similarly, Gottman, Markman and Notarius (1977) reported greater reciprocity of negative non-verbal affect among dissatisfied couples. Gottman (1979) replicated this finding. Furthermore, Gottman et al. (1977) and Gottman (1979) found that dissatisfied couples were more likely to engage in “cross-complaining” sequences (a complaint followed by a counter-complaint), and less likely to engage in validation sequences (a complaint followed by agreement) (cited in Pike & Sillars, 1985, pp. 304-305).

Pike and Sillars (1985) conducted a study on reciprocity in marital communication patterns. The data from two studies were combined (42 married couples participated in the first study and 40 couples in the second study). However, data from only 73 couples were fully analysed. The mean age was 30 years for the women and 32 years for the men, and the couples had been married an average of eight years. Data were analysed for sequential and distributional patterns of paralinguistic affect and verbal conflict. Pike and Sillars’ (1985) findings for patterns of paralinguistic affect supported behavioural skills approaches to marital communication,
in that on highly salient issues, there was greater "negative reciprocity" in the non-verbal affective communication patterns of dissatisfied couples than satisfied couples. With regard to verbal conflict, these authors found that dissatisfied couples were more likely to engage in (and confront) conflict; whereas satisfied couples tended to avoid it.

Indeed, the finding that more satisfied couples had a higher rate of conflict avoidance was concerning to these authors as it was inconsistent with prevailing assumptions about effective verbal communication. They therefore provided evidence to suggest that "the relationship between verbal communication patterns and marital satisfaction depends on a couple's implicit expectations and standards of communication" (Pike & Sillars, 1985, p. 303).

Marital Satisfaction: Gender Differences?

Peplau and Gordon (1985), reported the results of three large American surveys carried out in the 1960s and 1970s, which investigated gender differences in marital happiness and satisfaction. In general, it was found that most husbands and wives reported that their marital relationships were satisfying, and the happiness ratings of each spouse were found to be positively correlated. It was reported that when gender differences did emerge, they were small.

Although many smaller-scale studies of marital satisfaction have produced inconsistent gender differences, several studies have found that husbands report being happier and more satisfied with their marriages than wives (e.g., Burr, 1970; Argyle, 1987). However, in Maxwell's (1985) study of younger and older married couples, the overall satisfaction scores of the husbands and wives showed considerable agreement ($r = 0.72$); however, the wives' slightly higher scores indicated that they were more satisfied. Furthermore, the correlation of scores on the behavioural items (e.g., helping spouse, sharing interests, going out together) was even higher ($r =$
0.87), with the wives reporting that they were engaging in more of those behaviours that suggested closeness.

Research has also found gender differences in the importance placed on certain factors that contribute to marital satisfaction. For example, Levinger (1964) found that sexual satisfaction was more strongly related to overall marital satisfaction for husbands, and communication was of greater importance for wives. However, Wills, Weiss and Patterson (1974) found that marital satisfaction was associated with the frequency of pleasurable instrumental activities for husbands; whereas, for wives, it was related to the frequency of pleasurable affecional activities. Peplau and Gordon (1985) suggested that an investigation of the factors that contribute to marital satisfaction for both males and females is an important issue for future research.

In conclusion, from the above brief overview, it seems that the main factors that contribute to marital satisfaction in the early years of marriage are verbal and non-verbal communication patterns, understanding, reciprocity, and confirmation (or validation). With regard to reciprocity, it is acknowledged that mutual understanding, give and take, talking together etc. are very important for marital satisfaction; however, reciprocity can also be “negative”, in that dissatisfied couples can mutually abuse, or verbally invalidate, one another. With regard to gender differences, large-scale studies have reported only small (if any) gender differences; while some smaller-scale studies have reported inconsistent findings.

Relationship between Marital and Life Satisfaction

One of the problems with attempting to clarify issues of marital satisfaction is that it is possible that it is but a subset of general satisfaction. That is, it is not always clear if it is satisfaction with marriage that is measured, or life satisfaction more generally. Nevertheless, research has showed that marital satisfaction is highly
correlated with overall life satisfaction and happiness (Peplau & Gordon, 1985; Argyle, 1987). Furthermore, psychological well-being (life satisfaction) is often conceptualised as the balance of positive and negative affect (Derogatis, 1975; Stacey & Gatz, 1991). According to Peplau and Gordon (1985), married men and women report greater psychological well-being and happiness, enjoy better physical and mental health, and experience less psychological distress than people who are single, divorced or widowed.

Although Argyle (1987) reported little gender difference in satisfaction with life as a whole, some evidence suggests that males gain greater health benefits from marriage than females (Pearlin & Johnson, 1977; Gove, 1979). It is common for married men to score highest on measures of psychological well-being compared to married women and single women, who receive moderate scores, and single men, who score the lowest (Peplau & Gordon, 1985). Argyle (1987) also reported little gender difference in positive affect but found women experienced more negative affect, particularly higher levels of depression and anxiety.

In this chapter an overview of the general literature on marital intimacy was presented, including various definitions of the terms “intimacy” and “love”, as well as gender differences. A review of Sternberg's (1986) triangular theory of love was also presented, together with the findings of recent studies which have used the associated Sternberg Triangular Love Scale. A brief overview of the literature on marital satisfaction, including gender differences (focusing mainly on the early years), and the relationship between marital and life satisfaction was also provided. In the next chapter, a review of the literature on marital and life satisfaction, sexual relations, and commitment in long-term marriages will be presented. As spousal caregivers of dementia sufferers are generally older, the literature relating to this population will be discussed in that chapter.
CHAPTER FIVE

SATISFACTION, SEXUAL RELATIONS, AND COMMITMENT IN LONG-TERM MARRIAGE: A REVIEW OF THE LITERATURE
In this chapter, a review of the literature on satisfaction, sexual relations, and commitment in long-term marriage will be provided. This will be presented under three main headings: the marital satisfaction of older spouses, including the relationship between marital and life satisfaction; sexual relations in long-term marriage; and commitment in long-term marriage. It will also include a review of the literature of specific relevance to this thesis, viz., spousal caregivers (who are generally older spouses), as well as gender differences.

**Marital Satisfaction: Older Spouses**

The quality and nature of marital relationships changes over time (Maxwell, 1985). For many older couples, there are increases in marital satisfaction after children grow up and leave home (Brubaker, 1990). With the departure of the last child, couples have more time to get reacquainted and examine their marriages. This reassessment enables them to rediscover the reasons why they married (Coleman, 1988).

However, as mentioned in Chapter 2, studies of marital satisfaction in long-term marriage have reported contradictory findings. Whereas more recent studies have indicated that some couples experience increased marital happiness and satisfaction during the later years of life (Roberts, 1979; Gilford, 1984; Weishaus & Field, 1988), studies reported in the 1960s (e.g., Blood & Wolfe, 1960; Pineo, 1961) described a continuous decline in marital satisfaction as time goes on. Nevertheless, as previously argued, the results from these latter studies could be explained by the fact that the marriages studied were of shorter duration. Pineo (1961) reported on the changes that occurred to marriages up to 20 years (that is between the early and middle years). Hence, the decline in satisfaction, or “disenchantment”, reported by Pineo would be in keeping with the dip in marital satisfaction found during the middle years, especially after the arrival of children (Coleman, 1988; Weishaus & Field, 1988; Brubaker, 1990).
Although later studies have examined marriages that have lasted 50 years or more, some of these could be criticised for having methodological problems. As Noller (1996) pointed out, it is important to bear in mind that in cross-sectional studies, where the sample consists of people married for 25 years or more, it is likely that such samples are composed of people who are in highly stable marriages with strong commitment to their spouse and the relationship. Spouses with lower levels of commitment were likely to be divorced by this time. Furthermore, cross-sectional studies assess marriages at only one period of time, and therefore it cannot be determined whether any observed differences are due to cohort differences or to differences in marital-stage. Indeed, only a longitudinal study, where the same participants have been observed over a long period of time, can show the true progression of a marriage (Weishaus & Field, 1988). Despite all this, I believe it is still valuable to report the findings of cross-sectional studies, especially where both quantitative and qualitative analyses have been carried out.

In a descriptive cross-sectional study of 50 couples, married between 50 and 65 years, Roberts (1979) found high marital adjustment scores and a high perception of personal health. Almost 80 percent of the participants in this study also reported high marital happiness. Significant elements that contributed to these long-term marriages were commitment, companionship, independence and qualities of caring. Many participants reported that their marriages had "had its ups and downs" and "its problems" but most never seriously considered divorce, although a few people said, with a smile, "Divorce, no; murder, yes" (p. 267). Roberts reported that, for the majority of couples, the benefits of their long-term marriages far outweighed the costs. Indeed, the results of this study suggested that understanding, love and affection are needs which continue across the lifespan.

In a "quasilongitudinal" study involving three successive age groups (55-62 years, 63-69 years, and 70-90 years), Gilford (1984) contrasted the marital satisfaction
of 318 married men and women, and again found older spouses to be experiencing moderate to high levels of marital satisfaction. This researcher also found that the husbands and wives aged 63 to 69 years reported the highest level of marital satisfaction. She suggested that these spouses may be at the stage of their lives where they still enjoy good health, have more leisure time to spend with each other, and have adequate income. These resources may enhance their marital lifestyle and happiness.

Conversely, in Herman’s (1994) cross-sectional study of 168 married men and women categorised in four successive age groups (55-62 years, 63-69 years, 70-77 years, and 78-88 years), no significant differences in overall marital satisfaction were found among the age cohorts. In comparing his elderly sample to the general population, Herman found that the latter years of married life were no more or less satisfying than any other phase of marriage. However, he did find that communication, sexual relations, and time spent together were still important sources of marital satisfaction for the older spouses in his study. In keeping with Herman’s finding of the ongoing importance of communication in marriage, Fouquereau and Baudoin (2002) found that communication/companionship scores were strongly related to overall marital satisfaction for their elderly French sample. However, sex/affection scores were only moderately correlated with overall marital satisfaction for that sample.

As discussed in Chapter 2, a longitudinal study of 17 couples whose marriages lasted for 50 to 69 years, was conducted by Weishaus and Field (1988). These researchers reported no continuous decline (or continuous increase) in affect. However, they found four different types of couples and called them curvilinear (seven couples), stable-positive (five couples), stable-neutral (three couples) and stable-negative (two couples). The most common pattern was the curvilinear (or “U”-shaped), which, as mentioned previously, involves high satisfaction in the early years, with a decrease in the middle years, followed by an increase in later years, after children have left home. All the spouses in Weishaus and Field’s (1988) study were accepting of each
other, committed to their marriages and enjoyed both shared and separate interests. It was also found that ill health (even serious illness) did not have a negative effect on marital satisfaction. In fact, the well spouses were observed to be nurturing to their ill spouses, who were openly appreciative.

More recent research has reported similar findings. Wright (1993), whose study was described in Chapter 2, found that the ability of the older well couples (comparison group) in her study to “take the attitude of the other” was the hallmark of their long-term relationships (p. 111). These older spouses enjoyed each other’s company, showed high affectional expression, and shared household responsibilities. There was low tension between spouses. Wright also found that over time the well couples increasingly valued each other as unique persons.

**Marital Satisfaction of Older Spouses: Gender Differences?**

Several small-scale studies of long-term marriage have found that older husbands report being happier and more satisfied with their marriages than older wives (Gilford, 1984; Weishaus & Field, 1988; Herman, 1994). However, in their longitudinal study, Weishaus and Field (1988) found that husbands tended toward some idealisation or denial, while the wives were more realistic in evaluating their marriages. The following is an excerpt from the verbalisations of a long-term married couple in the latter study highlighting this point:

In the 1969 interview one man said, “We’re very close, doubt there’s any better or happier marriage; we do everything together”, while his wife was more pragmatic: “Married life is something you work out, you don’t just quit. When things aren’t going the way you want, you have to weigh both sides and work out your own ideas” ... When this couple was interviewed again in 1983, the same pattern was apparent. He said, “Married life has been perfect, gets better with maturity. We’re closer now, don’t have arguments”. Her comment was, “He’s more willing to go along with me than before, and we’re not so emotional, but we still feel the same way as earlier” (p. 770).
Relationship between Marital and Life Satisfaction of Older Spouses

Morrissey, Becker and Rubert (1990) cited several studies carried out in the 1970s which suggested that satisfaction with marriage and family life was the most important factor of life satisfaction (overall psychological well-being) for individuals 65 to 74 years.

Stacey and Gatz (1991) reported the findings of a study which looked at cross-sectional age differences and longitudinal change on overall psychological well-being and positive and negative affect, as measured by Bradburn's (1969) Affect Balance Scale. Data were collected in 1971 and 1985 from 1159 male and female participants, ranging in age from 15 to 86 years at Time 1 and 29 to 100 years at Time 2. The cross-sectional analyses showed older age groups reported greater overall psychological well-being but lower positive and negative affect than the younger cohorts. The longitudinal results were quite consistent with these findings, with small but significant changes toward decreased positive and negative affect but increased overall psychological well-being. According to Bradburn (1969), happiness is the degree to which people's positive feelings about their lives outweigh their negative feelings. Stacey and Gatz (1991) found that for the middle-aged and older respondents, happiness was quite stable.

High life satisfaction scores for older spouses have also been reported by other researchers (Roberts, 1979; Marshall, 2001). Furthermore, utilising Diener, Emmons, Larsen and Griffin's (1985) Satisfaction with Life Scale, Marshall (2001) also found marital satisfaction and social support to be the strongest predictors of the cognitive component of subjective well-being for his elderly sample.

On the other hand, an older spouse who has experienced a loss or bereavement may not only experience psychological distress, but also intense loneliness. Indeed, the
chronic sense of loneliness can be debilitating. In fact, loneliness, and the social isolation which often accompanies it, has been described as “the most pervasive psychological symptom associated with bereavement” for an older person (Hill, Lund & Packard, 1996, p. 53). Even when they have a strong social network, an elderly bereaved person may still feel lonely and alone. Furthermore, according to Skolnick (1983): “even when we find someone to love, we may find that love is not enough” (p. 219). A married person may feel emotionally isolated and lonely because of the lack of “intimate ties” with his or her spouse. This may lead to depression and loneliness, even though they may be deeply in love with their spouse (p. 219).

Furthermore, in their cross-sectional findings, Stacey and Gatz (1991) reported that women had higher levels of both positive and negative affect than men, but only a significant difference was found on positive affect. Conversely, Tower and Kasl (1996) found that marital closeness was related to more depressive symptoms in elderly husbands and fewer symptoms in elderly wives. In other words, these authors found that husbands had more depression when their wives were emotionally dependent on them but wives had lower levels when they felt emotionally important to their husbands.

**Marital Satisfaction: Spousal Caregivers**

As discussed in Chapter 3, the irreversible personality changes in a dementia sufferer have a profound impact on the marital relationship, especially in regard to marital intimacy and marital satisfaction. Furthermore, Perry (2002) reported that the quality of the past (that is, pre-dementia) relationship was the key to understanding the spousal caregiver's perception of his or her caregiving experience.

A cross-sectional, descriptive, correlational study by Knop, Bergman-Evans and McCabe (1998) examined the perceived quality of the past and present marital
relationships, coping and depression in 63 spousal caregivers (aged 55-88 years) whose demented spouses either resided at home or in a nursing home. Data were collected by standardised measures relating to coping (viz., Jalowiec Coping Scale - Jalowiec, 1988) and depression (viz., Centre for Epidemiologic Studies Depression Scale - Radloff, 1977), and a Background and Demographic Data Sheet that included questions about the caregiver's perception of the quality of his or her past and present marital relationship. Results from this study showed that the majority of caregivers rated the quality of their past marital relationships very positively, while the quality of the present relationship was rated less favourably. These researchers also found a negative relationship between perceived quality of the past marital relationship and level of depression.

This finding corroborates earlier research (Morris, Morris & Britton, 1988) that suggested that caregivers who perceived their past marital relationship to be poor suffered more depression; while those caregivers who perceived their past (and present) to be good were less depressed. However, in my prior study (Rudd, 1993; Rudd, Viney & Preston, 1999), although I found that the majority of spousal caregivers rated the quality of their past marital relationships as “excellent”, they still experienced considerably higher levels of sadness, anger, anxiety, and guilt than a normative group.

Other studies have compared spouses of those whose partner has a non-dementing illness, as well as control groups, with spousal caregivers of dementia sufferers. Barusch and Spaid (1996) found that caring for a spouse with dementia was associated with less marital closeness than caring for a spouse who was physically, but not cognitively, impaired. Owens (2001) compared marital satisfaction in spousal caregivers of dementia sufferers, caregivers of non-dementing Parkinson's disease patients, and a control group of spouses. Using a battery of standardised instruments and open-ended questions, this researcher found that all caregivers reported significantly lower levels of marital satisfaction than the controls. However, the
dementia caregivers reported significantly lower levels of current marital satisfaction, and a greater decrease in satisfaction since the onset of the illness, than did the Parkinson's caregivers. Furthermore, the dementia caregivers reported more loneliness and depression than did the Parkinson's caregivers and control participants.

In discussing the findings of her study, Wright (1991) reported that the presence of Alzheimer's disease affected all dimensions of the marital relationship. She further stated:

Even in the earlier to middle stages of Alzheimer's disease, shared meaning between spouses was lost for instrumental aspects of their marriage, for expression of tension, sexuality, and for total marital quality. This incongruence between spouses from the AD group was particularly striking when noting that spouses from the well group had shared meaning in all dimensions of their marriage (p. 233).

Marital Satisfaction of Spousal Caregivers: Gender Differences?

Although no studies appear to have specifically compared the marital satisfaction of male and female spousal caregivers, Zarit et al. (1986) suggested that caregiving husbands were more likely to become distressed when their demented wives could no longer interact with them. However, Fitting et al. (1986) found that more caregiving wives reported a deterioration in their marital relationships than caregiving husbands. In fact, an unexpected finding in this latter study was that 25 percent of the husbands reported an improvement in their marital relationship since assuming the caregiver role. Many of these husbands enjoyed their new "caregiver" role and reported that they wanted to repay their wives for the love and care they gave them throughout their marriages, or for the sacrifices their wives had made for the family.
Relationship between Marital and Life Satisfaction of Spousal Caregivers

As discussed in Chapter 3, not surprisingly, the results of a study carried out by Pruchno and Potashnik (1989) found that spousal caregivers of dementia sufferers exhibited more symptoms of psychological distress, were more depressed and expressed higher levels of negative affect than the general population, matched for age and gender.

In a study comparing spouses and adult children caregivers of dementia sufferers, George and Gwyther (1986) found spouses reported poorer physical health and psychological well-being, together with more symptoms of stress, than adult children. Moreover, Owens (2001) found that spousal caregivers of both institutionalised and community-dwelling dementia sufferers reported significantly more psychological distress (that is, higher depression) than did the caregivers of non-dementing Parkinson’s disease patients and control participants.

On the other hand, Borden and Berlin (1990) found that spousal caregivers who reported that they “tried to look on the bright side of things” experienced higher levels of psychological well-being. Furthermore, positive appraisals of their circumstances, such as “I count my blessings and appreciate the things my husband is still able to do”, also contributed to higher psychological well-being; whereas, wishful thinking such as “I hoped a miracle would happen” was associated with lower well-being (p. 607).

Nevertheless, loneliness, and the psychological distress that accompanies it, were found to be an immense problem for spousal caregivers. Barusch (1988) found that the majority (55 percent) of her sample reported experiencing loneliness; while Fitting et al. (1986) found that younger caregiving wives were the most lonely, burdened and resentful cohort. This latter finding was partly supported by the
Alzheimer’s Association Australia’s (1994) study, which showed that loneliness was more strongly felt by spousal caregivers of early onset sufferers than other caregivers. Furthermore, Owens (2001) found that spouses of institutionalised and community dwelling dementia sufferers reported significantly more loneliness than did the caregivers of non-dementing Parkinson’s disease patients and control participants. The greatest factor contributing to the loneliness, emotional isolation and separation of the spousal caregiver has been reported to be the inability of the dementia sufferer to relate to the caregiving spouse (Gruetzner, 1992).

In line with past studies of dementia caregivers (Cantor, 1983; Fitting et al., 1986; Pruchno & Resch, 1989), Borden and Berlin (1990) found that male caregivers reported lower levels of psychological distress than female caregivers. This finding was supported by Rudd (1993; Rudd, Viney & Preston, 1999) who found that caregiving wives experienced significantly more anxiety, sadness and guilt, as measured by the Affects Balance Scale (Derogatis, 1975), than caregiving husbands. Borden and Berlin (1990) suggested that men may experience less distress because they approach their caregiving in a more active, instrumental way and, hence, feel a sense of efficacy, which reduces their risk of depression.

In summary, despite the methodological problems with cross-sectional studies, both these and longitudinal studies have found increases in the marital satisfaction of older spouses after children grow up and leave home. It also seems that understanding, communication, love and affection are needs that continue across the lifespan. In line with the findings of some small-scale studies of gender differences in the early years of marriage, some studies of long-term marriages have found that older husbands report higher marital satisfaction than wives. However, older husbands tend towards idealisation or denial. Research has also suggested that individuals who are married report greater life satisfaction and psychological well-being than people who are not married, and older age groups have reported greater overall well-being than younger
cohorts. Moreover, high life satisfaction scores have been reported for older spouses. Nevertheless, older spouses who have experienced a loss or bereavement may not only suffer psychological distress, but also intense loneliness. The literature has indicated that it is common for married men to score higher than married women on measures of psychological well-being. Furthermore, studies have found that women report experiencing more negative affect, particularly higher levels of depression and anxiety, than do men. Nevertheless, when one spouse has dementia, there is a profound impact on the marital relationship and spousal caregivers have reported lower levels of marital satisfaction than caregivers of spouses with physical and non-dementing illnesses as well as control groups. It seems that the spousal caregiver studies have failed to distinguish between male and female caregivers in relation to marital satisfaction, when clearly this is an important issue. Hence, gender differences have been a focus of my study. Furthermore, as might be expected, research has found that spousal caregivers of dementia sufferers have reported poorer psychological well-being, more symptoms of psychological distress and higher levels of negative affect than the general population, matched for age and gender, as well as other caregiver groups. Male caregivers have also reported lower levels of psychological distress than female caregivers, and caregiving wives have been found to experience significantly more negative affect.
Sexual Relations in Long-Term Marriages

According to our folklore, what is 'virility' at twenty-five becomes 'lechery' at sixty-five.

(Botwinick, 1978, p.43)

In this section of the thesis, literature will be reviewed that focuses on the nature of sexual relations in long-term marriages. Specific comparisons relevant to the study at hand will be made that concentrate on gender differences and spousal caregivers.

In a society where sex is associated with the young and healthy, the idea of sexual activity on the part of older people is often referred to in a derogatory way. In fact, many younger people (and even some health professionals) are uncomfortable and intolerant with the notion that older people have sexual interests and needs (Botwinick, 1978). When people in their seventies or eighties marry, younger people often react with disapproval or by referring to the couple as "cute" or "sweet" (Sherman, 1998). Therefore, the sexual relationships of older, particularly dependent, people are greatly influenced by the responses of their families and health professionals (Rose & Soares, 1993).

There is not only a general taboo in our society about the appropriateness of older people engaging in sexual activity, but it is also evident in the attitudes of the elderly themselves (Falk & Falk, 1980). I have heard many elderly husbands and wives say: "I'm too old for all of that anyway". However, as Sherman (1998) states: "sexuality and making love are part of the fabric of our lives; part of the very essence of being human - even for older people" (p. 4).

When most people think of sex they are referring to the act of intercourse. However, sex and sexuality encompasses a gamut of behaviours and feelings - kissing,
touching, cuddling, caressing, feelings of mutual affection and closeness and of being valued and wanted as a unique person (Sherman, 1998). As well as emphasising the important role of touch in maintaining sexual intimacy in marriage, Davies, Zeiss and Tinklenberg (1992) also stressed the strong relationship between touch and physical and emotional well-being across the life span. They cited Zefron (1975) who stated: “human beings need to be cuddled, stroked, and touched to be healthy and survive” (Davies et al., 1992, p. 7).

The middle years of marriage have been called “the era of distractions” (Coleman, 1988, p. 253), and the stresses and crises experienced by middle-aged couples (e.g., children, jobs, aging parents) can have a negative impact on a couple’s sexual relationship. However, if couples can weather the middle years, their sexual intimacy is likely to improve in later years, which Coleman (1988) described as “a time for tenderness” (p. 254). Although the frequency of sexual intercourse may be less than when they were younger, older couples often report that it is the quality of the feelings that go along with the sex that is important (Coleman, 1988). Indeed, in later years a couple’s sexual interaction may become a shared activity that generates positive affect, but may not involve the intense passion of the early years (Beach & Tesser, 1988).

More than half of the elderly couples in Roberts’ (1979) study, married over 50 years, reported that they were still sexually active or had been within the previous five years. Fifteen couples reported that they had ceased sexual intercourse within the previous five years, the reasons being “illness of self or spouse”, “loss of interest of self or spouse” or “loss of potency of husband”. Many spouses in this study expressed a continuing need to give and receive affection and to be cherished by someone (p. 269). Furthermore, according to Botwinick (1978), the key to maintaining sexual ability has more to do with good physical and mental health, and regular sexual activity,
rather than age. In this case, spouses should be able to perform sexually to age 80 and beyond.

**Sexual Relations: Gender Differences?**

*Love comes to men in a sexual context,*
*while sex comes to women in a love context.*

(Przybyla & Byrne, 1981, p.121)

There seems to be a general assumption that men are more interested in sex than women (Noller et al., 2001). However, it is also maintained (Botwinick, 1978) that men’s sexual ability and interest in sex diminishes with age, whereas there is little sexual aging in women until late in life. The most frequent sexual expression for heterosexual, older, married men and women is sexual intercourse and, in general, it has been asserted that the wife sets the upper limit on coital activity and the husband sets the lower limit (Botwinick, 1978). It has been suggested that for older couples, the husband normally controls the frequency of sexual intercourse (Przybyla & Byrne, 1981), and sexual activity often ceases when the husband loses interest or capability (Noller et al., 2001). A major reason for loss of capability is erectile difficulties caused by illness or medication (Morrissette, Zeiss & Zeiss, 1996). Nevertheless, Falk and Falk (1980) argue:

> Lower expectations, not incapacity or lack of desire, are the principal inhibitors of sexual activity in the elderly. In short, the whole culture militates against sex by the old, and older persons buy this themselves, since they were once the young who learned that sex belongs only to beautiful bodies or must lead to reproduction (p. 52).

Some elderly women in Roberts’ study believed that it was their husband’s right to expect “favours” from them, and it was their obligation to acquiesce. Therefore, when the husband ceases to require sexual intercourse, the wife is often relieved.
Coleman (1988) reported a study which found that, during the middle years, more couples stated that they were distracted from their sexual relationship by nonsexual priorities, but husbands and wives expressed this distraction in different ways. Men still maintained an interest in sex but were “troubled by attractions” towards other women; whereas wives seemed to lose interest in sex and found it difficult to relax (p. 253). Despite this, more couples reported that they were satisfied, rather than dissatisfied, with their married sex lives. For those in the later years of marriage, sexual frequency was less and men reported greater difficulty in getting and maintaining an erection. However, the husbands seemed to accept this situation and rated their sex lives as satisfactory; whereas the wives reported more dissatisfaction, describing themselves as “less excited, less confident, and more resigned” (p. 255).

Sexual Relations: Spousal Caregivers

*Sexual intimacy is as much a meeting of minds as of bodies, and when one half of that is gone, then it destroys it all.*

A caregiving wife in the video
*A Thousand Tomorrows*
(Terra Nova Films, 1995)

According to Hanks (1992), there are very few illnesses that have a greater impact on sexual intimacy than a dementing illness. In contrast to other debilitating illnesses, Alzheimer’s disease and other dementias involve a “loss of self”.

The identity and character of the patient are forever altered and obliterated. The marital bond and physical presence of the spouse endures, but the caregiver feels emotionally and sexually abandoned on the one hand, and trapped on the other (Hanks, 1992, p. 141).

Lonely, and longing to be touched, hugged and comforted, many spousal caregivers actively pursue intimate (often sexual) relationships elsewhere, although they rarely leave their demented spouses (Wright, 1991; Hanks, 1992; Rudd, 1993).
A change in a person's sexual behaviour (such as an increased demand for sexual intercourse or inappropriate sexual behaviour) can sometimes be an early sign of dementia, and can precede diagnosis (Sherman, 1998). Although disinhibited and inappropriate sexual behaviours in people with dementia are uncommon (Mace & Rabins, 1991; Davies et al., 1992; Sherman, 1998), studies have reported that some afflicted individuals occasionally expose themselves or masturbate in public; while others may use sexually explicit language, which is out of keeping with their premorbid personality, or make sexual suggestions or lewd comments (Haddad & Benbow, 1993).

Nevertheless, the majority of spousal caregivers are dealing with more common problems, such as a demented partner who has rejected them both sexually and emotionally. Other spousal caregivers may feel distressed about having a sexual encounter with someone who no longer knows their name and, at times, does not recognise them; or are bothered several times a night by a demented spouse who did not remember the sexual act that occurred earlier in the evening (Litz, Zeiss & Davies, 1990). Furthermore, a spousal caregiver may no longer be sexually interested in their demented partner because of poor personal hygiene, changes in appearance, and incontinence. Sherman (1998) reported one husband who referred to his demented wife's incontinence as "a passion killer" (p. 90).

Some spousal caregivers want to maintain a sexual relationship with their demented partner but are concerned by the problems that may arise. For example, a dementia sufferer may forget the sequence of behaviours involved in having intercourse, leaving the caregiver frustrated and unsatisfied; or the spousal caregiver may feel that they are taking advantage of, or violating, their demented partner who cannot refuse or give consent (Davies et al., 1992). Litz et al. (1990) cited the case of a male caregiver whose demented wife demonstrated sexual interest but he felt "guilt and
fear that he was essentially raping his wife by continuing intercourse” (p. 114). His anxiety over this issue led to him experiencing erectile dysfunction.

The majority of dementia sufferers experience a decline in their desire for sexual activity, many losing interest in sex altogether (Sherman, 1998). This is often caused by erectile failure in men with dementia, the incidence of which is higher than that reported by non-dementing men (Davies et al., 1992). In their study of couples with one spouse with mild to moderate dementia, Ballard, Solis, Gahir, Cullen and colleagues (1997) reported that only nine out of 40 spousal caregivers in their study continued to have a sexual relationship with their demented partners. Furthermore, almost 40 percent of the caregivers who were not sexually active, were dissatisfied with the absence of a sexual relationship. Hanks (1992) reported that in order to deal with on-going sexual frustration, while providing highly personal care (such as bathing and dressing their spouse), spousal caregivers often desexualised their demented partner by labelling them: patient, baby, sister, brother and so on. As one caregiver said:

I’ve come to think of my wife as a sister. It used to be that whenever I bathed her, I would think of all the times we showered together and made love. I wanted to touch her. Now I block it all out and don’t think about who she is or what we were to each other (Hanks, 1992, p. 143).

Nevertheless, some dementia sufferers show a marked increase in their need for sexual gratification, and may make excessive sexual demands on their spouses (Haddad & Benbow, 1993). This increased desire for sexual activity, called “hypersexuality”, is often associated with male dementia sufferers (Wright, 1991; 1993; Hanks, 1992). Wright (1991; 1993) found that her AD couples were twice as sexually active as her well couples; the higher average in the AD group reflecting high sexual activity initiated or demanded by the male Alzheimer’s sufferers.
Spousal Caregivers' Sexual Relations: Gender Differences?

As mentioned previously, in our society, men are perceived as being more sexually aggressive, while women are perceived as being less interested in sex and setting the limits to sexual activity. When dementia is present, this perception remains. Davies et al. (1992) reported that, in their experience, regardless of which spouse has dementia, the wife has been seen as losing interest in sex, whereas the husband has not. This notion may lead to a caregiving husband experiencing anxiety if his demented wife becomes disinhibited and, hence, the sexual aggressor, as he may fear that he is essentially raping her if she cannot give her verbal consent. On the other hand, for a caregiving wife, sex may be acceptable while her demented husband still recognises her, but when that ends she may want to avoid sex. She may then feel guilty for rejecting her spouse’s sexual demands, partly out of concern for depriving him and partly because of her belief that it is her “duty” to provide sex if her husband wants it (Davies et al., 1992).

Furthermore, Sherman (1998), reported that there are gender differences between male and female spousal caregivers in the methods they use to accommodate the increased sexual desires of their demented partners.

Men seem to employ more manual love-making techniques than women in order to satisfy their partners, as well as taking full advantage of occasional erections. Women seem to have many and more varied problems than men in coping with increased sexual demands although some go out of their way to satisfy a spouse. The frequent comment made by female partners, ‘It’s only sex now, not making love any more’ (pp. 83-84).

As far as remaining sexually active, Ballard et al. (1997) found that male caregivers were more likely to be involved in a continuing sexual relationship. However, most spousal caregivers no longer have sexual relationships with their demented spouses, and many are faced with difficult and unique ethical and moral dilemmas (Hanks, 1992).
In seeking other relationships, gender differences also emerge in the needs and wants of spousal caregivers. Hanks (1992) reported a caregiving wife as saying: "I love my husband and I know I'm a married woman. I would never abandon him. But I'm lonely and I long to be touched, hugged and comforted" (p. 142). While a caregiving husband said: "I've been celibate for the last five years and felt like I was just waiting for one of us to die ... A few months ago I met a new woman and it has changed my life" (p. 142).

In summary, research has shown that for long-term married couples sexual relations becomes a shared activity that generates positive affect, but may not involve the intense passion of the earlier years. For older, heterosexual couples, the husband normally controls the frequency of sexual intercourse, and sexual activity often ceases when he loses interest or capability. Furthermore, the quality of the feelings and behaviours (e.g., kisses, cuddles, touching, affection etc.) that go along with sexual intercourse is very important to older couples. However, dementia has a devastating impact on sexual intimacy. Although some spousal caregivers may be dealing with a "hypersexual" spouse, more commonly spousal caregivers feel emotionally and sexually abandoned. This often leads to intense loneliness and a longing to be touched, hugged and comforted. Hence, spousal caregivers may actively pursue other intimate relationships. With regard to gender differences, men are seen as being more sexually aggressive than women and, whether dementia is present or not, the wife will be seen as losing interest in sex; whereas the husband will likely be pursuing a continuing sexual relationship.
Commitment in Long-Term Marriages

In this section of the thesis, literature will be reviewed that focuses on commitment in long-term marriages and how it is studied. Specific comparisons relevant to the study at hand will be made that concentrate on gender differences and spousal caregivers.

Although it is frequently reported that satisfaction significantly predicts commitment (Morgan & Shaver, 1999), marital relationships endure despite the fact that marital satisfaction declines (Swensen & Trahaug, 1985). Furthermore, there is evidence to suggest that in many relationships there is considerable longitudinal stability even if level of satisfaction is low. Examples of unhappy but stable marriages would be: a spouse who remained in an abusive relationship, perhaps because they thought they could “change” the perpetrator; or marriages that continue out of concern for children’s emotional well-being, religious beliefs, or financial reasons. Marriages that endure in the absence of happiness have been described as “empty shells” (Adams & Jones, 1999). This is in line with Sternberg’s (1986; 1988b) description of “empty love” - a relationship with commitment, but with little or no intimacy or passion (see Chapter 4).

Historically it has been suggested that commitment to the institution of marriage is what keeps spouses in unhappy marriages. In recent years, however, with marriage viewed in a less permanent way, the nature of the commitment between husband and wife has become a more important factor. It has been suggested that some couples stay together because they are committed to each other as unique persons rather than to the institution of marriage (Swensen & Trahaug, 1985).

In a study investigating the past and present commitment of 72 spouses (36 long-term married couples), Swensen and Trahaug (1985) found:
1) for most couples there was a reciprocity in commitment to each other; 
2) for most couples there was a decline in commitment to each other as unique persons over the course of the marriages; 
3) those who were committed to their spouses as unique persons had significantly fewer marriage problems; 
4) for those who increased their commitment to each other as unique persons, there were not only fewer marriage problems but an increased expression of love for each other (p. 944).

Wright (1991; 1993) followed Swensen and Trahaug's (1985) methodology (discussed in the Method section, Chapter 7) to assess past and present commitment. However, contrary to Swensen and Trahaug's findings, Wright's well spouses (i.e., comparison group) reported increased commitment to their spouses as unique persons over the course of their marriages. In order to assess commitment to the future, Wright used a 6 point measure, that is part of Spanier's (1976) Dyadic Adjustment Scale (discussed in the Method section, Chapter 7). Her well spouses were high in their commitment to the future of their relationships. In describing the overall commitment (past, present and future) of her well spouses, Wright (1993) stated:

Well couples in this study epitomize mutually satisfying commitment and the 'best as yet to be'. With the passing of time, husbands and wives increasingly value each other as unique persons, and they have high commitment to the future of their relationship (p. 104).

Six empirical studies involving 1787 participants carried out by Adams and Jones (1997) explored the conceptual structure of marital commitment. The findings suggested that three primary dimensions of marital commitment could be conceptualised: (1) an attraction component, based on satisfaction, love and devotion; (2) a moral component, based on a sense of personal responsibility for maintaining the marriage and the belief that marriage is an important religious and social institution; and (3) a constraining component, based on fear of the financial, emotional and social costs
of terminating the marriage. The authors reported that the three dimensions represented the general factors of interpersonal commitment contained in most theoretical accounts of the construct, as well as paralleling couples' personal accounts of relationship commitment.

**Commitment: Gender Differences?**

Research has consistently shown gender differences in commitment, with women tending to be more committed to their partners than men (Adams & Jones, 1999). In her doctoral study, Brewer (1993, cited in Adams & Jones, 1999) found that husbands tended to struggle more with competing commitments, such as career, and felt in more conflict with commitment to marriage than did wives. This researcher also found that wives reported a greater variety of meanings for commitment and engaged in more commitment-related behaviours than did their husbands.

However, Swensen and Trahaug (1985) found no significant differences between elderly husbands and wives on commitment at the start of their marriages, at the present time, or in their total commitment scores. There were also no significant differences on past, present and future commitment between well husbands and wives in Wright's (1991; 1993) study.

**Commitment: Spousal Caregivers**

Contrary to her well spouses, Wright's (1991; 1993) caregiver spouses indicated no increase or decrease in commitment over the course of their marriages. In fact, these caregivers reported remaining equally committed to the institution of marriage and the unique person. Wright (1993) commented that it was "remarkable" that the caregivers reported the same level of commitment. She said: "For caregivers, faithfulness and gratitude are remarkably powerful sentiments in maintaining the image of the spouse as a valued person" (p. 105). Nevertheless, when it came to commitment
to the future, Wright found the caregivers scored significantly lower in their commitment to the future than her well spouses. In providing an explanation for this finding, Wright (1993) said:

Why? Because commitment to the future requires energy. If the caregiver's own physical and emotional health is failing, then despite past marital happiness, despite still valuing the spouse as a unique person, and despite faithfulness and gratitude ... commitment to the future of the relationship is affected (p. 104).

As far as I am aware, no studies have included gender differences when researching commitment of spousal caregivers of dementia sufferers. In her study, Wright (1993) did not distinguish between male and female caregivers when she measured past, present and future commitment. Again, I have endeavoured to address this issue in my study.

In summary, it seems that marital relationships endure despite declining marital satisfaction. These marriages are often referred to as “empty shells” or “empty love”. It has been suggested that spouses stay in unhappy marriages because of commitment to the institution of marriage. However, in more recent times, couples are staying together because they are committed to each other as unique persons. In fact, research has indicated that even spousal caregivers of dementia sufferers are equally committed to the unique person as well as to the institution of marriage. However, whereas older well spouses have reported high commitment to the future of their relationship, spousal caregivers' commitment to the future is lower. With regard to gender differences, research, in general, has shown that women tend to be more committed to their partners than men. However, studies of older couples have reported no gender differences.

In this chapter, the literature on marital satisfaction, and its relationship to life satisfaction, as well as sexual relations and commitment in long-term marriage, together with gender differences was reviewed. A review of the literature in these areas relating
to spousal caregivers of dementia sufferers was also presented. In the following chapter, concepts from Kelly's (1955) PCT, together with details of the conceptual models, aims, research questions, and hypotheses, which I attempted to test in the original study, will be presented.
CHAPTER SIX

PERSONAL CONSTRUCT PSYCHOLOGY: THEORETICAL FRAMEWORK FOR CONCEPTUAL MODELS
As explained in Chapter 1, in this study, I originally set out to examine the impact of dementia on the intimate marital relationship. Hence, in order to formulate testable hypotheses, a conceptual model needed to be developed. As I had previously successfully developed and tested a constructivist model of spousal caregivers’ bereavement (Rudd, 1993), based on concepts from PCP (Kelly, 1955), I was eager to use this theory again. I refer the reader back to Chapter 1 for an outline of my prior study.

In searching for PCP accounts of marital intimacy, I came across Neimeyer and Hudson’s (1985) model of marital relationships, which these authors devised and tested with regard to differences between satisfied and dissatisfied spouses (see details later this chapter). I decided to follow this model, but extended it to include both older spouses and spousal caregivers of dementia sufferers. In doing this, two models emerged: the first, a model of intimate marital relationships in general and, the second, a model of the impact of dementia on the intimate marital relationship (Rudd & Viney, 1998). I attempted to test the latter model. Both models were based, in part, on concepts from PCP (Kelly, 1955) and drew on the work of Neimeyer and Hudson (1985) and McCoy (1977; 1980), as well as on relevant empirical literature (detailed in earlier chapters).

In this chapter an overview of those concepts from Kelly’s (1955) PCT that are relevant to an understanding of my approach will first be presented, followed by brief details of Neimeyer and Hudson’s (1985) model. The model that I attempted to test in this study will also be discussed; however, as it became redundant to this study, full details of the models can now be found in Appendix A. The initial aims, research questions and hypotheses will also be presented.
Concepts from Personal Construct Theory

Other things being equal, the man confronted with the alternative of marriage will choose marriage if that appears to provide him with an opportunity to enlarge or secure his anticipatory system. While it carries some uncertain implications, eventually he hopes that through marriage his world will become more predictable.

(Kelly, 1955, p. 523)

It is not intended here to provide an exhaustive account of Kelly’s (1955) theory. Rather, the focus will be on those central issues that have particular relevance to this thesis. Kelly’s basic assumption is that people try to make sense of their world by interpreting what has happened in the past as well as the present, and anticipating what is going to happen in the future. Individuals interpret and anticipate events by using their unique personal construct systems. Each person has his or her own view of the world which provides hypotheses about what will happen in given future situations. Their anticipations (or predictions) will either be validated (confirmed) or invalidated (not confirmed). Invalidated constructs can be revised or replaced. Kelly is therefore asserting that the way people approach their lives is similar to the method scientists use to study the world; hence, his “person as scientist” metaphor (Kelly, 1955).

According to Kelly (1955), a construct is a way of viewing the world and makes a discrimination between objects, people, or events (known as elements) in terms of similarity and contrast. Constructs are represented as dichotomous abstractions, such as “good-bad”. In the process of construing these elements, people find that some constructs are more useful to them than others. The range of experiences to which people might find a construct applicable is called its range of convenience. A construct which can embrace new elements within its range of convenience is called a permeable construct. Impermeable constructs, on the other hand, are not readily open to such inclusions. Furthermore, two principles that are of
central importance to an understanding of PCT (Walker, 1996) are that people both differ from (individuality), and are similar to (commonality), other people in their construction of events (Kelly, 1955).

Although Kelly (1955) sees people in a constant state of change, it is very difficult for individuals to change their core constructs, which they use to maintain their sense of identity and existence. However, peripheral constructs are continually being altered and amended without serious modification to an individual’s core structure. Other constructs which are hard to change are those high in a person’s hierarchical system of constructs. These abstract constructs, that subsume others, are called superordinate constructs. Those which are lower down the construct system, and are more concrete, are known as subordinate constructs (Dalton & Dunnett, 1990). People tend to have fewer superordinate than subordinate constructs (Kelly, 1955).

Whereas some have considered that Kelly’s theory is an individualist position, others have seen it as a social theory (Walker, 1996). According to Walker (1996), in Kelly’s theory, “there is no individual set apart from the social ... Who we are is inextricably bound up with the relationships we have engaged in and continue to be part of (p. 15). In other words, the person Kelly theorized about was essentially a person-in-relation (Walker, 1990).

Kelly emphasised the importance of interpersonal understanding in PCT by calling our most important constructs, core role constructs: “One’s deepest understanding of being maintained as a social being is his [sic] concept of his core role” (Kelly, 1955, p. 502). Furthermore, role relationships, which he defined as based upon the construing of the other person’s construction processes, were of vital importance to Kelly. His Sociality Corollary states: “To the extent that one person construes the construction processes of another, he may play a role in a social process involving the other person” (Kelly, 1955, p. 95). Regarding the deep role relationship
of marriage, Kelly remarked: "there is no greater tragedy than the failure to arrive at those understandings which permit this kind of role relationship (Kelly, 1955, p. 100). Leitner (1985) defined true intimacy as being "a reciprocity of extensive ROLE relationships" (p. 85). Here, Leitner was using Kelly's definition of the term. [As he said: "To avoid confusion, Kelly's definition will be termed 'ROLE' ..." (Leitner, 1985, p. 84).]

According to Walker (1996), further evidence supporting the centrality of the social in PCT comes from Kelly's "defining of important emotions" (p. 14). He redefined certain commonly used emotions in construct terms (Walker, 1996). According to Kelly (1955), these constructs (or emotions) accompany transition. For example, Kelly (1955) redefined guilt as "the awareness of dislodgement of the self from one's core role structure" (p. 565), and hostility as "the continued effort to extort validational evidence in favor of a type of social prediction which has already been recognized as a failure" (p. 565). He also redefined threat as "the awareness of an imminent comprehensive change in one's core structures" (p. 489), and anxiety as the awareness that "the events with which one is confronted lie outside the range of convenience of one's construct system" (p. 495). McCoy (1977) extended Kelly's set of emotions, to include both positive and negative emotions defined within a PCP framework. As she said: "Our construing man [sic], Homo Construens, can now be seen as happy or sad, in love, angry, bewildered, contemptuous or contented" (McCoy, 1977, p. 121).
Neimeyer and Hudson's Model of Marital Relationships

Marriage can be viewed as a vital form of intimate colleagueship in which two personal scientists develop an enduring collaboration with respect to one another's important life projects.

(Neimeyer & Hudson, 1985, p. 129)

According to Neimeyer and Hudson's (1985) model of marital relationships, "satisfying marital relationships involve a continuous and reciprocal process of personal elaboration" (p. 129). This requires spouses to both support and extend their partner's way of viewing the world, and two processes involved in this endeavour are validation and extension (Neimeyer & Hudson, 1985). According to these authors, "validation occurs when individuals obtain evidence in favor of their social hypotheses" (p. 129). With regard to extension, Neimeyer and Hudson (1985) state:

Because Kelly's (1955) personal scientist model implies that individuals seek not only to confirm, but also to extend their interpretive frameworks, it becomes important to study those processes by which they enlarge their existing network of constructions. Interpersonal understanding or sociality (Kelly, 1955, pp. 95-103) represents one vehicle for this personal elaboration (p. 133).

Neimeyer and Hudson (1985) tested their model by making predictions concerning differences between satisfied and dissatisfied couples in terms of their ability to validate and elaborate one another's construct system (p. 130). In their study of 20 couples (married for an average of 2.7 years) Neimeyer and Hudson (1985) found that satisfied couples validated and understood one another more accurately than dissatisfied couples. Furthermore, the difference between groups in understanding was due to satisfied spouses showing greater understanding at superordinate levels (that is, along more important constructs), whereas there was no significant difference between
the groups at subordinate (that is, less important) levels. Satisfied partners also showed more mutual understanding.

**Model of the Impact of Dementia on the Intimate Marital Relationship**

As discussed previously, and as can be seen from Chapter 8 onwards, the models in this study became redundant. Therefore, only an outline of the model, which I attempted to test, is presented hereunder (the full models are set out in Appendix A). As stated above, the models are based on concepts from PCP (Kelly, 1955) and follow Neimeyer and Hudson's (1985) model of marital relationships, as well as the work of McCoy (1977; 1980) and relevant empirical literature. It will be noted that, although coping with changes to marital intimacy was subsequently omitted from this present study, it remains in the original model and hypotheses.

**Outline of Model Intended to be Tested in this Study**

The constructivist model of the impact of dementia on the intimate marital relationship proposed that spousal caregivers of dementia sufferers would experience invalidation of their core role construing, and therefore experience negative emotions (such as sadness, anger, and guilt) (McCoy, 1980). They would also experience misunderstanding, two reactions to which are threat and anxiety (Neimeyer & Hudson, 1985). Furthermore, spousal caregivers' marital relationships would be non-reciprocal. They would also experience less intimacy, less passion, and be less committed to their marital relationships than long-term married men and women not married to dementia sufferers. However, they would be experiencing the same companionate kind of love; that is, their individual scores would be higher on intimacy and commitment and lower on passion. These spousal caregivers would also feel helpless and lacking control. Because of the impact on marital intimacy of the dementia sufferers' early personality changes, there would be no differences between the spousal caregivers with regard to
gender, place of care (i.e., home or nursing home), or age of caregiver (i.e., caregiver of either early or late onset dementia sufferer).

**Initial Aims and Research Questions**

**Initial Aims**

Initially, the aim of this research was to examine the impact of a dementing illness (in one partner) on the intimate relationships of married couples as experienced by spousal caregivers, and to investigate how these caregivers coped with changes to their marital intimacy. More specifically, the initial intention was to develop a general model of intimate marital relationships as well as a model of the impact of dementia on the intimate marital relationship. The research then aimed to test the latter model to compare men and women who were spousal caregivers of dementia sufferers with men and women not married to such sufferers with regard to satisfaction with their intimate marital relationships, including differences with regard to the components of marital love, and how they coped with any changes to their marital intimacy. Overall gender differences were also to be tested.

**Initial Research Questions**

1) Do spousal caregivers of dementia sufferers differ from men and women who are not married to such sufferers in relation to satisfaction with their intimate marital relationships?

2) Are there any gender differences within or between the groups in relation to satisfaction with their intimate marital relationships?

3) Do spousal caregivers of dementia sufferers differ from men and women who are not married to such sufferers in relation to the components of marital love; that
is, in terms of intimacy, passion, commitment and the "kind of love" they are experiencing?

4) Are there any gender differences within or between the groups in relation to the above components of marital love?

5) Do spousal caregivers of dementia sufferers differ from men and women who are not married to such sufferers in how they cope with changes to their intimate marital relationships?

6) Are there any gender differences within or between the groups in relation to coping with changes to their intimate marital relationships?

7) Are there any differences between home or nursing home caregivers or caregivers of early onset or late onset dementia sufferers with regard to any of the above.

**The Hypotheses Intended to be Tested**

The model of the impact of dementia on the intimate marital relationship led to the following hypotheses which I attempted to test:

**Satisfaction with the Intimate Marital Relationship**

1) It is hypothesised that men and women who are spousal caregivers of dementia sufferers (regardless of the place of care of the dementia sufferers or the age of the caregivers) will be more dissatisfied with their intimate marital relationships than men and women who are not married to such sufferers. That is:

(a) Spousal caregivers will experience more invalidation of their core role construing, as evidenced by them experiencing more negative emotions and less positive emotions;
(b) spousal caregivers will experience more misunderstanding, as evidenced by them experiencing more threat and anxiety;

(c) spousal caregivers will experience less reciprocity in their marital relationships.

2) It is hypothesised that:

(a) men will not differ from women in relation to satisfaction/dissatisfaction with their intimate marital relationships, whether they are married to a dementia sufferer or not; however,

(b) the meanings of marital intimacy will differ for men and women.

Components of Marital Love

3) It is hypothesised that men and women who are spousal caregivers of dementia sufferers (regardless of the place of care of the dementia sufferers or the age of the caregivers) will experience less intimacy, less passion and be less committed to their spouses than men and women who are not married to such sufferers. However, both these groups of middle-aged and older spouses will be experiencing a companionate kind of love.

4) It is hypothesised that males will differ from females in relation to intimacy, passion, and commitment to their spouses, whether they are married to a dementia sufferer or not.

Coping with Changes to the Intimate Marital Relationship

5) It is hypothesised that men and women who are spousal caregivers of dementia sufferers (regardless of the place of care of the dementia sufferers or the age of
the caregivers) will *not cope as well* with changes to their intimate marital relationships as men and women who are not married to such sufferers in that:

(a) spousal caregivers will feel *more* helpless and lacking control; and

(b) they will *differ* in how they attempt to cope with these changes.

6) It is hypothesised that males will *differ* from females in how they attempt to cope with changes to their intimate marital relationships, whether they feel competent and in control, or helpless and lacking control, and are married to a dementia sufferer or not.

When I commenced this study, there was no successful means of measuring validation-invalidation for *individuals*. The methods adopted by Neimeyer and Hudson (1985) could only be used with dyads. I therefore had little choice, at that stage, but to attempt to follow McCoy's (1977) elaboration of Kelly’s emotions and her argument that “positive emotions are those which follow validation of construing. Negative emotions follow unsuccessful construing” (McCoy, 1980, p. 97), and attempt to measure validation-invalidation with content analysis scales of positive and negative affect. Of late, there has been justified criticism in the literature regarding McCoy’s claims (e.g., Walker, Oades, Caputi, Stevens & Crittenden, 2000). Walker et al. (2000) state: “None of us are likely to experience happiness if we receive confirmation that a core construct about our incompetence is true” (p. 102). However, these authors concede that:

It may be the case ... that what Bannister (1965) termed serial invalidation will result in a preponderance of negative emotions and serial validation in positive emotions (p. 102).

Nevertheless, as the original study changed direction, and the above models and hypotheses could no longer be tested, the measurement of validation-invalidation was no longer an issue. (The reader is referred to the end of Chapter 7 for a presentation of
the new aims of this study, and a description of how the dependent variables were measured.

In this chapter I presented concepts from Kelly’s (1955) PCT and brief details of Neimeyer and Hudson’s (1985) model of marital relationships, which led to the conceptual models in this study. The original aims, research questions and hypotheses (which I attempted to test) were also outlined. Although these models, aims and hypotheses became to a large extent redundant, it was essential that the original study be presented in order that others could understand the nature of the journey I have undertaken. In the next chapter, I shall introduce my 124 research participants and the methodology used to collect the data.
CHAPTER SEVEN

METHOD
I commence this chapter by introducing the 124 married men and women who participated in this study. The procedure for collecting the data is then reported, followed by the instruments and methods used. The research design, changes to the original study, and the methods used for analysing the data will then be addressed.

**The Research Participants**

One hundred and twenty four research participants took part in this study. The caregiver group consisted of 61 spousal caregivers of dementia sufferers (30 husbands and 31 wives), aged between 48 and 88 years, and married to their spouses for an average of 41.4 years. The comparison group consisted of 63 men and women whose spouses did not have a dementing illness (30 husbands and 33 wives, including 18 married couples), aged between 48 to 84 years. The comparisons were married to their spouses for an average of 41.9 years. All research participants lived in either New South Wales or the Australian Capital Territory, Australia. As discussed in Chapter 2 no spouses with dementia were interviewed, and it was the individual husband's or wife's perception of his or her intimate marital relationship that was the focus of this study. Therefore, the men and women in the comparison group who were married to each other were treated as individuals and formed part of either the male comparison group or female comparison group.

In the caregiver group, 29 were spousal caregivers of early onset dementia sufferers (11 husbands and 18 wives) and 32 were spousal caregivers of late onset dementia sufferers (19 husbands and 13 wives). Also, 31 were home caregivers (12 husbands and 19 wives) and 30 were providing ongoing nursing home care (18 husbands and 12 wives). The caregivers' impaired spouses living at home had dementia for a mean of 4.3 years (SD 2.0; range 1 to 10 years) and the caregivers' impaired spouses living in nursing homes had dementia for a mean of 8.3 years (SD 4.0; range 3 to 17 years). As stated above, the comparison group included 18 married
couples which meant that the data for this group were not independent and therefore some separate analyses had to be carried out (see Results section, Chapter 9).

A number of aspects of the participants' circumstances were collected in a demographic and psychosocial survey (see Appendix B). The variables chosen were based on my prior study (Rudd, 1993), as well as those found relevant by Wright (1991; 1993). Further details and analyses based on this demographic and psychosocial data are reported in the Results section (Chapter 9).

**Procedure**

**The Recruitment of the Research Participants**

The research participants for the caregiver group in this study were recruited through Alzheimer's support groups, *Intouch* (the quarterly journal of the Alzheimer's Association NSW), a local newspaper article, respite centres, day-care centres, nursing homes, and other organisations providing services to caregivers of dementia sufferers. Initial contact with each spousal caregiver was made, either by telephone or in person, by the social worker, psychologist, matron, or community worker connected with the relevant organisation. Participants recruited from the *Intouch* and newspaper articles contacted me directly. All potential research participants were given a copy of the Research Project Information Sheet (see Appendix C) which sets out details of the study, or if the initial contact was made by telephone, the study was explained to them in terms of this Information Sheet. If they agreed to be interviewed, I was contacted and then took steps to arrange a mutually convenient appointment.

The research participants for the comparison group in this study were recruited through retirement villages, senior citizens' centres, churches, the University of the Third Age (U3A) and other organisations for older people. I either contacted the organisation by telephone or letter and explained my study to the person in charge and
asked for his or her help in recruiting volunteers, or obtained permission from that person to attend a group meeting so I could talk to the people directly. The study was again explained in terms of the Research Project Information Sheet. Although this Information Sheet requested that the participants for the comparison group be aged 50+, volunteers aged 48 and 49 were recruited. Since this Information Sheet was circulated my supervisor has also changed.

The topic of this research is extremely sensitive and some research participants were difficult to obtain; hence, it took me two years to collect the data for this study. It was particularly difficult to recruit long-term married men for the comparison group. I was surprised to find many middled-aged men would not volunteer as they were reluctant to talk about their intimate marital relationships; whereas elderly men were more willing to share their experiences with me.

The Interview

All interviews were conducted by me, the researcher, personally. I travelled extensively throughout New South Wales and the Australian Capital Territory interviewing the research participants in private, usually in their own homes. However, on a few occasions the interviews had to be held in other premises because the dementia sufferer was at home or the participant was at work. In these cases a quiet room was found in which to conduct the interview. The interviews for the participants in the caregiver group took an average of three hours each and for those in the comparison group an average of two hours each. The husbands and wives in the comparison group who were married to each other were interviewed separately one after the other.

All participants were assured of confidentiality. As marital intimacy is a very private issue for most people, and especially as many spousal caregivers had lost this part of their marriage, it was important to be sensitive to the participants' feelings.
Hence, time was spent building a rapport with them before commencing the interview. I listened carefully to what they had to say, and informed them of the availability of professional help at the end of the interview if they required it. The men and women who were spousal caregivers were often pleased to have someone to listen to them and most cried (some sobbing uncontrollably) during the interview.

After the participant had signed a Consent Form (see Appendix D), extensive demographic and psychosocial details were collected (see Appendix B), including information relating to the sexual aspects of his or her marital relationship. Data were then collected by the open-ended questions and standardised instruments described in the next section, which were administered in the following order:

* The Clinical Dementia Rating Scale (spousal caregivers only).
* Open-ended questions regarding the meanings of “intimacy” and “love”.
* Two “commitment to the spouse” questions (Swensen & Trahaug, 1985).
* Dyadic Satisfaction and Affectional Expression subscales of the Dyadic Adjustment Scale (Spanier, 1976; Spanier & Thompson, 1982).
* The Sternberg Triangular Love Scale (Sternberg, 1988b).
* Derogatis Affects Balance Scale (Derogatis, 1975).
* Three more open-ended questions in relation to: (a) their present intimate marital relationship (for collecting content analysis data); (b) past compared to present intimate marital relationship; and (c) coping with changes to marital intimacy.

The participants’ responses to all the open-ended questions were tape recorded, with their permission, and later transcribed verbatim by me.
Instruments and Methods for Data Collection

As mentioned in Chapter 2, most studies on marriage focus on the couple and include both partners in the dyad in order to make within-couple comparisons. Hence, standardised dyadic measures are generally used to collect data. However, most of these instruments are not able to be used with couples where one partner has dementia. Furthermore, in this study, I was interested in some questions for which there are no standardised measures, in an area where the likely outcome was not readily predictable from prior research. Hence, a combination of qualitative and quantitative methodologies was more appropriate. In line with Wright (1991; 1993) some standardised measures have been used. However, in view of the exploratory nature of the study, extensive data were collected from several open-ended questions. These are set out below, together with details of each standardised measure, including its reliability and validity, and details of how the measure was administered, rated and scored.

The Clinical Dementia Rating Scale

In my previous study (Rudd, 1993), severity of dementia was included as a covariate. Therefore, I decided to administer the Clinical Dementia Rating Scale (CDR) (see Appendix E), devised by Hughes, Berg, Danziger, Coben and Martin (1982), to the caregiver group to rate the severity of the sufferers' dementia, as perceived by these caregivers. The CDR has proven most useful when dementia is being studied and global assessment of cognitive functioning is required.

Reliability and Validity

The staging of clinical dementia in older persons by the CDR has shown good interjudge reliability ($r = .89$), when independently rated by clinicians (Hughes et al., 1982). Although the CDR was developed to be clinically-rated, Whitmont and Brodaty (unpublished data, cited in Brodaty, Griffin & Hadzi-Pavlovic, 1990) found that the CDR scores provided by relatives ($n=30$) significantly correlated ($r = .6, \ p < .05$) with
clinician-rated scores, indicating that relatives can reasonably accurately rate the severity of dementia. Furthermore, the fact that the CDR shows strong correlations with previously devised dementia rating scales (the Dementia Scale of Blessed, Tomlinson & Roth, 1968; the Short Portable Mental Status Questionnaire of Pfeiffer, 1975; and the Face-Hand Test of Fink, Green & Bender, 1952, all cited in Hughes et al., 1982) suggests that these scales all measure similar qualities.

Hughes et al. (1982) found that the CDR was able to distinguish unambiguously among elderly subjects with a wide range of cognitive function, from healthy to severely impaired. At six to nine months after entry into a longitudinal study (which of course would require further years), they found the original CDR had accurately predicted the subsequent rating. The CDR has also been successfully used in other studies (Brodaty & Hadzi-Pavlovic, 1990; Brodaty, Griffin & Hadzi-Pavlovic, 1990; Rudd, 1993; Rudd, Viney & Preston, 1999) to rate the severity of sufferers’ dementia as perceived by caregivers.

**Rating and Scoring the CDR**

The caregivers rated their demented spouses in each of the six cognitive and behavioural categories (see Appendix E): memory (M), orientation (O), judgment and problem solving (JPS), community affairs (CA), home and hobbies (HH), and personal care (PC). The demented spouse was then assigned a rating of healthy (CDR 0), mild (CDR 1), moderate (CDR 2), or severe dementia (CDR 3). The CDR also includes a rating of questionable dementia (CDR 0.5) for those who are neither clearly demented nor healthy. Hughes et al.’s (1982) recommended procedure for scoring the CDR was adopted.
Meanings of “Intimacy” and “Love”: Open-Ended Questions

As it was important to know how the research participants in this study construed the terms “intimacy” and “love”, they were all asked the following open-ended questions:

Question 1: I am interested in understanding the importance of intimacy and love in the relationships of people in long-term marriages, and how partners cope with changes to their intimate relationship. As these terms mean different things to different people, I would be grateful if you could first briefly tell me what the word “intimacy” means to you?

Question 2: Now could you please briefly tell me what the word “love” means to you?

As mentioned previously, their responses were tape-recorded (with their permission) and later transcribed verbatim by me. Thematic analyses were carried out on their responses to these questions to ascertain the research participants’ meanings of “intimacy” and “love” (see Chapters 9 and 10).

Present Compared to Past Marital Relationship: Open-Ended Question

It was important to know the perceived quality of the research participants’ intimate marital relationships in the past, in order to ascertain if both groups were similar before dementia changed the caregivers’ relationships with their demented spouses. Therefore, the participants were asked the following open-ended question:

Question 3: Could you please spend a few minutes to tell me how your present intimate relationship with your husband/wife is the same or different from your past relationship with him/her?

Again, their responses were tape-recorded (with their permission) and later transcribed verbatim by me. The data were then analysed to ascertain whether their present marital relationship was better, worse, or the same as their past marital relationship.
Measure of Commitment to the Spouse

In order to fully examine past and present commitment to the marital relationship, it was important to see if there had been a perceived change in commitment (or in the kind of commitment) over the course of the spouses' marriages. The research participants were therefore asked two independent questions based on Swensen and Trahaug's (1985) differentiation of commitment in long-term marriages. That is, two people may remain married because they are committed to the institution of marriage or they may remain married because they are committed to each other as unique persons.

All the research participants in this study were asked two questions: (a) "Why did you marry your spouse?" and (b) "Why have you stayed married to your spouse?". Answers such as "All my friends were getting married" and "I made the vow 'til death do us part" would indicate a spouse's commitment to the institution of marriage; while answers such as "I thought she was beautiful. I wanted to marry her the moment I set eyes on her" and "There's no-one I'd rather be with. I love her more than ever" would indicate the spouse is valued as a unique person.

Reliability and Validity

Swensen and Trahaug (1985) reported interjudge reliability of the answers to the two questions as .86. They also reported good face validity, and research using the two questions has established the measure's construct validity (Swensen & Trahaug, 1985; Wright, 1993).

Rating and Scoring the Two Questions

The answers to the two questions were either written out by the research participants themselves on the sheets provided or they dictated their answers and I wrote them down. Two independent raters then scored them in line with the procedure adopted by Wright (1993). That is, the research participants' answers were rated on a
continuum of 1 to 5, with 1 and 2 indicating that marriage was valued as an institution, 4 and 5 indicating that the spouse was valued as a unique person, and a 3 was given to answers that included both sentiments; for example, "We married for better or worse but I still love her very much". See Results section (Chapter 9) for interrater reliability for the two questions. The participant’s rating for question (a) would indicate their perception of past commitment, and their rating for question (b) refers to their present commitment.

The Dyadic Adjustment Scale

The Dyadic Adjustment Scale (DAS) (Spanier, 1976; Spanier & Thompson, 1982) is a paper and pencil measure. It is widely used in marriage research and was used by Wright (1991; 1993) with her AD and well couples. It can also be used with individuals (Spanier & Filsinger, 1983), so I attempted to use it in this study. The DAS has four subscales: Dyadic Consensus, Dyadic Cohesion, Dyadic Satisfaction and Affectional Expression. However, Spanier (1976) states that “researchers with more limited needs can use one of the subscales alone without losing confidence in the reliability or validity of the measure” (p. 22). As many of the statements in the Dyadic Consensus and Dyadic Cohesion subscales related to issues that were irrelevant to this study (such as career decisions, household tasks and dealing with in-laws and so on), I decided to only use the Dyadic Satisfaction and Affectional Expression subscales, however, the latter needed to be revised (Wright, 1991; 1993).

Reliability and Validity

The DAS has established content, criterion-related and construct validity as well as internal consistency reliability (alpha .96) (Spanier, 1976). Spanier and Thompson (1982) conducted a confirmatory factor analysis procedure on the DAS and found that the consensus, cohesion and satisfaction subscales were interrelated, but affectional expression was statistically orthogonal to the other three. Hence, these authors
suggested that additional affectional expression items be generated. In addition to the original items (extent of agreement over affection and sex relations, agreement/disagreement over being too tired for sex and not showing love, and frequency of kissing the spouse), Wright (1991; 1993) added five new items measuring affection. The new subscale yielded a Cronbach’s alpha of .85. The revised Affectional Expression subscale in this study was based on the work of Spanier and Thompson (1982) and Wright (1991; 1993); however, only four new affection items were added instead of five. These are indicated below, however, the item regarding “sleeping in the same bed” was inappropriate for a study where many partners were living in nursing homes.

Also, as within-couple comparisons were not being made in this study, it was of interest to ask the research participants about their perceptions of the affection they received from their spouses. Therefore, after the original item, “Do you kiss your mate?”, they were asked “Does your mate kiss you?”. The four new items were: “Do you lovingly touch your mate?” (“Does your mate lovingly touch you?”); “Do you put an arm around your mate?” (“Does your mate put an arm around you?”); “Do you cuddle your mate?” (“Does your mate cuddle you?”); and “Do you and your mate hold hands?”. As far as I am aware, this has not been done previously, but no measures of internal consistency, which included the perceived items, were made. However, it will be noted, that the data collected for the Affectional Expression subscale was not able to be used in the amended study (for reasons see Chapter 8).

**Rating and Scoring the Two Subscales**

The research participants were required to indicate the extent of their agreement or disagreement with the Dyadic Satisfaction subscale items with scores ranging from 0 to 5 for all items except the happiness line which ranged from 0 (“extremely unhappy”) to 6 (“perfect” happiness). The higher the score suggested the greater the satisfaction
with a maximum score of 46. The revised Affectional Expression subscale items ranged from 0 ("always disagree") to 5 ("always agree") for two items, 0 ("never") to 4 ("every day") for 9 items, and 0 ("yes") to 1 ("no") for two items with a maximum score of 48. The higher the score the greater the affectional expression. The two subscales are shown in Appendix F.

The Sternberg Triangular Love Scale

Although no one theory will successfully answer all possible questions about love, I felt confident in using Sternberg’s (1986; 1988b) theory (detailed in Chapter 4) and associated scale, the Sternberg Triangular Love Scale (1988b), with the research participants in this study to measure the intimacy, passion, and commitment components of love and to ascertain the "kind of love" that these middle-aged and older married men and women were experiencing.

Reliability and Validity

Sternberg sought to validate the Triangular Love Scale and simultaneously validate the triangular theory (Sternberg, 1988a; 1988b). Construct validation of Sternberg’s (1986) triangular theory of love was first attempted by two studies carried out by Sternberg (1988a). The construct validation considered issues of both internal and external validity of the theory and scale. I shall only include Study 2, which involved a replication sample somewhat larger than in Study 1, and set out to remedy deficiencies in the scale, which were observed in Study 1.

The participants in the validation Study 2 were 101 adults from New Haven (50 men and 51 women) aged between 18 and 71 years with a mean age of 31 years (SD 11). They were either married or currently involved in a close heterosexual relationship. The length of the relationships ranged from one to 42 years, with a mean of 6.3 years (SD 8.6) (Sternberg, 1988a).
The subjects in the validation study first completed a demographic questionnaire and a relationship satisfaction questionnaire which asked them to evaluate on a scale of 1 ("not at all") to 9 ("extremely") how satisfying, happy, rewarding, close, important, good, personally inspiring, emotionally intimate, passionate, and committed their current close relationship was. They also completed the Sternberg Triangular Love Scale as well as the Rubin Liking and Loving Scales. They rated each statement on the scales twice: once on how characteristic it was of their present relationship; and then on how important they felt the statement to be in making an ideal relationship (Sternberg, 1988a; 1988b).

Focusing on the Sternberg Triangular Love Scale, mean scores for characteristic ratings (out of a possible 9) were 7.39 (SD 1.19) for intimacy, 6.51 (SD 1.65) for passion, and 7.20 (SD 1.49) for commitment. The typical high scores were 8.6 for intimacy, 8.2 for passion, and 8.7 for commitment; whereas, the corresponding low scores were 6.2 for intimacy, 4.9 for passion and 5.7 for commitment. The high scores represented approximately the top 15 percent of scores; and the low scores, the bottom 15 percent. The mean scores for importance were slightly higher: 8.18 (SD 0.8) for intimacy, 6.75 (SD 1.3) for passion, and 7.64 (SD 1.12) for commitment. The typical high and low scores were also slightly higher than the characteristic scores. There were no significant gender differences on any of the three components (Sternberg, 1988b).

The internal-consistency reliabilities of the three components were all very high, which indicated that the items were measuring distinct attributes. For characteristic ratings, the coefficient-alphas were .91 for intimacy, .94 for passion, .94 for commitment and .97 overall. For importance ratings, they were .90 for intimacy, .91 for passion, .91 for commitment, and .95 overall (Sternberg, 1988a).

The Sternberg Triangular Love Scale was correlated with the Rubin Liking and Loving Scales, and then each of these scales was correlated with the ratings from the
measure of relationship satisfaction. Characteristic ratings were generally more highly correlated than importance ratings. Sternberg scale scores were more highly correlated with Rubin Love scores than with Rubin Liking scores. Furthermore, all three components of the Sternberg scale showed higher correlations with overall satisfaction than did either of the Rubin scale scores (Sternberg, 1988b).

Overall, the empirical data provided "quite good support for the triangular theory of love" (Sternberg, 1988b, p. 103). With regard to internal validation, both characteristic and importance ratings revealed a three-factor structure corresponding to the components of the triangular theory. With respect to external validation, correlations of Sternberg component scores (characteristic ratings) with overall relationship satisfaction ratings were high (median = .76 for the three subscales), and higher than those for the Rubin scales.

Chojnacki and Walsh (1990) also tested the reliability and concurrent validity of Sternberg's Triangular Love Scale. These investigators had 90 university students, who were currently involved in dating relationships, complete Sternberg's Love Scale as well as other measures. The scale demonstrated adequate internal consistency and 2-week test-retest reliability, but high subscale interrelatedness.

As I was focusing on each participant's perception of his or her present intimate marital relationship (that is, how characteristic the statements were at present), it was not necessary to collect importance data in this study.

*Rating and Scoring the Sternberg Triangular Love Scale*

All the research participants were administered the Sternberg Triangular Love Scale (Sternberg, 1988b), a paper and pencil instrument containing 45 statements measuring three components of love: intimacy, passion and commitment (see Appendix
These three components give rise to eight kinds of love. (For full details of the three components and kinds of love see Chapter 4.)

The research participants were asked to rate their responses to the 45 random statements (15 statements measuring each component) on a 1 to 9 scale, where 1 = “not at all”, 5 = “moderately”, and 9 = “extremely”. Intermediate points on the scale indicated intermediate levels of feelings. Sternberg’s (1988b) recommended scoring procedures were adopted. In brief, in order to obtain an individual’s average score for each of the three components, the ratings between 1 and 9 for his or her responses to each of the 15 statements were added up and divided by 15. Hence, the maximum score for each of the three components was 9.

The Derogatis Affects Balance Scale

In order to gauge how the research participants had been feeling generally (life satisfaction), the Derogatis Affects Balance Scale (DABS) was administered (see Appendix H). The DABS, which is a multidimensional, self-rating, adjective mood scale developed by Derogatis (1975), comprises forty items which have been factorially derived to represent eight primary mood dimensions, four positive and four negative. There are five words for each of the four positive affect dimensions (joy, contentment, vigour and affection) and five words for each of the four negative affect dimensions (anxiety, depression, guilt and hostility). The DABS provides three global scores: a Positive Affects Total, a Negative Affects Total, and the Affects Balance Index (which is the difference between them divided by 20). The standard time referent for the DABS, and the one used in this study, is “the past 7 days including today” (Derogatis, 1996).
Reliability and Validity

Although there do not appear to be any published studies regarding internal consistency and reliability of this scale over time, the DABS has excellent face validity (Templer, 1985). Also, the research using the DABS has established its construct validity. Sexually dysfunctional men and women were found to have higher Negative Score Totals and lower Positive Score Totals and Affects Balance Index than normal men and women (Derogatis & Meyer, 1979, cited in Templer, 1985). Transsexual men were found to have a significantly higher Negative Score Total and a significantly lower Positive Score Total than normal men (Derogatis, Meyer & Vazquez, 1978, cited in Templer, 1985). Cancer patients who scored in the more pathological direction on other measures exhibited more negative affect and less positive affect on the DABS, with long-term metastatic breast cancer survivors experiencing significantly more psychological distress than short-term survivors (Derogatis, Abeloff & Melisaratos, 1979).

Rating and Scoring the DABS

The research participants were instructed to rate each item in terms of the “degree” to which they have felt the emotion during the past seven days on a five point scale ranging from “never = 0” to “always = 4”. The recommended procedures for scoring the DABS were adopted and are included in Appendix H.

The Content Analysis Scales

The psychological states (set out hereunder), which were originally predicted as being experienced by the spouses in this study when asked to talk about their intimate marital relationships, were assessed using content analysis scales. The scales were applied to the research participants’ responses to the question that is set out in the next section.
Collecting Content Analysis Data: Open-Ended Question

The research participants were asked to respond for approximately five minutes to the following open-ended question:

Question 4: I'd now like you to talk to me for approximately five minutes about what your intimate relationship with your husband/wife is like for you at the moment, the good things and the bad, what it's like for you now. Once you have started I'll be listening to you; but I'd rather not reply to any questions you may have until the five minutes is over. Do you have any questions you would like to ask me before we start?

Their responses were tape-recorded, with their permission, and their verbalisations were later transcribed by me and cloned for the application of the nine content analysis scales used in this study.

Measurement by Content Analysis Scales

The usefulness of content analysis scales for the measurement of such states has been widely demonstrated (Viney, 1981; 1983; Gottschalk, Lolas & Viney, 1986). Content analysis is “based on the assumption that the language people use to express themselves contains information about the nature of their psychological states” (Viney, 1983, p. 542). It is a non-obtrusive way of listening to and interpreting the responses of research participants who are asked to talk freely about their experiences (Viney, 1983).

Content analysis overcomes many of the problems that arise when people are asked to describe their states, particularly the difficulties encountered through their emotional ambivalence or the effects of socially desirable responding (Viney, 1990). Content analysis also allows an ethical approach to discuss marital intimacy with husbands and wives that is open and honest, and can be used successfully in community settings. It gives the research participants the opportunity to deal with what
is important to them and not what is important to the researcher, as in rating scales and questionnaires (Viney, 1990). The results from content analysis scales appear to be less influenced by interviewer characteristics than are other measures (Gottschalk, 1982). Content analysis scales have been successfully applied to verbal communications with middle-aged and elderly people (Rudd, 1993; Rudd, Viney & Preston, 1999; Viney, 1986; Preston, 1987). Most importantly, they meet the personal construct criteria that research should focus on the experience and interpretations of the people being investigated (Viney, 1987). McCoy (1980) believes that the content analysis scale methodology is consistent with the personal construct psychology view of emotions, and agrees with Viney (1983) that they provide access to the construing processes associated with those emotions.

**Measuring Positive and Reciprocal Interactions**

The Sociality Scale developed by Viney and Westbrook (1979) was used to assess whether the research participants were currently experiencing satisfying interpersonal relationships with their spouses, by way of participating in positive and reciprocal interactions with them. The scale comprises four types of relationships. **Solidarity** was scored when reference was made to a nurturant or supportive relationship or common commitment, for example: “My husband is always there to help me”. **Intimacy** was scored when reference was made to personal satisfaction, for example, “My wife and I enjoy being together”. **Influence** was indicated by statements of power or control, for example, “She makes me take my medication”. Although **Shared Experience** is normally scored when the type of relationship is not clear, this subscale was not applicable in this study. The Sociality Scale also comprises the relationship roles of **Reactor** (speaker as sole reactor), **Initiator** (speaker as sole initiator) or **Joint Actor** (takes a joint role in interaction).
Although the total Sociality score was the main concern, it was also of interest to determine what type of relationship the spouses had (solidarity, intimacy or influence) and the type of role they most often saw themselves as playing (reactor, initiator, or jointly reacting or initiating interactions).

**Measuring Positive Affect**

The Positive Affect Scale developed by Westbrook (1976) was employed to assess positive affect such as happiness, love and satisfaction. Scoring of this scale focused on responses that referred to any feeling states that were pleasurable, agreeable or desirable (e.g., “I am so happy”; “I love my husband”; “It was terrific travelling together”; “We are very contented living in our unit”; “I wouldn’t change her for anything”).

**Measuring Negative Affect**

Sadness was assessed using the Hostility In Scale, which was developed by Gottschalk and Gleser (1969). Scoring of this scale focused on responses that referred to feelings of grief (e.g., “I’ve lost my whole relationship with him”); depression (e.g., “I can’t stop crying”); deprivation (e.g., “I don’t have anyone to hold me”); disappointment (e.g., “I don’t get any response from her”); despair (e.g., “I’m always rejected”); and lonesomeness (e.g., “I have nobody to talk to most of the time”).

The Hostility Out Scale, also developed by the Gottschalk-Gleser (1969) research team, was used to assess directly expressed anger and scored comments reflecting anger turned on others (e.g., “I got so angry with him that I hit him”; “I don’t like having sex with her anymore”); as well as on inanimate objects or external situations (e.g., “I hate this disease that robbed me of my husband”).
Guilt was measured by the Guilt Anxiety Subscale which is one of the six subscales of Gottschalk and Gleser's (1969) Total Anxiety Scale. To score on this scale the research participants made comments referring to feeling guilty for what they said or did (e.g., "Sometimes I feel so guilty for having another relationship"); "I feel terrible for yelling at her"); "I am really ashamed of myself for hitting him").

Measuring Threat (for original study)

Weekes (1999) convincingly argued that death anxiety, mutilation anxiety and separation anxiety can be understood as experiences of threat and can be measured by the respective subscales of the Total Anxiety Scale (Gottschalk & Gleser, 1969). The Death Anxiety Subscale was used to score references that related to fear or threat of death or dying (e.g., "I will probably die before he does"). The Mutilation Anxiety Subscale was used to score references to injury, tissue damage, or physical damage, or the threat of such (e.g., "I was a lot more virile before the kidney transplant"). The Separation Anxiety Subscale was employed to score references that related to fear or threat of desertion, abandonment, ostracism, loss of support, loneliness, loss of love or love object (e.g., "I always class myself as a widow with my husband still alive").

Measuring Cognitive Anxiety

The Cognitive Anxiety Scale developed by Viney and Westbrook (1976) was used to assess cognitive anxiety which occurred when husbands and wives had difficulty in making sense of their experiences. The scores on this scale effectively discriminate between psychological reactions to new situations and those that are not new. The kinds of comments that were scored on this scale included references to unusual experiences (e.g., "Taking my wife to the toilet was a new experience for me"); experiences for which extra information was needed before they could be made meaningful (e.g., "I didn't know people in their forties could get dementia"); incongruous experiences (e.g., "I always feel worried when he goes for more tests");
not knowing what to do (e.g., "I don’t know what’s happened to him, he’s like a stranger to me"); and overwhelming experiences (e.g., "I couldn’t believe that she thought I was her father").

**Reliability of the Content Analysis Scales**

According to Kelly (somewhat facetiously), reliability is “a measure of the extent to which a test is insensitive to change” (cited in Bannister & Fransella, 1986, p. 54). As Kelly (1955) saw people as constantly changing and in motion he would not expect a measure to yield almost identical scores for the same subjects on all occasions. I believe this assumption also applies when measuring the psychological states experienced by spousal caregivers of dementia sufferers and long-term married men and women not married to such sufferers. Although some stability in the content and organisation of superordinate constructs of the spousal caregivers and married men and women would be expected (Hinkle, 1965), some evidence of progressive modifications to construing would also be expected. Therefore, reliability of measures of construing would be expected to differ for different types of constructs (Preston, 1987).

Although it has been argued that stability over time is not necessary for measures of psychological states, which should vary in response to situational change, interjudge reliability is necessary. Interjudge reliability refers to the “consistency with which the assessment technique can be used by different, independent raters; that is, the consistency with which interpretations of verbal communications can be made” (Viney, 1983, p. 546). The means and ranges of the interjudge reliability coefficients from past studies, that used the content analysis scales adopted in this study, can be seen in Appendix I (Table I.1).
Validity of the Content Analysis Scales

Construct validity best reflects whether a content analysis scale is achieving its aims (Viney, 1983). Evidence of construct validity is revealed by the relationship of the scales with other indices. Any biases according to the sex, age, educational level and occupational status of the research participants should be known for every scale (Viney, 1983). Reported evidence from previous studies of the validity of the content analysis scales used in this study is extensively detailed in Appendix I (Table I.2).

The Scoring of the Content Analysis Scales and Interjudge Reliability for the Present Study

Standard scoring instructions for each scale indicate which categories of content are to be scored and what weightings are to be given (Gottschalk & Gleser, 1969; Westbrook, 1976; Viney & Westbrook, 1979; Westbrook & Viney, 1980). To allow for the increased opportunity for those who speak longer or faster to make more scorable statements, and thus achieve a higher score, a correction factor is used in which the number of words in each transcript are divided into 100:

\[
\text{CF} = \frac{100}{N}
\]

(Gottschalk, Winget & Gleser, 1969)

The score for each scale is defined as: Total Raw Score x CF. As some transcripts contain no scorable content and would all receive the same score, even though they differ in length of verbalisation, half the correction factor is added to each score: (Total Raw Score x CF) + 1/2 CF. A square root transformation is applied to this total in order to provide distributions of scores which have minimal skew. Thus, the final formula for calculating individual scores for all of the scales, except the Sociality Scale, is:

\[
\sqrt{\text{Total Raw Score x CF} + \frac{1}{2} \text{CF}}
\]
For the Sociality Scale, Viney and Westbrook (1979) found that the log transformation was more satisfactory, with a constant of 1 added to ensure positive scores. Hence, the formula for this scale is:

\[ SS = \log [(Total \ score \times CF) + 1/2 \ CF + 1] \]

Scoring of the 124 transcripts in this study was undertaken by me. Interjudge reliability of scoring was established by the random selection of a subset of 20 transcripts which were independently scored by a trained scorer before she received any information regarding the research participants. Correlations for the nine content analysis scales were as follows: Sociality 0.96; Positive Affect 0.96; Hostility In 0.96; Hostility Out 0.80; Cognitive Anxiety 0.91; Death Anxiety 1.00; Mutilation Anxiety 0.93; Separation Anxiety 0.95; and Guilt Anxiety 0.83. There were no significant differences between the mean scores of the two scorers when t-tests were performed.

_Footnote: Coping Measures Administered but now Omitted from this Study_

All research participants were also asked to respond to the following open-ended question in order to collect data on _coping with changes_ to the intimate marital relationship.

**Question 5:** When you experience situations or events (such as dementia, physical problems etc.) which change your intimate relationship from what it used to be, what do you do? How do you cope with these changes in intimacy?

As explained in Chapter 1, the volume of data collected was beyond the scope of this thesis and therefore, at this stage, analyses have not been carried out on the participants' responses to this question. Similarly, with regard to the hypotheses on _coping with changes_, it was intended to apply two more content analysis scales to the responses to Question 4 - the Origin Scale (Westbrook & Viney, 1980) to measure feelings of competency and control, and the Pawn Scale (Westbrook & Viney, 1980) to
measure feelings of helplessness and lacking control. These also have not been applied.

The Design

The study used a two by two factorial design. The between-subjects factors (or independent variables) were spousal group (caregiver or comparison) and gender of spouse (male or female). Although the caregiver group comprised of caregivers of early onset and late onset dementia sufferers and also home and nursing home caregivers, when it came to the analyses, there were no substantial differences between these cohorts of caregivers on marital intimacy. Therefore, all these caregivers were combined as the caregiver group. The dependent variables are listed in Table 7.1.

In order to understand marital intimacy as experienced by the spouses in this study, the dependent variables (with the exception of coping) were measured by the instruments and methods referred to. Due to the problems experienced during the data collection process (see Chapter 8), and the resulting redundancy of the conceptual models and hypotheses, I shall only set out the measures that I have been able to use. The three subscales of the Total Anxiety Scale (Death Anxiety, Mutilation Anxiety and Separation Anxiety), which were originally intended to measure Threat (Weekes, 1999) and the Cognitive Anxiety Scale, which was to measure Anxiety (Threat and Anxiety being two reactions of misunderstanding) will now be included in the measure of overall negative affect.
Table 7.1. Dependent variables and methods of measurement.

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<th>Measures</th>
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<td>Intimacy component of Sternberg Triangular Love Scale</td>
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<tr>
<td>Passion/Sexual Relations</td>
<td>Frequency of sexual intercourse per month from Demographic and Psychosocial survey</td>
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<td>Commitment</td>
<td>Commitment component of Sternberg Triangular Love Scale</td>
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<td></td>
<td>Past and present commitment - Swensen &amp; Trahaug’s two “Commitment to the Spouse” questions</td>
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</table>
The Methods Used to Analyse the Data

Data were analysed by submitting them to procedures from SPSS 6.1.1 for Macintosh. Multivariate analysis of variance (MANOVA) is recommended for analysing data with several dependent variables (Tabachnick & Fidell, 1989) and is commonly used for analysing content analysis scales when the scales are independent (Viney, 1986; Preston, 1987; Bell, 1990; Nagy, 1995; Rudd, 1993; Rudd, Viney & Preston, 1999). MANOVA was used in this study to test the effects of the two between-subject factors (or independent variables) on all the content analysis scales as well as the eight Derogatis Affects Balance Scale dimensions, the three components of Sternberg’s Triangular Love Scale, and the two “Commitment to the Spouse” questions.

When significant overall differences are found using the multivariate analyses it is necessary to inspect the univariate analyses to find out which of the dependent variables were affected. As this study was interested in the differences between the means of two groups for each factor (i.e., caregivers vs comparisons; males vs females) on each separate scale, the notion of Type 1 error refers to each individual comparison (Huitema, 1980). Furthermore, the interactions were also considered separately because they represent conceptually distinct questions (Maxwell & Delaney, 1990). Hence, the alpha level for all the analyses in this study was set at .05 per comparison. As well as multivariate and univariate analyses, t-tests of differences were used where applicable and thematic analyses were applied to the transcripts of several of the open-ended questions to identify themes and patterns.

In this chapter, I introduced the 124 research participants and set out, in detail, the methodology for the collection of the data. In the next chapter I shall discuss the unexpected issues which dramatically changed the focus of this study and present the new aims of this research.
CHAPTER EIGHT

JOURNEY INTERRUPTED
In this chapter I shall provide a personal account of the events that occurred to change the direction of this study. I shall first discuss the problems I encountered with the data collection process and my feelings of invalidation, which led to the necessity for me to re-construe the study. Finally I shall present my amended aims.

**Problems with Data Collection**

As stated previously, the data collection process took two years to complete because of the geographic area I covered and the number of research participants I interviewed. However, while conducting the interviews with the spousal caregivers, I encountered an unexpected problem which concerned me but somehow did not deter me from carrying on with (and eventually completing) the data collection. The problem was that many of the caregivers insisted that some of the items in the research instruments, particularly Spanier's (1976) Dyadic Adjustment Scale, "did not capture" their situations because they no longer had a “marital relationship” with their spouse. These caregivers therefore refused to respond to the items that asked about their current marital situations saying the questions were “not applicable” to them or “wrong and silly”.

In fact, some caregivers became quite hostile and upset. One elderly male nursing home caregiver seemed quite exasperated when he said:

"Look love, this piece of paper is nonsense. You obviously don’t understand my situation, but I can’t fill it in."
I was very quick to assure this man that the instrument to which he was referring - two subscales of Spanier's (1976) Dyadic Adjustment Scale - had not been designed by me. I explained that this was a valid and reliable marriage research instrument which unfortunately did not capture his current experiences. In time, and with my open-ended questions, I established a good rapport with this spousal caregiver. However, he was not the only one to complain. On another occasion a 49 year old female home caregiver of an early onset dementia sufferer became very angry when I asked questions about her marital relationship saying:

I'm his carer only; he's like a job to me. We don't have a relationship. I have a 24 hour-a-day job that I don't get paid for. ... I always class myself as a widow with my husband still alive.

This woman's comments were echoed by the majority (if not all) of the caregivers who now thought of themselves in a "caregiving relationship" rather than a "marital relationship". Many described their role as "caring for a baby". A 75 year old male nursing home caregiver said:

I haven't got my wife any more. What I've really got is a 5 foot 7 inch nine month old baby who is deaf and dumb and that's what I'm caring for ...

Others described their demented spouse as a stranger. I could relate to this as I, too, had thought of my mother as some sort of stranger. Despite this similarity, the spousal caregivers’ experiences were beyond my range of convenience (Kelly, 1955). I was obviously not truly understanding how they construed their situations, no matter
how hard I tried to get into their worlds. I had expected the caregivers to have "unsatisfactory" marital relationships, and even to say that they were in a "caregiving relationship", but when so many of them vehemently denied having a "marital relationship" at all (and they were not only talking about an intimate marital relationship), then I was quite bewildered. I had not read about this anywhere.

I was particularly surprised by the caregivers' refusal to complete the two sub-scales of Spanier's (1976) Dyadic Adjustment Scale which I administered, as the whole instrument was reported to have been successfully used by Wright (1991; 1993). Although Wright (1991) states that the scale's usefulness may be questioned because it "had to be supplemented with many open-ended questions in order to ferret out the essence of the relationships" (p. 236), she did not report any problems with data collection or that the caregivers in her study denied having a marital relationship. In fact, she had the demented spouses successfully complete the scale as well!

So the reconciliation of Wright's (1991; 1993) experiences with my own has been one of my dilemmas. I will discuss this in more detail in Chapter 13.

Interestingly, despite the fact that I had trouble collecting data with some of the standardised instruments, I had no problems with the open-ended questions even though I asked about their intimate marital relationships. This is probably because these questions not only allowed the caregivers to articulate that they "did not have a marital relationship", but also enabled them to go on and describe in their own words their unique experiences and how they felt about their situations. Furthermore, during
this part of the interview they were also able to express their emotions and many sobbed uncontrollably throughout.

Although I was aware that the marital relationships of the spousal caregivers would be significantly different from those of the spouses in the comparison group, it was only after the data collection process that I realised that the differences between these groups were a lot more complex than I had anticipated. I was not merely looking at “satisfactory” and “unsatisfactory” marital relationships as I had expected from the marital research literature. It appeared that the intimate marital relationships of the caregivers in this study were not only “unsatisfactory”, but these caregivers were insisting that they no longer regarded themselves as being in a “marital relationship” at all. I did not encounter any of these problems with the men and women in my comparison group (even though some of these spouses were on the brink of separation) and, as a result, I realised that there was something quite different (and somewhat unusual) about the relationships experienced by the spousal caregivers.

**Researcher’s Feelings of Invalidation**

The 180 hours or so that I spent with the caregivers in this study left me feeling “burnt out” and invalidated. During that time I regularly met with a psychologist for support and debriefing. Due to my extensive experience with caregivers of dementia sufferers I understood, expected, and was equipped to handle, their crying and sobbing. In fact, I even found that some of the men and women in the comparison group cried or shed a few tears. They all said that they had “ups and downs” during
their married life and some were experiencing serious health problems (some had heart disease and cancer, one man had recently undergone a kidney transplant, and one elderly man was a double amputee). I even understood, and was able to handle, the subtle advances made towards me by some of the male caregivers. Being caring and understanding can certainly be misconstrued when talking about intimate issues!

However, I was not prepared for feeling totally invalidated as a researcher. At first, I avoided facing the fact that I had missing data because I had pages of verbalisations from the caregivers and hence was able to justify that I had enough data. I therefore continued recruiting and interviewing for my comparison group. Then I started working on my conceptual model, which my original supervisor encouraged. Finally, the time came for the data analysis and I could not avoid the missing data any longer. I realised that I had to address the reasons for the missing data on the standardised instruments and could not just proceed with the data elicited from the verbalisations, even though I knew I was fortunate to have this. Had I simply relied on standardised instruments, which many researchers do, then I would not have a doctoral study at all.

During this time I felt anxious and hopeless as I tried to find excuses why I should not proceed with this study:

"I am too old for all this."

"I have a frozen shoulder so I can't type."

"My scholarship has finished so I need to find a job and earn some money."
The excuses were endless. Then to top it off, I presented my conceptual models at a conference in Brisbane (Rudd & Viney, 1998) and that experience not only invalidated me as a researcher but also as a presenter! I knew something was terribly awry with my study but I could not put my finger on it. Had I administered the wrong instruments? Maybe I had missed something in the literature? Finally, I assumed I did not have a study at all and was going to discard it. I reasoned that because I did not have the numbers I needed to make meaningful comparisons, then I did not have a study. Furthermore, my research questions and hypotheses, and even the model itself, seemed redundant when one group of research participants were denying that they presently had a marital relationship.

I changed supervisors and was given the opportunity to look at the study from a different perspective. I began to loosen my construing of this complex topic. I started working again, albeit slowly, but still did not know where I was headed. Then a family crisis brought not only my research but my whole life to an abrupt halt. I had lost my son, but not through death.

It was bizarre - his personality and behaviour (his identity) had suddenly, and radically, changed. I no longer recognised my bright, caring, loving son. He became a different person; he was very strange. His personality seemed to have been dismantled and then "re-frozen" into a new identity (Hassan, 2000). My husband, daughter and I could no longer relate to him and he did not want to relate to us. Within weeks he was gone. He eventually left his entire past life - family, friends, university colleagues, former church and ministers, activities - everything. This was a
trauma that immobilised me and I had 18 months leave of absence from my Ph.D. I shall briefly expand on this issue later in the thesis.

Re-construal of Study

In time I resumed my study and, despite some hiccups, progressed steadily. Then my supervisor insisted that I present my research to the Wollongong personal construct group. I am forever grateful for that experience because my wise, objective audience made me realise that the fact that I had missing data was my data. The group reinforced that the problem really did lie with some of the standardised instruments, which were simply not suitable to use with the spousal caregivers in this study. I had tried too hard to rigidly follow other researchers, particularly Wright (1991; 1993) and felt invalidated when I failed. At last I had realised that, in my study, the numbers were meaningless; it was the caregivers' words that were important. I had hundreds of pages of wonderful, rich, verbalisations and I knew I was free to proceed to completion.

Of course, this meant that I had to change the focus of my study. My models and hypotheses were indeed redundant. I had not made a mistake; I had stumbled across something new. I was no longer simply looking for differences between groups on marital intimacy! I shall begin to unravel this conundrum in Chapter 11.

**********

In the next Chapter, I shall present the results of the analyses that I carried out. It became apparent that other than the 6 point measure dealing with commitment to the future of the relationship, and the line scale measuring perception of marital happiness
(which are part of the Dyadic Satisfaction subscale), Spanier's (1976) Dyadic Adjustment Scale was not suitable for use with the spousal caregivers of dementia sufferers in this study. The husbands and wives in the comparison group had no problems with the subscales, and full scores have been generated for this group and may be used at another time.

Although a few of the caregivers commented that some of the statements in Sternberg’s Triangular Love Scale were “not applicable” to them, they did not object to completing the instrument as the 9 point scale gave them adequate scope for giving a considered rating. Furthermore, the majority of research participants in this study said that they enjoyed completing this scale.

**Amended Aims of this Study**

This study now aims to examine the complex nature of the intimate marital relationships of spousal caregivers of dementia sufferers compared to the intimate marital relationships of older men and women who are not married to such sufferers. Overall gender differences will also be examined. The study further aims to explain the type of relationship these caregivers are experiencing using PCT (Kelly, 1955) and, if necessary, by extending this theory.

In the concluding chapters I shall not be referring to the conceptual models or hypotheses, as they are no longer applicable. However, I shall integrate the results of the analyses, together with the research participants' own words, as I endeavour to fulfil the amended aims of this research. Furthermore, as the amended study was unexpected, I may need to introduce literature that has not been previously mentioned in the literature review, as I attempt to evaluate my findings and make some conclusions.
CHAPTER NINE

RESULTS
The results of the analyses carried out in this empirical study are presented in this chapter. As stated previously, the hypotheses set out in Chapter 6 are now redundant and will not be mentioned in this section. The analyses will be used instead to explain some of my unexpected findings and to help support my conclusions as I attempt to address the amended aims of this study, which were reported in the previous chapter. An explanation of the methods used to analyse the data, particularly the multivariate and univariate analyses, is set out at the end of the Method section (Chapter 7). Details and analyses of the demographic and psychosocial characteristics of the four groups which made up this total sample commence this chapter.

**Demographic and Psychosocial Details**

**Comparison of Caregiver and Comparison Groups**

The mean age of the caregiver group was 67.3 years (SD 9.4; range 48 to 88 years) and the mean age of the comparison group was 66.4 years (SD 9.5; range 48 to 84 years), while the mean age of the impaired spouses of the caregiver group was 69.4 years (SD 8.8; range 51 to 91 years) and the mean age of the well spouses of the comparison group was 66.2 years (SD 9.6; range 48 to 85 years). The caregivers were married to their spouses for a mean of 41.4 years (SD 12.0; range 12 to 61 years) and the participants in the comparison group were married to their spouses for a mean of 41.9 years (SD 10.5; range 13 to 60 years). No significant differences were found between the two groups on age (t = .56, ns), age of spouse (t = 1.89, ns) or length of marriage (t = -.28, ns).

Frequencies and percentages of the demographic characteristics and psychosocial details of the caregiver and comparison groups, presented as ordinal or categorical (nominal) data, are set out in Appendix B (Table B.1). The majority of participants in both groups were born in Australia, were Protestant and were currently unemployed, either because of retirement or because they had given up work to care for
a demented spouse. As well as being similar in age, age of spouse and length of marriage (as stated above), the two groups were also similar in spirituality and in the perceived quality of their past marital relationships. Chi-square tests were performed on this data and appropriate Bonferroni corrections for alpha were applied (Judd & McClelland, 1989). Although these chi-square tests showed no significant differences between the groups on overall levels of education and overall personal health, there were obvious differences in some categories. For example, 47.6 percent of comparisons had a tertiary education compared to 27.9 percent of caregivers, and 37.7 percent of caregivers described their health as either poor or fair compared to 15.9 percent of comparisons. Nevertheless, most caregivers (like comparisons) described their health as either good or excellent.

There was a significant difference between the groups on income level ($\chi^2 = 14.08, \text{ df } 4, p < .01$) with the comparison group having a higher annual income. This could be explained by the fact that caring for a dementia sufferer is both costly (especially when the afflicted person is in a nursing home) and limits the caregiver's earning potential. Also, the income of the men and women in the comparison group included their spouse's income. As might be expected, there was a significant difference between the groups in the perceived quality of their present marital relationship ($\chi^2 = 58.2, \text{ df } 2, p < .001$) with the comparison group rating it as significantly better.

Comparison of Husbands and Wives in Caregiver and Comparison Groups

The mean age of the male caregivers was 71.3 years (SD 8.7; range 51 to 88 years) and the mean age of the female caregivers was 63.5 years (SD 8.5; range 48 to 81 years), while the mean age of the male comparisons was 68.1 years (SD 8.7; range 50 to 84 years) and the mean age of the female comparisons was 64.8 years (SD 10.0; range 48 to 83 years). The only significant gender difference on age was between the
male caregivers and female caregivers ($t = 3.5, p < .001$). However, it might be expected that husbands of this generation would be older than wives. Nevertheless, there were no significant gender differences on mean age of spouse within and between the groups.

In turn, the mean years married of the male caregiver group (46.9 years, SD 9.5) was significantly higher than the mean years married of the female caregiver group (35.9 years, SD 11.8) ($t = 4.02, p < .001$). There was no significant difference between the male comparison group and female comparison group on length of marriage. However, as mentioned previously, these groups included 18 married couples.

See Appendix B (Table B.2) for a gender breakdown for frequencies and percentages of the demographic characteristics and psychosocial details of the husbands and wives in the caregiver and comparison groups. Again, chi-square tests were carried out and Bonferroni corrections for alpha applied. No significant differences were found between male caregivers and female caregivers, male comparisons and female comparisons, male caregivers and male comparisons or female caregivers and female comparisons on education level reached, income level, spirituality, personal health or perceived quality of their past marital relationship. However, with regard to the perceived quality of their present marital relationship, as expected chi-square tests showed significant differences between male caregivers and male comparisons ($\chi^2 = 26.9, df 2, p < .001$) and female caregivers and female comparisons ($\chi^2 = 33.4, df 2, p < .001$) with both male and female comparisons rating it as significantly better. However, there were no significant differences between the overall population of males and females with regard to perceived quality of either their present or past marital relationships.
The characteristics of the caregiver group with respect to age, length of marriage, education and income are representative of the broader population of English-speaking husbands and wives of dementia sufferers, living in Australia. That is, the sample displays variations among its members that are proportional to the variations that exist in the Australian population of spousal caregivers (Neale & Liebert, 1980). This has been confirmed by information obtained from the Australian Bureau of Statistics (1988; 1993) as well as from the demographic data presented by other researchers working in the area of spousal caregivers of dementia sufferers (Rudd, 1993; Rudd, Viney & Preston, 1999). Furthermore, the caregiver and comparison groups in this study are similar to Wright’s (1991; 1993) AD and well groups with respect to age, age of spouse, length of marriage, education and income.

In summary, the participants in the caregiver and comparison groups in the present study are similar in age, age of spouse, length of marriage, education level reached, nationality, employment status, religion and spirituality, personal health, and the perceived quality of their past marital relationships. The differences between the two groups on income level and the perceived quality of their present marital relationships might be expected from these cohorts. Similarly, there were no major gender differences within the groups; the differences that did occur would be expected between men and women of this generation. More importantly, there were no confounding differences between the male caregivers and male comparisons or female caregivers and female comparisons.

Although the caregiver group comprised of caregivers of early onset and late onset dementia sufferers and also home and nursing home caregivers, the original hypotheses predicted no differences between these groups. Despite these hypotheses becoming redundant, it was still necessary to carry out some analyses comparing these groups. In line with the original predictions, it was found that there were no substantial differences between these cohorts of caregivers on the dependent variables. Therefore,
as mentioned in Chapter 7, for the amended study all these caregivers were combined as the caregiver group.

**Analysis of Non-Independent Data**

As previously stated (see Chapter 2), because I left the dementia sufferers out of the study and focused on the experiences of male and female spousal caregivers only, then I had to focus on individuals, rather than couples, in the comparison group. However, due to availability of research participants, the comparison group (n=63) included 18 married couples. The men and women who were married to each other were interviewed separately (one after the other) and then treated as individuals, forming part of the male and female comparison groups (see Chapter 7).

The inclusion of married couples meant that the data for the comparison group were not independent. Hence, it was necessary to ascertain that the inclusion of these couples did not affect the analyses when the whole comparison group (n=63) was compared with the caregiver group (n=61). In order to test this, it was necessary to first split the comparison group into those husbands and wives, who were a couple and both interviewed ("couples" n=36) and those who were interviewed as only one partner in the dyad ("individuals" n=27).

T-tests were carried out for 18 major analyses, separately comparing the "couples" and caregivers and the "individuals" and caregivers, to see if the inclusion of "couples" made any differences to the results. The results showed no differences in 16 out of the 18 analyses.

Of the two differences in results, one was in the Commitment component of Sternberg's Love Scale with the mean score of the "couples" (8.6, SD 0.4) being significantly higher than the mean score of the caregivers (8.1, SD 1.0) (t = -3.86, p <
.001), while the difference between the latter and the mean score of the “individuals” (8.2, SD 1.1) was non-significant (t = .67, ns). As shown below, the mean of the overall comparison group (8.5, SD 0.8) was significantly higher than the mean score of the caregiver group (8.1, SD 1.0) at the .05 level.

The other difference was in the Cognitive Anxiety Scale with the mean score of the caregivers (1.6, SD 0.7) being significantly higher than the mean score of the “couples” (1.1, SD 0.7) (t = 3.13, p < .01), while the difference between the former and the mean score of the “individuals” (1.3, SD 0.6) was non-significant (t = 1.88, ns). As shown below, the mean score of the caregiver group (1.6, SD 0.7) was significantly higher than the mean score of the overall comparison group (1.2, SD 0.7) at the .01 level.

Several points need to be made regarding the above two differences in results. First, when splitting the comparison group into “couples” and “individuals” the sample sizes became small and uneven and this decreased the robustness of the tests (Jaccard & Becker, 1990). Second, because of the number of tests carried out, a correction factor should be applied which would make the difference in the Cognitive Anxiety Scale analyses disappear. This only leaves one difference in the results, which could happen by chance.

However, statistical significance is often misleading. For example, in the Commitment component analyses, the mean score of the “couples” is 8.6 and the mean score of the “individuals” is 8.2. As the maximum score is 9, both groups show high commitment but the “couples” score is significantly higher than the caregivers’ score (M = 8.1) whereas the “individuals” score is not. In the scheme of things, what is really important is that both groups show high commitment. Following the above analyses, I am confident to treat all the husbands and wives in the comparison group as individuals.
Clinical Dementia Rating Scale

The results of the Clinical Dementia Rating Scale (CDR), which rated the severity of the sufferers’ dementia as perceived by the spousal caregivers, showed that eight caregivers (13 percent), being all home caregivers, rated their spouses as having mild dementia; 20 caregivers (33 percent), comprising 17 home caregivers and three nursing home caregivers, rated their spouses as having moderate dementia; and 33 caregivers (54 percent), comprising six home caregivers and 27 nursing home caregivers, rated their spouses as having severe dementia. There was a significant difference between the home caregivers and nursing home caregivers in how they perceived the severity of their spouses’ dementia ($\chi^2 = 31.2$, df 2, $p < .001$). As expected, and in line with Rudd (1993; Rudd, Viney & Preston, 1999), the nursing home caregivers perceived their spouses’ dementia as more severe.

However, as explained previously, it was decided to combine the nursing home caregivers and home caregivers into the caregiver group (place of care no longer being relevant to the study). Therefore, it was no longer relevant to include severity of dementia as a covariate. Hence, the results of the CDR are no longer necessary.

Participants’ Themes of “Intimacy” and “Love”

The research participants’ responses to the open-ended questions regarding the meaning of “intimacy” and “love” were analysed for the common themes that defined these terms for these men and women. Words or statements that were sub-themes or categories were first identified and combined into broader units, the themes (Leininger, 1985). Most research participants defined the terms by using more than one theme in their verbalisations. Although this means that the data were not independent, this was
peripheral as it was the research participants’ definitions of these terms that was of interest.

All 124 verbalisations were rated by me and the main themes that defined each term were elicited as indicated above. Two independent raters each rated a subset of 40 verbalisations. Details regarding agreement between raters, as well as correlation coefficients, will be given after the themes for both “intimacy” and “love”, for the whole sample, have been presented.

What is “Intimacy”?

Frequencies and percentages of the themes defining “intimacy” by the husbands and wives in the caregiver and comparison groups are set out in Table 9.1. Examples of the words or statements (that is, sub-themes or categories) that made up these themes are as follows:

<table>
<thead>
<tr>
<th>Themes of “intimacy”</th>
<th>Sub-themes or categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex relations ..........</td>
<td>Making love; sexual intercourse; sexuality; go to bed.</td>
</tr>
<tr>
<td>Closeness ..............</td>
<td>Being close to someone; closeness of body and mind.</td>
</tr>
<tr>
<td>Reciprocal love ..........</td>
<td>Two way love; love each other; loving relationship.</td>
</tr>
<tr>
<td>Communication ..........</td>
<td>Talking; intellectual intimacy; being able to discuss things.</td>
</tr>
<tr>
<td>Sharing ..................</td>
<td>Sharing thoughts/secrets; sharing everything.</td>
</tr>
<tr>
<td>Mutual understanding ......</td>
<td>Accepting one another; understanding each other’s needs.</td>
</tr>
<tr>
<td>Companionship ..........</td>
<td>Doing things together; friendship; togetherness.</td>
</tr>
<tr>
<td>Expressing affection ..........</td>
<td>Cuddles and kisses; touching; hugs; warmth; tenderness.</td>
</tr>
<tr>
<td>Caring ....................</td>
<td>Compassion; care about; kind and considerate.</td>
</tr>
</tbody>
</table>
As shown in Table 9.1, sex relations was by far the most common theme used to define the term “intimacy” by both the male caregivers and male comparisons in this study. An average of 85 percent of these males mentioned sex relations, with the next most common theme for both groups of men being reciprocal love (38 percent). For the female caregivers, sex relations was again the most often used theme, however, only 58.1 percent of these women included it as part of their definition of “intimacy”. This was followed by closeness (51.6 percent), communication (41.9 percent) and reciprocal love (41.9 percent). For the female comparisons, the most common theme used was sharing (57.6 percent) followed by closeness (54.5 percent), sex relations (51.5 percent) and communication (42.4 percent). The male caregivers and male

<table>
<thead>
<tr>
<th>Themes of intimacy</th>
<th>Caregiver group</th>
<th></th>
<th></th>
<th></th>
<th>Comparison group</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Husbands (n=30)</td>
<td>Wives (n=31)</td>
<td></td>
<td></td>
<td>Husbands (n=30)</td>
<td>Wives (n=33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex relations</td>
<td>26 86.7</td>
<td>18 58.1</td>
<td></td>
<td>25 83.3</td>
<td>17 51.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closeness</td>
<td>7 23.3</td>
<td>16 51.6</td>
<td></td>
<td>10 33.3</td>
<td>18 54.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reciprocal love</td>
<td>12 40.0</td>
<td>13 41.9</td>
<td></td>
<td>11 36.7</td>
<td>11 33.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>8 26.7</td>
<td>13 41.9</td>
<td></td>
<td>11 36.7</td>
<td>14 42.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing</td>
<td>6 20.0</td>
<td>11 35.5</td>
<td></td>
<td>6 20.0</td>
<td>19 57.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mutual understanding</td>
<td>3 10.0</td>
<td>10 32.3</td>
<td></td>
<td>6 20.0</td>
<td>12 36.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Companionship</td>
<td>5 16.7</td>
<td>9 29.0</td>
<td></td>
<td>8 26.7</td>
<td>8 24.2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expressing affection</td>
<td>7 23.3</td>
<td>7 22.6</td>
<td></td>
<td>4 13.3</td>
<td>9 27.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caring</td>
<td>5 16.7</td>
<td>5 16.1</td>
<td></td>
<td>1 3.3</td>
<td>5 15.2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1Themes in order of importance to whole sample (N=124)
comparisons and the female caregivers and female comparisons were generally similar in the themes they used.

What is “Love”?

Frequencies and percentages of the themes defining “love” by the husbands and wives in the caregiver and comparison groups are set out in Table 9.2. Examples of the words or statements (that is, sub-themes or categories) that made up these themes are as follows:

<table>
<thead>
<tr>
<th>Themes of “love”</th>
<th>Sub-themes or categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reciprocity</td>
<td>Give and take; two way love; mutual love; need to receive love as well as give it; reciprocal relationship.</td>
</tr>
<tr>
<td>Caring</td>
<td>Compassion; cherish; care very deeply; protect; concern.</td>
</tr>
<tr>
<td>Commitment</td>
<td>Bond that ties us together; complete love; enduring; giving my whole life; it should be there forever.</td>
</tr>
<tr>
<td>Happiness/warm feelings</td>
<td>Feel happy; tickly sensation in the heart; warm inner glow; a little bit magical; feel good; warmth of the love.</td>
</tr>
<tr>
<td>Passion/sex relations</td>
<td>Intimate relationship; physical love; lust; make love; sexual love; passionate love.</td>
</tr>
<tr>
<td>Companionship</td>
<td>Friendship; being good mates; do everything together.</td>
</tr>
<tr>
<td>Affection</td>
<td>Touching; kissing; fondness; love is just a big hug; cuddles.</td>
</tr>
<tr>
<td>Sharing</td>
<td>Sharing our emotions; sharing similar interests; sharing your life; mutual sharing.</td>
</tr>
<tr>
<td>Mutual understanding</td>
<td>Appreciating each other’s differences; understanding each other’s needs; see each other’s point of view.</td>
</tr>
</tbody>
</table>
Table 9.2. Frequencies ($f$) and percentages (%) of the husbands and wives in the caregiver and comparison groups who included the theme as defining “love”.

<table>
<thead>
<tr>
<th>Themes of love</th>
<th>Caregiver group</th>
<th></th>
<th></th>
<th></th>
<th>Comparison group</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Husbands (n=30)</td>
<td>Wives (n=31)</td>
<td>Husbands (n=30)</td>
<td>Wives (n=33)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reciprocity</td>
<td>23 76.7</td>
<td>15 48.4</td>
<td>24 80.0</td>
<td>25 75.8</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caring</td>
<td>11 36.7</td>
<td>20 64.5</td>
<td>14 46.7</td>
<td>20 60.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commitment</td>
<td>11 36.7</td>
<td>10 32.3</td>
<td>13 43.3</td>
<td>12 36.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Happiness/warm feelings</td>
<td>11 36.7</td>
<td>11 35.5</td>
<td>8 26.7</td>
<td>6 18.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Passion/sex relations</td>
<td>11 36.7</td>
<td>5 16.1</td>
<td>10 33.3</td>
<td>7 21.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Companionship</td>
<td>8 26.7</td>
<td>9 29.0</td>
<td>6 20.0</td>
<td>8 24.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affection</td>
<td>5 16.7</td>
<td>9 29.0</td>
<td>8 26.7</td>
<td>6 18.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing</td>
<td>8 26.7</td>
<td>4 12.9</td>
<td>6 20.0</td>
<td>8 24.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mutual understanding</td>
<td>6 20.0</td>
<td>3 9.7</td>
<td>6 20.0</td>
<td>9 27.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Themes in order of importance to whole sample (N=124)*

As shown in Table 9.2, reciprocity was the most common theme of “love” for the male caregivers (76.7 percent), male comparisons (80 percent) and female comparisons (75.8 percent). The themes of caring and commitment followed next for each of these groups. However, the theme of caring was used by more of the female comparisons (60.6 percent) than the male caregivers (36.7 percent) or male comparisons (46.7 percent). Furthermore, the most common theme of “love” used by the female caregivers was caring (64.5 percent) followed by reciprocity (48.4 percent), happiness/warm feelings (35.5 percent) and commitment (32.3 percent).
Again, the male caregivers and male comparisons and female caregivers and female comparisons were similar in the themes they used. However, a noticeable difference for the female groups was the theme of reciprocity, with only 48.4 percent of female caregivers compared to 75.8 percent of female comparisons including reciprocity in their definition of "love".

As stated previously, the above information was required in order to ascertain the research participants' meanings of the terms "intimacy" and "love". As differences between groups on these definitions were not of central importance to this study they were noted, but statistical analyses of differences were not carried out.

Agreement between Raters: Themes Defining "Intimacy" and "Love"

Two independent raters each rated a subset of 40 verbalisations and they were instructed to obtain their own themes and rank them in order of importance for each term. Because of the innovative way the co-raters were instructed to analyse the verbalisations, interrater reliability became an issue and normal Kappa coefficients could not be applied. I was not only interested in agreement of themes, but agreement of perceived importance of themes. Table 9.3 sets out the percentages (in the sub-set of 40 verbalisations) that the themes of "intimacy" elicited were found by each rater; while Table 9.4 provides the same information for "love".
Table 9.3. Percentages (%) of themes relating to “intimacy” rated in a sub-set of verbalisations (n=40)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Rater 1 (researcher)</th>
<th>Rater 2</th>
<th>Rater 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% of 40</td>
<td>% of 40</td>
<td>% of 40</td>
</tr>
<tr>
<td>Sex relations</td>
<td>65.0</td>
<td>75.0</td>
<td>75.0</td>
</tr>
<tr>
<td>Closeness</td>
<td>45.0</td>
<td>37.5</td>
<td>35.0</td>
</tr>
<tr>
<td>Reciprocal Love</td>
<td>37.5</td>
<td>37.5</td>
<td>30.0</td>
</tr>
<tr>
<td>Communication</td>
<td>47.5</td>
<td>42.5</td>
<td>45.0</td>
</tr>
<tr>
<td>Sharing</td>
<td>35.0</td>
<td>40.0</td>
<td>32.5</td>
</tr>
<tr>
<td>Mutual Understanding</td>
<td>25.0</td>
<td>20.0</td>
<td>25.0</td>
</tr>
<tr>
<td>Companionship</td>
<td>27.5</td>
<td>30.0</td>
<td>30.0</td>
</tr>
<tr>
<td>Expressing Affection</td>
<td>25.0</td>
<td>35.0</td>
<td>37.5</td>
</tr>
<tr>
<td>Caring</td>
<td>10.0</td>
<td>7.5</td>
<td>10.0</td>
</tr>
</tbody>
</table>

1Themes in order of importance to whole sample (N=124)

Table 9.4. Percentages (%) of themes relating to “love” rated in a sub-set of verbalisations (n=40)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Rater 1 (researcher)</th>
<th>Rater 2</th>
<th>Rater 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% of 40</td>
<td>% of 40</td>
<td>% of 40</td>
</tr>
<tr>
<td>Reciprocity</td>
<td>65.0</td>
<td>72.5</td>
<td>70.0</td>
</tr>
<tr>
<td>Caring</td>
<td>55.0</td>
<td>52.5</td>
<td>52.5</td>
</tr>
<tr>
<td>Commitment</td>
<td>50.0</td>
<td>50.0</td>
<td>47.5</td>
</tr>
<tr>
<td>Happiness/warm feelings</td>
<td>30.0</td>
<td>32.5</td>
<td>32.5</td>
</tr>
<tr>
<td>Passion/sex relations</td>
<td>22.5</td>
<td>20.0</td>
<td>12.5</td>
</tr>
<tr>
<td>Companionship</td>
<td>22.5</td>
<td>15.0</td>
<td>20.0</td>
</tr>
<tr>
<td>Affection</td>
<td>25.0</td>
<td>10.0</td>
<td>17.5</td>
</tr>
<tr>
<td>Sharing</td>
<td>15.0</td>
<td>15.0</td>
<td>15.0</td>
</tr>
<tr>
<td>Mutual understanding</td>
<td>10.0</td>
<td>7.5</td>
<td>7.5</td>
</tr>
</tbody>
</table>

1Themes in order of importance to whole sample (N=124)
Spearman's rank-order correlation coefficient $r_s$ was used to measure agreement between raters about the order of importance of the themes elicited on the 40 verbalisations. For "intimacy", Spearman correlations were $r_s = .90$ between rater 1 and rater 2; $r_s = .73$ between rater 1 and rater 3; and $r_s = .88$ between rater 2 and rater 3 (average $r_s = .84$). For "love", Spearman correlations were $r_s = .90$ between rater 1 and rater 2; $r_s = .92$ between rater 1 and rater 3; and $r_s = .88$ between rater 2 and rater 3 (average $r_s = .90$). This provided justification for the criteria that I used, the results of which were reported in the previous sections for the sample as a whole.

**Present Compared to Past Marital Relationship**

The research participants' responses to Question 3 (see Chapter 7) were analysed to ascertain whether their present marital relationship was better, worse, or the same as their past marital relationship. Of the 61 caregivers, four (6.5 percent) indicated it was better, 55 (90.2 percent) indicated it was worse, and two (3.3 percent) indicated it was the same. Of the 63 comparisons, 50 (79.4 percent) indicated it was better, seven (11.1 percent) indicated it was worse, and six (9.5 percent) indicated it was the same.

**Reported Sexual Relations**

As part of the demographic and psychosocial survey, the research participants were asked questions regarding their sexual relationship with their spouse, the most direct question being: "How often per month do you and your spouse have sexual relations?". Frequencies and percentages of times of sexual relations per month reported by the husbands and wives in the two groups (ranging from 0 to 20) are shown in Appendix J (Table J.1). Overall, 82 percent of the caregivers (one female refused to answer the question) compared to 30 percent of the comparisons did not engage in sexual intercourse.
However, one female caregiver reported having sexual relations with her demented husband 20 times a month. As hypersexuality is not the norm for people with dementia, this caregiver was considered an outlier and was left out of this dimension when means were calculated. Although large variances were found, there was a significant difference between the mean times of sexual relations per month of the caregiver group (0.71, SD 2.2) and the mean of the comparison group (3.03, SD 3.7), with the comparison group reporting significantly more sexual activity (t = -4.25, p < .001). There was no significant difference between males and females (t = .13, ns).

The research participants were also asked: “To what do you attribute any decline or change in sexual relations?” Frequencies and percentages of the reasons attributed to the decline or change in sexual relations by the husbands and wives in the two groups are shown in Appendix J (Table J.2). Overall, 58 percent of the caregiver group stated that dementia was the reason why sexual intercourse had ceased. The next most popular reason for this group was health of spouse (17 percent), with twice as many female than male caregivers blaming the physical health of their spouse. Only one caregiver stated nursing home placement as the reason why they no longer had a sexual relationship. In the comparison group, the most common reason attributed to the decline in sexual relations for females was the health of spouse (39.4 percent), while the most common reason for males was age (26.7 percent). Notably, 15.2 percent of female comparisons and 6.7 percent of male comparisons rated their sexual relations as better now than in the past, whereas no caregivers made this claim.
"Commitment to the Spouse" Questions (Past and Present Commitment)

As stated previously, the research participants' answers to the two questions were rated by two independent raters in accordance with the procedure adopted by Wright (1993) and outlined in Chapter 7. As stated, the research participants' answers were rated on a continuum of 1 to 5, with 1 and 2 indicating that marriage was valued as an institution, 4 and 5 indicating that the spouse was valued as a unique person, and a 3 was given to answers that included both sentiments. For Question One: "Why did you marry your spouse?" (past commitment) interrater reliability was $r = .87$ (similar to the .85 reported by Wright, 1993); and for Question Two: "Why have you stayed married to your spouse?" (present commitment) interrater reliability was $r = .95$ (the same as Wright, 1993).

Table 9.5 shows means and standard deviations for the two questions comparing the caregiver and comparison groups and males and females. Wright's (1993) means are also included for comparison but no standard deviations were reported by her. Furthermore, as Wright (1993) reported the means of the husbands and wives separately, for her well group I have provided an average of the two means.
Table 9.5. Means and standard deviations for the two “commitment to the spouse” questions for caregivers and comparisons and males and females (N = 124)

<table>
<thead>
<tr>
<th>Question One</th>
<th>Question Two</th>
</tr>
</thead>
<tbody>
<tr>
<td>Past commitment</td>
<td>Present commitment</td>
</tr>
<tr>
<td><strong>Group</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver (n = 61)</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>4.41</td>
</tr>
<tr>
<td>Comparison (n = 63)</td>
<td>3.87</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male (n = 60)</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>4.12</td>
</tr>
<tr>
<td>Female (n = 64)</td>
<td>4.16</td>
</tr>
<tr>
<td><strong>Wright's (1993) results for comparison</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver spouses (n = 30)</td>
<td>3.50</td>
</tr>
<tr>
<td>Well spouses (comparison) (n = 34)</td>
<td>3.65</td>
</tr>
</tbody>
</table>

As shown in Table 9.5, most scores were very similar to the Wright study with a couple of exceptions. With regard to Question One, the mean of the caregiver group in this study was higher than the means of Wright’s caregiver spouses, well spouses and the spouses in this comparison group but similar to the means of the entire population of males and females in this study. Conversely, for Question Two, the mean of Wright’s well spouses was higher than the means of her caregiver spouses, as well as both the caregiver and comparison groups and entire population of males and females in this study.

Multivariate analysis of variance (MANOVA) was used to test for overall differences on the two “commitment to the spouse” questions in this study. The results
showed a significant overall effect of group ($\text{Wilks' Lambda } F (2, 119) = 9.10, p < .001$) but the effect of gender ($\text{Wilks' Lambda } F (2, 119) = 1.05, \text{ns}$) and the group x gender interaction ($\text{Wilks' Lambda } F (2, 119) = 1.07, \text{ns}$) were non-significant.

Due to the significant overall difference, it was necessary to inspect the univariate analyses (as explained in Chapter 7). These showed that a significant main effect of group was found for scores on Question One ($F (1, 120) = 14.07, p < .001$) with the caregiver group scoring significantly higher than the comparison group on past commitment (see Table 9.5).

Finally, as can be seen from the means, over the course of their marriages there was only a slight change for the comparison group in this study, whereas the caregivers reported a decrease in their commitment to their demented spouses. Nevertheless, they still valued their demented spouses as unique persons. This is opposite to Wright (1993), who found that there was no change for her caregiver spouses, whereas her well spouses reported an increase in their commitment over the course of their marriages. With regard to the males and females in this study, both cohorts reported a decrease in commitment. However, in line with the caregiver group, all the men and women in this study were still committed to their spouses as unique persons more than to the institution of marriage.

**Commitment to the Future of the Relationship**

Spanier's (1976) Dyadic Adjustment Scale contained a 6 point measure which assessed commitment to the future of the relationship. Responses ranged from *I would go to almost any length to see my relationship succeeds* (score of 5 = highest commitment) to *There is no more that I can do to keep the relationship going* (score of 0 = lowest commitment).
Nineteen (30.2 percent) of the comparison group compared to seven (11.5 percent) of the caregiver group stated that they would go to almost any length to see that their relationship succeeded. However, 30 (47.6 percent) of the comparison group, compared to 18 (29.5 percent) of the caregiver group stated they would do all they can to see it does. Twenty seven (44.3 percent) of the caregiver group, stated that they can't do much more than they are doing now.

A t-test was carried out comparing the mean score of the comparison group (4.06, SD 0.76) to the mean score of the caregiver group (2.85, SD 1.36). The results showed that the comparison group was significantly more committed to the future of their relationship than the caregiver group ($t = -6.08$, $p < .001$). There was no significant difference between males and females ($t = 1.57$, ns).

**Happiness in the Marital Relationship**

Spanier’s (1976) Dyadic Adjustment Scale contained a line measuring the research participants’ perception of their marital happiness “all things considered”. The line consisted of points representing different degrees of happiness from $0 = \text{"extremely unhappy"}$ to $6 = \text{"perfectly happy"}$. Research participants were informed that the middle point, $3 = \text{"happy"}$, represented the degree of happiness in most relationships.

Forty three (70 percent), the majority of the caregiver group, rated their marital happiness as less than happy, with most of those, 28 (46 percent), rating it as “a little unhappy”. Eighteen (29.5 percent) rated it as “happy” or above. Fifty seven (90 percent), the majority of comparison group, stated they were either “happy” (22 percent); “very happy” (29 percent); “extremely happy” (30 percent); or “perfectly happy” (10 percent).
A t-test was carried out comparing the mean score of the comparison group (4.06, SD 1.18) to the mean score of the caregiver group (2.19, SD 1.21). The results showed that the comparison group was significantly happier with their marital relationships than the caregiver group ($t = -8.71, p < .001$). There was no significant difference between males and females ($t = .98, ns$).

**Multivariate Analyses**

**Examination of the Data**

Prior to analysis, the continuous variables (that is, the scores for the scales on the measures hereunder) were examined through various SPSS programmes for fit between their distributions and the assumptions of multivariate analysis, which relate to normality, linearity and homoscedasticity. When the assumption of normality is met, the relationship between variables are also homoscedastic. Linearity is fundamental to multivariate statistics, as solutions are based on the general linear model (Tabachnick & Fidell, 1989).

**Sternberg’s Triangular Love Scale**

**Shape of the Distributions**

Examination of the shape of the distributions indicated that Intimacy and Passion were approximately normal (as indicated by normal quantile-quantile plots), while Commitment was obviously non-normal, having a curvilinear shape. However, as the tails were “thin”, according to Judd and McClelland (1989), it was safe to continue with regular analyses without transformation. Nevertheless, several transformations were attempted but there were no changes in significance of any of the tests after transformation. This finding, together with the argument put forward by Tabachnick and Fidell (1989) that larger samples are more robust to violations of normality, justified the decision to analyse the data without transformation.
Correlations between the Three Components of Love

The correlations among the scores of the Intimacy, Passion and Commitment components of Sternberg's Triangular Love Scale are shown in Appendix K (Table K.1). Bivariate correlations show that the three components were moderately correlated and, overall, were lower than those shown in Sternberg's (1988a) validation study, which were all in the low .70s. According to Tabachnick and Fidell (1989), if two variables have a bivariate correlation below .70, they can both be kept in the analysis. Although the correlation between the Intimacy component and Passion component in this study was above .70, it is not surprising as passion tends to interact strongly with intimacy (Sternberg, 1986). Furthermore, this result is similar to all Sternberg's (1988a) intercorrelations.

Major Analyses for Sternberg's Triangular Love Scale

Table 9.6 shows the means and standard deviations for the three components of love comparing the caregiver and comparison groups and the males and females. Sternberg's (1988a) data are also included for comparison, however, no separate results for males and females were provided.
Table 9.6. Means and standard deviations for the three components of love for caregivers and comparisons and males and females (N = 124)

<table>
<thead>
<tr>
<th></th>
<th>Intimacy</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td><strong>Group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver (n = 61)</td>
<td>5.56</td>
<td>1.29</td>
<td>4.98</td>
<td>1.92</td>
<td>8.07</td>
</tr>
<tr>
<td>Comparison (n = 63)</td>
<td>8.07</td>
<td>1.06</td>
<td>6.65</td>
<td>1.53</td>
<td>8.47</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (n = 60)</td>
<td>6.93</td>
<td>1.66</td>
<td>6.35</td>
<td>1.84</td>
<td>8.38</td>
</tr>
<tr>
<td>Female (n = 64)</td>
<td>6.76</td>
<td>1.78</td>
<td>5.34</td>
<td>1.88</td>
<td>8.16</td>
</tr>
<tr>
<td><strong>Sternberg’s (1988a) results for comparison</strong></td>
<td>7.39</td>
<td>1.19</td>
<td>6.51</td>
<td>1.65</td>
<td>7.20</td>
</tr>
</tbody>
</table>

Multivariate analysis of variance (MANOVA) was used to test for overall differences between the groups on the three components of love. The results showed significant overall effects of group (Wilks’ Lambda $F (3, 118) = 57.07$, $p < .001$) and gender (Wilks’ Lambda $F (3, 118) = 5.3$, $p < .01$) but the group x gender interaction was non-significant (Wilks’ Lambda $F (3, 118) = 0.11$, ns).

Once again, because of the significant overall differences, it was necessary to inspect the univariate analyses for the three components of love. These indicated that a significant main effect of group was found for scores on the Intimacy ($F (1, 120) = 139.66$, $p < .001$), Passion ($F (1,120) = 31.72$, $p < .001$) and Commitment ($F (1, 120) = 5.98$, $p < .05$) components, with the comparison group scoring significantly higher than the caregiver group on all three components of love. The univariate analyses also indicated that a significant main effect of gender was found for scores on
the Passion component \( F(1, 120) = 11.85, p < .001 \), with males scoring significantly higher than females on Passion (see Table 9.6).

Furthermore, it can be seen from inspection of Table 9.6 that the means for the comparison group appear higher than Sternberg’s data on all three components, whereas the means for the caregiver group were lower than Sternberg’s on Intimacy and Passion but higher on Commitment. Similarly, the means for males and females were also lower than Sternberg’s on Intimacy and Passion but higher on Commitment. In both Sternberg’s study and this study the Intimacy and Commitment components were higher than the Passion Component.

**Derogatis Affects Balance Scale**

**Shape of the Distributions**

Examination of the shape of the distributions indicated that all four positive affect dimensions as well as the negative affect dimensions of Anxiety, Depression and Hostility were all approximately normal (as indicated by normal quantile-quantile plots), while Guilt showed a slight positive skew with a “thin” tail. As argued by Judd and McClelland (1989) above, and in line with Rudd (1993), it was decided to analyse the data without transformation.

**Correlations among Dimensions**

The correlations among the four positive affect dimensions and four negative affect dimensions of Derogatis Affects Balance Scale are shown in Appendix K (Table K.2). Bivariate correlations show that the dimensions were moderately correlated and all were below .70 except the bivariate correlation of .78 between the positive affect dimensions of Contentment and Joy. The bivariate correlations between the four negative affect dimensions were in line with Rudd (1993).
Major Analyses for Derogatis Affects Balance Scale

Table 9.7 shows the means and standard deviations for the eight Derogatis Affects Balance Scale dimensions (four positive affects and four negative affects) as well the Positive Affects Total score, Negative Affects Total score and the Affects Balance Index comparing caregiver and comparison groups and males and females. Appropriate norms are not available for the purpose of comparison.

<table>
<thead>
<tr>
<th>Group</th>
<th>Caregiver (n=61)</th>
<th>Comparison (n=63)</th>
<th>Gender</th>
<th>Male (n=60)</th>
<th>Female (n=64)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Positive Affects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affection</td>
<td>13.11</td>
<td>3.15</td>
<td>14.02</td>
<td>2.87</td>
<td>13.63</td>
</tr>
<tr>
<td>Contentment</td>
<td>10.34</td>
<td>3.51</td>
<td>14.43</td>
<td>2.31</td>
<td>13.02</td>
</tr>
<tr>
<td>Vigour</td>
<td>10.03</td>
<td>4.51</td>
<td>11.54</td>
<td>3.95</td>
<td>11.10</td>
</tr>
<tr>
<td>Negative Affects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>8.21</td>
<td>4.10</td>
<td>5.79</td>
<td>3.60</td>
<td>5.92</td>
</tr>
<tr>
<td>Depression</td>
<td>7.85</td>
<td>3.79</td>
<td>4.02</td>
<td>2.52</td>
<td>5.28</td>
</tr>
<tr>
<td>Guilt</td>
<td>5.33</td>
<td>3.63</td>
<td>3.87</td>
<td>3.24</td>
<td>4.17</td>
</tr>
<tr>
<td>Hostility</td>
<td>6.21</td>
<td>4.00</td>
<td>4.49</td>
<td>3.09</td>
<td>5.22</td>
</tr>
<tr>
<td>Totals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Affects Total</td>
<td>43.51</td>
<td>11.96</td>
<td>53.38</td>
<td>9.92</td>
<td>49.68</td>
</tr>
<tr>
<td>Negative Affects Total</td>
<td>27.61</td>
<td>12.32</td>
<td>18.17</td>
<td>10.15</td>
<td>20.58</td>
</tr>
<tr>
<td>Affects Balance Index</td>
<td>0.80</td>
<td>1.02</td>
<td>1.76</td>
<td>0.72</td>
<td>1.46</td>
</tr>
</tbody>
</table>
Multivariate analysis of variance (MANOVA) was used to test for overall differences between the groups on the four positive affect dimensions and four negative affect dimensions. The results of the positive affect dimensions showed significant overall effects of group (Wilks' Lambda $F(4, 117) = 16.63$, $p < .001$) and group x gender interaction (Wilks' Lambda $F(4, 117) = 2.9$, $p < .05$), but the overall effect of gender was non-significant (Wilks' Lambda $F(4, 117) = 1.84$, ns). The results of the negative affect dimensions showed significant overall effects of group (Wilks' Lambda $F(4, 117) = 12.87$, $p < .001$) and gender (Wilks' Lambda $F(4, 117) = 3.44$, $p < .05$) but the group x gender interaction was non-significant (Wilks' Lambda $F(4, 117) = 0.23$, ns).

Once again, because of the significant overall differences, it was necessary to inspect the univariate analyses. With regard to the positive affect dimensions, these indicated that a significant main effect of group was found for scores on the Contentment ($F(1, 120) = 61.30$, $p < .001$) and Joy ($F(1, 120) = 32.29$, $p < .001$) dimensions of Derogatis Affects Balance Scale, with the comparison group scoring significantly higher than the caregiver group on contentment and joy (see Table 9.7). As there was a significant group x gender interaction for scores on the Affection dimension ($F(1, 120) = 6.24$, $p < .05$), it was necessary to perform a simple main effects analysis to determine the nature of the interaction. The results indicated that female comparisons experienced a significantly higher degree of affection than female caregivers, while there was no significant difference between male comparisons and male caregivers (see Appendix L. Figure 1).

Inspection of the univariate analyses for the negative affect dimensions indicated that a significant main effect of group was found for scores on the Anxiety ($F(1, 120) = 13.28$, $p < .001$), Depression ($F(1, 120) = 45.84$, $p < .001$), Guilt ($F(1, 120) = 5.69$, $p < .05$) and Hostility ($F(1, 120) = 7.23$, $p < .01$) dimensions of Derogatis Affects Balance Scale, with the caregiver group scoring significantly higher than the
comparison group on anxiety, depression, guilt and hostility. The univariate analyses also indicated a significant main effect of gender was found for scores on the Anxiety ($F(1, 120) = 9.93, p < .01$) and Depression ($F(1, 120) = 4.87, p < .05$) dimensions, with females scoring significantly higher than males on both anxiety and depression (see Table 9.7).

As the Positive Affects Total score, Negative Affects Total score and Affects Balance Index were linearly dependent on preceding scores, multivariate analyses could not be performed and therefore two-way analyses of variance were carried out for each total. With regard to the Positive Affects Total score, a significant main effect of group was found ($F(1, 120) = 25.16, p < .001$), with the comparison group scoring significantly higher than the caregiver group on overall positive affect (see Table 9.7). The main effect of gender ($F(1, 120) = 1.56, ns$) and the group x gender interaction ($F(1, 120) = 2.43, ns$) were non-significant.

With regard to the Negative Affects Total score, there was a significant main effect of group ($F(1, 120) = 22.60, p < .001$), with the caregiver group scoring significantly higher than the comparison group on overall negative affect. There was also a significant main effect of gender ($F(1, 120) = 4.98, p < .05$), with the females scoring significantly higher than the males on overall negative affect (see Table 9.7). The group x gender interaction was non-significant ($F(1, 120) = 0.03, ns$).

With regard to the Affects Balance Index, there was a significant main effect of group ($F(1, 120) = 38.33, p < .001$), with the comparison group scoring significantly higher than the caregiver group on overall well-being. There was also a significant main effect of gender ($F(1, 120) = 4.91, p < .05$), with the males scoring significantly higher than the females on overall well-being (see Table 9.7). The group x gender interaction was non-significant ($F(1, 120) = 0.76, ns$).
Content Analysis Scales

Shape of the Distributions

Examination of the shape of the distributions indicated that the Positive Affect Scale, Hostility In Scale, Hostility Out Scale, Cognitive Anxiety Scale, and Sociality Scale were approximately normally distributed (as indicated by normal quantile-quantile plots). However, the Separation Anxiety Subscale had a slight negative skew, while the distribution of scores on the Death Anxiety, Mutilation Anxiety and Guilt Anxiety Subscales were obviously non-normal; the distributions of these scores being slightly curvilinear. As the content analysis scale scores have already undergone either a square root or log transformation (see Chapter 7), in line with Rudd (1993) it was decided not to further transform the four subscales. Further transformation of these subscales is likely to make interpretation less clear, which is a potential disadvantage of transforming data (Maxwell & Delaney, 1990).

Correlations between the Content Analysis Scales

The correlations among the scores of the nine content analysis scales are shown in Appendix K (Table K.3). The majority of the bivariate correlations among the content analysis scales were quite low indicating that the scales were relatively independent of each other. However, two bivariate correlations were above .70. The Positive Affect Scale and the Sociality Scale were correlated at .76, which is not surprising as Positive Affect interacts strongly with Sociality, which assesses the experience of satisfying interpersonal relationships (Viney & Westbrook, 1979). With regard to the bivariate correlation of .81 between the Hostility In Scale (which measures sadness) and Separation Anxiety Subscale, again the strong interaction was expected as in both scales clauses with similar references (particularly references to loneliness and loss) were coded.
Major Analyses for the Content Analysis Scales

Table 9.8 shows the means and standard deviations for the nine content analysis scales comparing the caregiver and comparison groups and the males and females. As I asked a specific question in this study in order to apply the content analysis scales, rather than the standard question used (Gottschalk, Winget & Gleser, 1969; Viney, 1983; Rudd, 1993), then appropriate norms are not available for comparison. Table 9.9 sets out the number of research participants who mentioned each content analysis scale in their verbalisations. This latter data is not usually collected. However, Walker (personal communication, 2001) argued that it was the only way of discerning whether significant findings are really important to the study. I shall elaborate on the reasons for using this “new” method in later chapters, and shall provide a critique in the content analysis scales section in Chapter 13.

Table 9.8. Means and standard deviations for the nine content analysis scales for caregivers and comparisons and males and females (N=124)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Group</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caregiver (n=61)</td>
<td>Comparison (n=63)</td>
</tr>
<tr>
<td>Positive Affect</td>
<td>M  1.12 SD 0.40</td>
<td>M  1.61 SD 0.54</td>
</tr>
<tr>
<td>Hostility In</td>
<td>M  2.34 SD 0.77</td>
<td>M  1.14 SD 0.60</td>
</tr>
<tr>
<td>Hostility Out</td>
<td>M  1.53 SD 0.58</td>
<td>M  1.16 SD 0.55</td>
</tr>
<tr>
<td>Cognitive Anxiety</td>
<td>M  1.60 SD 0.67</td>
<td>M  1.22 SD 0.65</td>
</tr>
<tr>
<td>Death Anxiety</td>
<td>M  0.45 SD 0.21</td>
<td>M  0.59 SD 0.36</td>
</tr>
<tr>
<td>Mutilation Anxiety</td>
<td>M  0.58 SD 0.31</td>
<td>M  0.65 SD 0.38</td>
</tr>
<tr>
<td>Separation Anxiety</td>
<td>M  1.83 SD 0.75</td>
<td>M  0.63 SD 0.40</td>
</tr>
<tr>
<td>Guilt Anxiety</td>
<td>M  0.90 SD 0.54</td>
<td>M  0.53 SD 0.24</td>
</tr>
<tr>
<td>Sociality</td>
<td>M  0.34 SD 0.15</td>
<td>M  0.61 SD 0.20</td>
</tr>
</tbody>
</table>
Table 9.9. Frequency ($f$) that each content analysis scale was mentioned by caregivers and comparisons (N=124)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Caregiver group (n = 61)</th>
<th>Comparison group (n = 63)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Affect</td>
<td>56</td>
<td>63</td>
</tr>
<tr>
<td>Hostility In</td>
<td>61</td>
<td>43</td>
</tr>
<tr>
<td>Hostility Out</td>
<td>55</td>
<td>47</td>
</tr>
<tr>
<td>Cognitive Anxiety</td>
<td>54</td>
<td>43</td>
</tr>
<tr>
<td>Death Anxiety</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Mutilation Anxiety</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td>Separation Anxiety</td>
<td>58</td>
<td>14</td>
</tr>
<tr>
<td>Guilt Anxiety</td>
<td>32</td>
<td>9</td>
</tr>
<tr>
<td>Sociality</td>
<td>55</td>
<td>62</td>
</tr>
</tbody>
</table>

Multivariate analysis of variance (MANOVA) was used to test for overall differences between the groups on the means for the nine content analysis scales. The results showed a significant overall effect of group (Wilks’ Lambda $F(9, 112) = 23.70, p < .001$) but the overall effect of gender (Wilks’ Lambda $F(9, 112) = 0.78$, ns) and the group x gender interaction (Wilks’ Lambda $F(9, 112) = 0.75$, ns) were non-significant.

Once again, because of the significant overall differences, it was necessary to inspect the univariate analyses. These showed that a significant main effect of group was found for scores on the Positive Affect Scale ($F(1, 120) = 32.54, p < .001$), Sociality Scale ($F(1, 120) = 77.37, p < .001$) and Death Anxiety Subscale ($F(1, 120) = 7.58, p < .01$), with the comparison group scoring significantly higher than the caregiver group on Positive Affect, Sociality and Death Anxiety (see Table 9.8). However, it will be noted from Table 9.9 that only a small number of research
participants mentioned Death Anxiety in their verbalisations. A significant main effect of group was also found for scores on the Hostility In Scale ($F(1, 120) = 95.38, p < .001$), Hostility Out Scale ($F(1, 120) = 13.71, p < .001$), Cognitive Anxiety Scale ($F(1, 120) = 9.51, p < .01$), Separation Anxiety Subscale ($F(1, 120) = 127.62, p < .001$) and Guilt Anxiety Subscale ($F(1, 120) = 22.83, p < .001$), with the caregiver group scoring significantly higher than the comparison group on Hostility In, Hostility Out, Cognitive Anxiety, Separation Anxiety and Guilt Anxiety (see Table 9.8).

Sociality Subscales

Table 9.10 shows the means and standard deviations for six Sociality subscales, comparing caregiver and comparison groups and males and females. One subset of subscales are the Relationship Types of Solidarity, Intimacy and Influence and the other subset of subscales are the Relationship Roles of Reactor, Initiator and Joint Actor. Table 9.11 sets out the number of research participants who mentioned each subscale in their verbalisations.
### Table 9.10. Means and standard deviations for the six Sociality subscales for caregivers and comparisons and males and females (N=124)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Type of Relationship</th>
<th>Solidarity</th>
<th>Intimacy</th>
<th>Influence</th>
<th>Type of Role</th>
<th>Reactor</th>
<th>Initiator</th>
<th>Joint</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Group</td>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caregiver (n=61)</td>
<td>M 0.14</td>
<td>M 0.21</td>
<td>M 0.09</td>
<td>Male (n=60)</td>
<td>M 0.14</td>
<td>M 0.21</td>
<td>M 0.09</td>
</tr>
<tr>
<td></td>
<td>Comparison (n=63)</td>
<td>SD 0.09</td>
<td>SD 0.15</td>
<td>SD 0.17</td>
<td>Gender Female (n=64)</td>
<td>SD 0.14</td>
<td>SD 0.23</td>
<td></td>
</tr>
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</table>

### Table 9.11. Frequency (f) that each Sociality Subscale was mentioned by caregivers and comparisons (N=124)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Type of Relationship</th>
<th>Caregiver group (n = 61)</th>
<th>Comparison group (n = 63)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>f 34</td>
<td>f 46</td>
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<td></td>
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<td>f 52</td>
<td>f 62</td>
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<td></td>
<td></td>
<td>f 9</td>
<td>f 6</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Type of Role</th>
<th>Caregiver group (n = 61)</th>
<th>Comparison group (n = 63)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Reactor</td>
<td>f 30</td>
<td>f 33</td>
</tr>
<tr>
<td></td>
<td>Initiator</td>
<td>f 48</td>
<td>f 40</td>
</tr>
<tr>
<td></td>
<td>Joint</td>
<td>f 32</td>
<td>f 59</td>
</tr>
</tbody>
</table>
Multivariate analysis of variance (MANOVA) was used to test for overall differences on the six subscales. The results showed a significant overall effect of group (Wilks' Lambda $F (6, 115) = 21.46, p < .001$) but the overall effect of gender (Wilks’ Lambda $F (6, 115) = 1.08$, ns) and the group x gender interaction (Wilks’ Lambda $F (6, 115) = 1.40$, ns) were non-significant.

Once again, because of the significant overall difference, it was necessary to inspect the univariate analyses. These showed that a significant main effect of group was found for scores on the subscales of Solidarity ($F (1, 120) = 19.87, p < .001$), Intimacy ($F (1, 120) = 64.08, p < .001$) and Joint Actor ($F (1, 120) = 115.60, p < .001$), with the comparison group scoring significantly higher than the caregiver group on the relationship types of solidarity and intimacy and relationship role of joint actor.

The results of the analyses that were carried out in this empirical study were presented in this chapter. In the next chapter I shall discuss these results under four major headings, including excerpts from the research participants' verbalisations.
CHAPTER TEN

DISCUSSION OF RESULTS
A discussion of the results set out in Chapter 9 is presented in this chapter. It is not possible to deal with the results in the order shown in the Results section, as the instruments and open-ended questions measured variables across several different categories (as shown in Table 7.1). Therefore, the results will be discussed under four main headings: Participants’ Meanings of “Intimacy” and “Love”, Components of Marital Love, Marital and Life Satisfaction (Affect), and Patterns of Marital Relationships.

**Participants’ Meanings of “Intimacy” and “Love”**

As indicated in the Results section, most of the research participants in this study responded to my open-ended questions regarding the meaning of “intimacy” and “love” by using multiple themes to define these terms. For example, a male caregiver defined “intimacy” as follows:

Intimacy to me means very much a closeness, a sharing of two people of lots of things, not just sexual things. You can almost be intimate at a distance because you can share something that no-one else in the room is sharing - a wink can bring that across. But if you’re talking about sexual intimacy, well that’s exactly what it means - two people who love one another.

While a female comparison described “love” as:

There are different levels of love and so the beginning of a marriage is the romantic love and as the marriage develops then that love develops and I would say now I have a warmer, closer love. I’ve learnt to love and sometimes it requires effort and sometimes it’s romantic but mostly to me love means a commitment to someone. For a marriage to be successful that love needs to be reciprocal and you need to have your own needs fulfilled as in you need to receive from that person recognition, love and warmth to be able to continue giving it.

As the thematic analyses of these qualitative data were only carried out in order to establish the 124 research participants’ meanings of the terms “intimacy” and “love”, as explained previously, it was not relevant whether the differences between groups were significant or not; nor was it relevant that these data were not independent.
Participants’ Meaning of “Intimacy”

As indicated by the results of the thematic analyses, the middle-aged and elderly married men and women in this study, believed “intimacy” involved sexual relations, closeness, reciprocal love, communication, sharing, mutual understanding, companionship, expressing affection and caring. Furthermore, the results indicated that males and females (no matter whether they were caregivers or comparisons) differed in the importance placed on some of these themes of “intimacy”. In line with Duck (1988) and Riessman (1990), discussed in Chapter 4, the majority of all the men in this study (85 percent) defined “intimacy” mainly in terms of sexual relations, while considerably more women than men referred to closeness, communication, sharing and mutual understanding as well as sexual relations. However, many men and women within both groups similarly believed “intimacy” involved reciprocal love. As shown in Table 9.1, the majority of female comparisons (57.6 percent) believed sharing was the most important theme to define “intimacy”, immediately followed by closeness and sex relations; whereas, the majority of female caregivers (58.1 percent) believed sex relations was the most important theme, followed by closeness, reciprocal love, communication, and then sharing.

Participants’ Meaning of “Love”

Again, as indicated by the results of the thematic analyses, for the research participants in this study, “love” in marriage involved reciprocity, caring, commitment, happiness/warm feelings, passion/sex relations, companionship, affection, sharing and mutual understanding. Most of these themes appear to be in keeping with Beck’s (1988, cited in Noller, 1996) list of characteristics of mature love. Contrary to the findings of prior research (discussed in Chapter 4) involving college students and young married couples (Dion & Dion, 1973; Hendrick et al., 1984), it was found that the majority of all the men in this study (78.35 percent) as well as the female comparisons (75.8 percent) defined “love” mainly in terms of reciprocity (give and
take). This was followed by caring and commitment for these groups. However, as shown in Table 9.2, the theme of caring was used by considerably more female comparisons (60.6 percent) than male caregivers (36.7 percent) or male comparisons (46.7 percent). Furthermore, the majority of female caregivers (64.5 percent) believed that caring was the most important theme defining “love”, followed by reciprocity, happiness/warm feelings and commitment.

Whereas the male caregivers and male comparisons and the female caregivers and female comparisons were quite similar in their definition of “love”, there was one noticeable difference between the female groups. Only 48.4 percent of female caregivers compared to 75.8 percent of female comparisons included the theme of reciprocity in their definition. Furthermore, in accord with Sternberg (1986), when it came to “love”, commitment was more important than passion for the majority of these long-term married men and women.

With regard to the above differences between the female groups, it could be suggested that the female caregivers would have previously defined the term “love” (especially in regard to the importance of reciprocity) similarly to the female comparisons. However, because of their current situation, it might be assumed that some female caregivers have now re-construed the term in some respects. Nevertheless, this is only an assumption as there were no differences between the male caregivers and male comparisons. Furthermore, I did not ask the research participants how they defined the terms at the present time, but more generally as can be seen from Questions 1 and 2 (open-ended questions) in Chapter 7.

In summary, as indicated above, for the majority of men in this study, whether caregivers or comparisons, “intimacy” was defined mainly in terms of sexual relations followed by reciprocal love, while “love” mainly involved reciprocity followed by caring and commitment. Although there were some differences between the two groups
of women in relation to the importance placed on some of the themes, for the majority of women “intimacy” meant more than just sexual relations; it meant closeness, sharing, communication and reciprocal love. In turn, “love” for the majority of women meant reciprocity, caring and commitment. Furthermore, the terms “intimacy” and “love” both engendered similar themes from the research participants, confirming that these terms are intertwined when we refer to marital intimacy (as discussed in Chapter 4).

Components of Marital Love

As mentioned in Chapter 4, the phenomenon of love has been called a “very elusive entity” (Hendrick & Hendrick, 1992, p.62) and the study of love was once seen as fundamentally inconsistent with the notion of quantification (Sternberg, 1988b). Therefore, it is not surprising that the correlation between the Intimacy and Passion components of Sternberg’s Triangular Love Scale might be higher than the .70 recommended by Tabachnick and Fidell (1989). Nevertheless, I believe it was important to keep both of these components in the study, especially as they had lower correlations with the Commitment component. I shall discuss the results of Sternberg’s three components of love separately below, under the headings of Intimacy, Passion, and Commitment, together with a discussion of the results of other measures of these components of marital love. As reciprocity (give and take) was very important to the husbands and wives in this study when reporting their meanings of “love”, I have included the measurement of reciprocity under this heading.

Intimacy

Intimacy Component - Sternberg’s Triangular Love Scale

According to Sternberg (1986), intimacy is the emotional component of love, and the common core in all loving relationships. In the context of the triangular theory, “intimacy refers to those feelings in a relationship that promote closeness, bondedness,
and connectedness” (Sternberg, 1988b, p. 38). The results of Sternberg’s Triangular Love Scale showed, as expected, that the mean score of Intimacy for the comparison group was significantly higher than that for the caregiver group. Furthermore, the comparisons’ mean score for Intimacy was considerably higher than that reported in Sternberg’s validation study (see Table 9.6), indicating that the comparisons were experiencing very strong feelings of intimacy with their spouses. These feelings included:

1) A desire to promote their spouse’s welfare;
2) Enjoyment in being with, and sharing good times with, their spouse;
3) Thinking highly of, and respecting, their spouse;
4) Being able to count on their spouse in times of need;
5) Having mutual understanding with their spouse;
6) Sharing themselves and their possessions with their spouse;
7) Receiving emotional support from their spouse;
8) Giving emotional support to their spouse;
9) Communicating deeply and honestly with their spouse, and sharing innermost feelings;
10) Valuing their spouse (Sternberg, 1988b).

In line with Sternberg (1988a; 1988b), there were no significant differences between the mean scores of Intimacy for the males and females in this study.

Passion/Sexual Relations

Passion Component - Sternberg’s Triangular Love Scale

According to Sternberg (1986), passion is the motivational component of love and refers to the drives and desires that lead to physical attraction, romance, and sexual consummation. The results of Sternberg’s Triangular Love Scale showed, as expected, that the mean score of Passion for the comparison group was significantly higher than
that for the caregiver group. However, the comparisons’ mean score was similar to Sternberg’s validation study.

Contrary to Sternberg’s study, where no significant gender differences were found, the mean score of Passion for the males in this study was significantly higher than the mean score of Passion for the females. As previously mentioned, passion in love tends to interact strongly with intimacy (Sternberg, 1986). Hence, this finding is in keeping with 85 percent of the males in this study mentioning sexual relations when defining “intimacy”. Furthermore, this result indicates that even though their mean scores were typically average (rather than high), the middle-aged and older married men in this study considered passion to be significantly more important to love than the middle-aged and older married women.

Sexual Relations

Having a sexual relationship is generally regarded as an important part of marriage, but it has been reported to be by no means essential in order for spouses to have a happy and satisfying marital relationship, as studies of elderly long-term married couples indicate (Coleman, 1988). It has been suggested that for older couples the husband normally controls the frequency of sexual intercourse (Przybyla & Byrne, 1981). When intercourse stops it is usually due to the husband having health problems, often resulting in erectile difficulties (Morrissette et al., 1996).

In this study, it was found that, although sex relations did decline with advancing age and physical limitations, some spouses in their eighties still engaged in sexual intercourse on a regular basis. Nevertheless, 82 percent of the caregivers and 30 percent of the comparisons reported that they did not engage in sexual intercourse.
As mentioned previously, one female caregiver (an outlier) was left out of the analysis when groups were compared on mean times of sexual relations per month. This 48 year old woman was the caregiver of an early onset sufferer, who was most likely hypersexual because of his dementia. Sexual intercourse was the only intimacy she shared with him as he could no longer talk, and he rejected her emotionally. Some studies (discussed in Chapter 5) have reported hypersexuality in some dementia sufferers (Wright, 1991; 1993; Hanks, 1992); however, as previously stated, high sexual activity is not the norm for people with dementia (Davies et al., 1992; Sherman, 1998).

The results of the above showed a significant difference between the two groups, with the comparison group reporting significantly more sexual activity. This was contrary to Wright (1993) who found the reverse. Her AD group had a significantly higher mean per month than her well group. However, Wright left the hypersexual dementia sufferers in her analysis.

Although it has been reported that men are more interested in sex than women (Coleman, 1988; Noller et al., 2001), there was no significant difference in reported sexual activity between the males and females in this study. This finding should be considered in the context of reports that husbands control the frequency of sexual relations (Przybyla & Byrne, 1981), and discontinuance is generally determined by them (Roberts, 1979), as well as reports that older women believe that it is their "duty" to acquiesce (Roberts, 1979; Davies et al., 1992).

With regard to the reasons for the decline or change in sexual relations (see Appendix J, Table J.2), the majority of caregivers blamed the dementia followed by the general health of their spouse. Only one caregiver (a husband) stated nursing home placement as the reason why he and his demented spouse no longer had a sexual relationship. In the majority of cases, the caregivers reported that sex relations had
ceased long before nursing home placement. In the comparison group, the most common reason for females was the health of their spouse, while the most common reason for males was their age. The next most common reason for both males and females was their own health. The comparison group’s reasons were quite similar to Roberts’ (1979) findings (see Chapter 5). Although considerably more comparisons than caregivers reported no change in sex relations, the numbers were small. Interestingly, seven spouses in the comparison group (two males, five females) stated that their sexual relations were better now than in the past, whereas no caregivers made this claim.

Commitment

Commitment Component - Sternberg’s Triangular Love Scale

According to Sternberg (1986), commitment is the cognitive component of love and encompasses, in the short term, the decision that a person loves another person and, in the long term, the decision to maintain that love. As stated previously (see Chapter 4), the commitment component of love keeps relationships together when couples experience hard times. This is because a person has considerable control over their commitment, whereas it can be very difficult to control the emotion of intimacy or the arousal of passion.

The results of Sternberg’s Triangular Love Scale showed that the mean score of Commitment for the comparison group was significantly higher than that for the caregiver group. Despite this significant difference, the means for both groups were very high. In fact, not only was the comparison group’s mean substantially higher than Sternberg’s mean, but so too was the mean of the caregiver group (see Table 9.6), indicating that the caregivers were highly committed to their love for their demented spouses. In line with Sternberg (1988a; 1988b), there were no significant differences between the mean scores of Commitment for the males and females in this study.
Past and Present Commitment

In line with Wright (1993), Swensen and Trahaug's (1985) "Commitment to the Spouse" questions were used in this study to measure past and present commitment. The results showed that the caregiver group scored significantly higher than the comparison group on past commitment, with the mean of the caregivers' scores indicating commitment to the unique person and the mean of the comparisons' scores indicating commitment to both the unique person and the institution of marriage (although more towards the unique person). A plausible interpretation of this unanticipated finding was that the caregivers were idealising their past perceptions of their spouses. There was no difference between the groups on present commitment, with the mean scores of both groups indicating commitment to both the unique person and the institution of marriage.

For the men and women in the comparison group, there was reported to be only a slight change in commitment over the course of their marriages, whereas the caregivers, because of their elevated evaluation of their past commitment, reported decreased commitment to their demented spouses. Interestingly, despite presently regarding their demented spouses as "strangers", most caregivers still valued them as unique persons. Although they may have mentioned their commitment to their marriage vows, these caregivers also mentioned their love for their demented spouses. For example, a 79 year old home caregiver said: "I don't think of her as she is; I think of her as she was. I married 'til death do us part. I still love her". In fact, the results suggested that all the men and women in this study were committed to their spouses as unique persons (both in the past and present) more than to the institution of marriage.

Although the results showed no gender differences in past and present commitment, the overall samples of males and females reported a decrease in their
commitment over the course of their marriages, from commitment to the unique person to commitment to both the unique person and the institution of marriage.

The results of this study are opposite to those reported by Wright (1993), who found no change in commitment for her caregiver spouses, whereas her well spouses reported an increase in their commitment over the course of their marriages. Indeed, the results of my study are more in line with Swensen and Trahaug (1985) who found that for most older spouses there is a decline in their commitment to their spouse as a unique person over the course of their marriage.

Future Commitment

Again, in line with Wright (1993), a 6 point measure on Spanier’s (1976) Dyadic Adjustment Scale assessed future commitment to the marriage. The results showed that the spouses in the comparison group were significantly more committed to the future of their marriages than the spouses in the caregiver group. Many of the latter spouses indicated that they can’t do much more than they are doing now to preserve their marriages. There were no significant differences between the overall samples of males and females in this study.

The above finding is in line with Wright (1993), who also found that her caregiver spouses were significantly lower in commitment to the future than her well spouses. In order to address the contradiction of lower commitment to the future, but stable commitment to the spouse as a unique person, as mentioned in Chapter 5, Wright (1993) explained that commitment to the future requires energy. Hence, if the caregiver’s own emotional and physical health is failing, then despite past commitment and love, commitment to the future of the relationship is affected (p. 104).
In summary, the caregivers in this study reported being significantly more committed to their past marital relationships than the spouses in the comparison group. There was no difference between these groups in regard to their present commitment. However, the comparisons were significantly more committed to their future marital relationships than the caregivers. The comparisons also scored significantly higher than the caregivers on the Commitment component of Sternberg’s Triangular Love Scale.

Reciprocity

As stated previously, when discussing the concept of love, most authors include the components of intimacy, passion/sex, and commitment (e.g., Sternberg, 1986; Beach & Tesser, 1988). Moreover, for most people, love seeks reciprocation (Skolnick, 1983). This fact was highlighted in this study, with the majority of the research participants reporting reciprocity to be their most important theme defining “love”; whilst reciprocal love was the third most important theme defining “intimacy” for these men and women.

The Viney and Westbrook (1979) Joint Role Subscale (see Table 9.10) of the Sociality Scale was used to measure the research participants’ perceptions of reciprocity between themselves and their spouses; that is, when they saw themselves as playing a joint role (either reactor or initiator) with their spouses rather than as sole reactor or sole initiator. The results of the analyses showed that the comparison group scored significantly higher than the caregiver group on the Joint Role Subscale, indicating that the comparisons were experiencing significantly more reciprocity (give and take) with their spouses than the caregivers. This finding was highlighted by a 74 year old man in the comparison group who said:

We both love and understand each other and we enjoy intimacy ... we’re still there for each other. ... We do everything together. We go out together. We talk about everything together. We talk about our family together. Everything we do, we do it together. It is a give and take.
While a 55 year old female comparison shared the same view when she commented:

There's a willingness for both of us to be together and share life experiences and have fun. It's wonderful, we have physical contact most days of kisses and cuddles and it's a very loving relationship. We have a good compatible sexual relationship where I feel that our needs are both met equally. It's a mutual give and take.

**Marital and Life Satisfaction (Affect)**

**Marital Satisfaction**

Perceived Quality of Present Compared to Past Marital Relationship

As discussed in Chapter 5, it has been argued that the quality of the past marital relationship was the key to understanding the spousal caregivers' perceptions of their caregiving experiences (Perry, 2002). Furthermore, studies (Morris et al., 1988; Knop et al., 1998) have found that perceived quality of the past and present marital relationships influenced spousal caregivers' emotional reactions to caregiving.

The demographic and psychosocial data collected during the interviews (see Results section, Chapter 9) indicated that there was no significant difference between the caregiver and comparison groups with regard to the perceived quality of their past marital relationships. However, whereas 50.8 percent of the comparisons rated the past as "good", 62.3 percent of the caregivers rated it as "excellent". This was mainly due to 80 percent of caregiving husbands, who again appeared to be idealising their past marital relationships.

With regard to the perceived quality of their present marital relationships, as expected, the comparison group rated it significantly higher than the caregiver group, with 66.6 percent of comparisons rating the present as "excellent" compared to 59
percent of caregivers who rated their present relationship as “fair”. These results are in line with Knop et al. (1998) who reported that the caregivers in their study rated the quality of their past marital relationships very positively; whilst the quality of the present relationship was rated less favourably. There were no significant differences between the overall populations of males and females on either the past or present.

The above results are also supported by the analyses (see Chapter 9) of the research participants’ responses to Question 3 (Chapter 7), asking how their present intimate relationship with their spouse was the same or different from their past relationship with him or her. In line with previously mentioned past research (Roberts, 1979; Gilford, 1984; Weishaus & Field, 1988), the husbands and wives in the comparison group indicated increased marital happiness and satisfaction during their later years of life, with 79.4 percent indicating that it was better at the present time compared to the past; whereas 90.2 percent of the spousal caregivers indicated it was worse.

Interestingly, however, four out of the 61 caregivers indicated that their present relationships - even though their spouses had dementia - were better now than in the past. The following are extracts from these caregivers’ responses:

1) Nursing Home Male Caregiver (76 years old. Wife had dementia for 6 years.)

Now I feel nearer to Mary than I probably have done since possibly the first couple of years of marriage ... it’s the state she’s in at the moment has probably affected that [wife is dependent on him] ... I’m mainly less selfish than I was and when I go [to the nursing home] and she’s happy, it makes me happy ... She knows my name but calls me daddy or Robert ... I just get on with life ... I’m always working and in fact I never have a minute to myself ... Other than no meaningful conversations or sexual intimacy there’s not much difference and in fact in some sense it is better.
2) **Home Male Caregiver** (67 years old. Wife had dementia for 3 years.)

As far as sexual intimacy goes, it’s very much the same. She hasn’t changed that much except she’s just enjoying the stimulation more ... There’s a little bit more affection now because she needs the affection, she needs the comfort so she will be a bit more demonstrative that way now. ... [In the past] she’d always have an objection or contradict something or make excuses as to why it wasn’t right ... At the moment it’s quite smooth sailing to what it was in the past because she’s depending on me to do things, look after things. She’s allowing me to make decisions, whereas in the past she contradicted anything I did.

3) **Home Male Caregiver** (73 years old. Wife had dementia for 2 years.)

I think because we’ve spent so much time together since I’ve retired our feelings, our relationship has gotten closer. I think it’s gotten closer since the children left home because we have more time to devote to one another. ... At the moment my wife only has a mild short term memory loss so it doesn’t seem to be a great problem to me ... we must adapt to change. I’ve developed the philosophy that I’ll accept the situation as it is and do my best to retain a happy relationship. I have sought counselling from the experts ... it’s very wonderful to have the support of a family ... being Catholics we do pray together on a daily basis as well as practice our religion.

4) **Home Female Caregiver** (69 years old. Husband had dementia for 1 year.)

I think it’s changed a lot. I’ve had to help him so much over the last 12 months; we’ve had to do so many things together, we’ve probably had to come a little bit closer together ... Perhaps it took this to make it happen. ... We have come a bit closer I suppose in some ways. There were good times in the past ... but it always has to have its down side because of the schizophrenia [which her demented husband also suffered, causing great distress throughout their marriage] ... Yes, there were pretty good times but there were a lot of stormy times too. ... I now have more control over his medication and things.

In three of the four extracts above, the caregivers verbalised (or implied) that their marriages were better now than in the past because their demented spouses were now dependent on them and the caregivers felt that they had more control over their spouses and their lives. In the other extract (number 3 above), this caregiver’s wife was in the very early stages of dementia with only mild short-term memory loss. This caregiver appeared to be in denial as he stated later in the interview: “I hope in the future I will be able to cope with it if it does deteriorate but I don’t think it will”.
Satisfaction with Interpersonal Spousal Relationship

The Viney and Westbrook (1979) Solidarity and Intimacy Subscales (see Table 9.10) and total Sociality score (see Table 9.8) were used to measure satisfaction with the interpersonal spousal relationship. The results of the analyses showed that the comparison group scored significantly higher than the caregiver group on all three measures, not unexpectedly indicating that the comparisons were experiencing significantly more satisfying interpersonal relationships with their spouses.

These results further found that overall the husbands and wives in the comparison group considered that they had supportive and nurturant relationships with their spouses, and were committed to working towards common goals (Solidarity). A 48 year old woman in the comparison group commented:

We are there for each other. He knows that I’m job hunting at the moment and he’s very supportive about that and I know that he’s worried about the paddocks and we get out there and do stuff together. We’re very preoccupied with a way to turn this [their farm] into something that’ll make money for ourselves. But we work on that kind of stuff together.

It is noted (see Chapter 4) that Viney and Westbrook’s (1979) meaning of intimacy implies "empathy, fellowship, affection, friendliness, sociality or efforts to maintain a close interpersonal relationship" (p. 131), rather than Sternberg’s (1986) meaning of intimacy as the emotional component of love (see Chapter 4). With this distinction in mind, the comparisons construed their spouses as sources of personal satisfaction (Intimacy), as indicated by the following extract from the verbalisation of a 68 year old male comparison:

Life is good between us. We exchange views all the time and we talk a lot. We’ve been together so long we’re like two peas in a pod ... We’ve become like each other ... We enjoy being together and enjoying life together, planning to do things together ... Being together, that’s really intimacy.
Although it has been suggested by Viney and Westbrook (1979) that three types of relationship - Solidarity, Intimacy and Influence - are required for a comparison of interactions, as can be seen from Table 9.11, the spouses in this study made very few references regarding influence and power, and there was no difference between the groups on the Influence subscale. There were also no significant differences between the overall samples of males and females on any of the measures.

The mean of the caregivers' total Sociality score (0.34) was lower than the means from all eight normative groups reported by Viney and Westbrook (1979); whereas, the comparisons' total Sociality score (0.61) was higher than seven of those normative groups and equal only to the mean of a sample of 52 housewives who had been relocated to a new community (0.61).

Positive Affect

According to Argyle (1987), married people are happier and more satisfied, on average, than those who are not married. In the present study, positive affect (that is, feelings of love, happiness, satisfaction) was measured by the Positive Affect Scale (Westbrook, 1976) and also the Happiness line of Spanier's (1976) Dyadic Adjustment Scale. Furthermore, according to McCoy (1977), the extent to which people express positive emotions, such as love, happiness and satisfaction, gives some indication of their experience of validation. It will again be noted that when collecting data for application of the content analysis scales, the research participants were asked to talk about their present intimate marital relationship, not their life in general (see Question 4, Chapter 7).

The results of the analyses indicated that the comparison group scored significantly higher than the caregiver group on Westbrook's (1976) Positive Affect Scale. There were no significant gender differences. An extract from the verbalisation
of a 50 year old woman is typical of the positive feelings expressed by many sexually active husbands and wives in the comparison group:

I’m very happy and we are very close and very caring of each other. We enjoy sex and it’s exciting and it’s great. ... I don’t just feel comfortable in our relationship, I think it’s great, it’s exciting and it’s joyous and I’m really happy. ... the caring is what’s so nice and so wonderful ... I just feel loved and cared for and I feel I do the same to my husband.

Indeed, as suggested by Beach and Tesser (1988), having a sexual relationship can certainly be a shared positive activity that generates positive affect, even if the passion is less intense than it was earlier in the relationship. However, many older couples experience high positive affect without having a sexual relationship. The following is an extract from a 72 year old man who depicts the positive feelings of many husbands and wives in the comparison group who were not sexually active:

At the present moment there is no sexual relationship between my wife and I because of my diabetes. But the love is still there, the affection is still there, the caring is still there and the communicating is still there. ... I’m so happy that I have a loving wife.

Although a few spouses in the comparison group indicated that they were unhappy with their intimate marital relationships, the majority of the comparisons expressed a high level of positive emotions. In fact, all 63 comparisons referred to feelings of positive affect in their verbalisations, as did 56 out of the 61 caregivers (see Table 9.9). However, the caregivers’ references to positive emotions were more subdued. For example, whereas the comparisons used phrases like “I felt excited”, “it was really wonderful”, and “we’re so happy together”; the caregivers used phrases such as “I like it when he smiles”, or as one 58 year old caregiving wife said:

I like going [to the nursing home] and could sit with him for hours just holding his hand ... it’s sort of the highlight of my day when I go to see him. ... I like to feel I’m doing something for him ... I like to do things for him so I like to spend time with him.
The Happiness line contained in Spanier’s (1976) Dyadic Adjustment Scale assessed the research participants’ perceptions of their present marital happiness “all things considered”. As expected, the results of the analysis showed that the spouses in the comparison group were significantly happier with their marital relationships than the spouses in the caregiver group. The majority of the comparisons (90 percent) stated they were either happy (22 percent), very happy (29 percent), extremely happy (30 percent) or perfectly happy (10 percent), whereas the majority of the caregivers (70 percent) rated themselves as being less than happy. Again, there were no significant differences between the overall samples of males and females. Wright’s (1993) findings cannot be included for comparison as she used the Happiness line to assess past marital happiness.

The results from the above two measures clearly indicate that the husbands and wives in the comparison group were experiencing significantly more positive affect than the caregivers. It could therefore be suggested that these positive emotions followed validation of construing for the comparisons (McCoy, 1980).

**Negative Affect**

Although intimacy and love mostly relate to positive affect, Argyle (1987) argued that overall satisfaction with marriage depends on both positive and negative emotions. In this amended study, negative affect was measured by several content analysis scales: sadness (Gottschalk & Gleser’s, 1969, Hostility In Scale); anger (Gottschalk & Gleser’s, 1969, Hostility Out Scale); cognitive anxiety (Viney & Westbrook’s, 1976, Cognitive Anxiety Scale); separation anxiety, guilt anxiety, death anxiety, and mutilation anxiety (Subscales of Gottschalk & Gleser’s, 1969, Total Anxiety Scale).
The results of the analyses found that the caregiver group scored significantly higher than the comparison group on sadness, anger, cognitive anxiety, separation anxiety and guilt anxiety. However, the comparison group scored significantly higher than the caregiver group on death anxiety. There were no significant differences on mutilation anxiety. There were also no gender differences on any of the content analysis scales (see Table 9.8). In order to discuss these significant findings, I shall focus on each negative emotion separately and use extracts from the research participants’ verbalisations to illustrate how they felt.

**Sadness**

In line with Rudd (1993), the most frequently expressed emotion by the caregivers was sadness (Hostility In - see Table 9.9), with all 61 caregivers making references to feelings of grief, depression, deprivation, disappointment, despair or lonesomeness. It was also the most intensely felt emotion for the caregivers. The following extracts from the verbalisations of four caregivers are typical of the sadness and despair articulated by most caregiving husbands and wives, many of whom broke down and sobbed uncontrollably during the interviews:

**59 year old male nursing home caregiver**

Your life is so devastated by what’s happened that you find it very hard to cope - the loneliness is dreadful. The loneliness is there all the time... There’s no laughter in your life anymore and life’s just so bloody miserable. Coming home to an empty house is the worst thing in the world, it really is. Going to bed on your own - into a cold bed; getting up in the morning on your own; having to cook your own meals - it’s just so miserable. ... There’s no kisses and cuddles and companionship... You’re desperately looking for companionship somewhere along the line.

**60 year old female nursing home caregiver**

There’s no love or no intimacy with him - I mean no cuddles. You miss out on everything you used to have because he can’t cuddle you. He doesn’t know how to cuddle - he just stands as a blank. We had no sexual relationship for about five or six years [before he went in nursing home]. I mean he didn’t want that, he just cut me straight off so I just had to accept that too. ... I find it so hard to go up to see
him; it just aches so much inside when I have to leave him. ... He doesn’t say anything to me ... it eats me up inside ... I have my [male] friend but my husband is still my number one.

79 year old male home caregiver

[Our intimate relationship] is very bad because there’s no love and there’s no intimacy at all, and it looks very bleak for the future that there ever will be any as far as the wife’s concerned. There’s no love - there’s no giving of love as far as the wife’s concerned. There’s no actual good friendship even. I’m only here to be a servant to her and look after her. But as far as companionship and that, there’s nothing. ... When I try to show love and affection I’m rejected, completely rejected. ... It started four years ago and then gradually got to nothing at all. I’m totally rejected.

49 year old female home caregiver

I don’t have an intimate relationship with him, I’ve lost that. He was a very romantic person and I have completely lost that. There’s no romance. ... there’s no intimate times at all. I always class myself as a widow with my husband still alive, so I can’t close the door and start my life again. I’m grieving but it’s the most long drawn out thing because it’s not like he’s got cancer and he’ll live or he’ll die. I don’t have a time limit on this and it only gets worse. ... And I cry ... I’m starving for affection, not to be touched, not to be loved ... that’s very hard. I don’t have anyone to talk to ... I miss our physical relationship and I miss our romance like crazy ... I’m really robbed of all that ... it’s very sad ... Everything is taking and there’s no giving back.

The profound sadness these caregivers experienced could be viewed as the response to an awareness of the invalidation of implications of a portion or all of their core structures (McCoy, 1977). They felt deprived and grief-stricken because their demented spouses had previously validated their central identities as husbands or wives, lovers, and companions. However, they were now neither married nor single, and they realised that this situation could go on for a very long time, as verbalised by the 49 year old woman above.

Separation Anxiety

After sadness (Hostility In), Separation Anxiety was the next most frequently expressed emotional state by the caregivers, with 58 out of 61 caregivers making
references that related to fear or threat of desertion, abandonment, ostracism, loss of support, loneliness, loss of love or love object. In contrast, only 14 out of 63 comparisons made such references (see Table 9.9). The following extracts from the verbalisations of four caregivers are typical of the separation anxiety articulated by most caregiving husbands and wives:

74 year old male nursing home caregiver
I really do miss her ... I miss her sitting here in the chair ... I really do miss her talking. That's one of the real things that you do miss around the place. ... She was always the life of the party and that would be one of my greatest losses. The greatest loss would be not having her with me in the house. That's all I can say about that, the greatest loss is not having her here.

69 year old female nursing home caregiver
I miss him. ... he's getting more and more away from what living is about. ... I don't want to lose him. I just don't want him to go away from me. ... we used to go to bed and have a cuddle - we don't do that any more. ... I find the separation because he's in the nursing home very difficult.

64 year old male home caregiver
Then there's the rejection. Any sexual tendencies I have are normally rejected ... she's gone back that far that she thinks she's only 20 years old. ... She thinks I'm some other fellow ... and she'll come out and say, "I'm glad he's gone". ... She changed from a very loving, happy person to one that's irritable all the time. It doesn't matter what you do for her, she's going. ... She doesn't know who I am ... Every time I ask her who I am she says, "Joe Blow". ... It's been a very close relationship but that relationship has gone ... that's gone, completely gone. She's gone. She isn't the person I married.

75 year old female home caregiver
I miss not being able to go out together ... everything I do is on my own nowadays. ... We used to travel quite a bit ... and have a holiday almost every year ... I miss all that. I have nobody to go with ... He used to do jobs outside and if anything goes wrong now I've got nobody to turn to to fix it. I miss all that. I miss the car ... When I do go out I still miss not being with my husband. He's continually sleeping all the time. I am very lonely.
For most caregivers in this study their separation anxiety stemmed from the loss of their marital relationships with their spouses, as well as their feelings of rejection and their loneliness. It is likely that their core role structures would have involved the belief that an intimate marital relationship is characterised by love, affection, companionship, communication and so on, and they may have felt threatened and invalidated when they became aware that their spouses were not the same people they had married. According to Neimeyer and Hudson (1985), threat "damages a relationship by implying the need for major reconstruction of superordinate understandings" (p.134). In other words, the invalidation experienced by the caregivers, which resulted from superordinate misconstructions of their role relations with their spouses, jeopardised their most central constructions of their marital relationships and forced massive reconstruction of their personal construct systems (Neimeyer & Hudson, 1985).

**Anger**

Although the caregivers' feelings of anger (Hostility Out) were not as intense as their feelings of sadness and separation anxiety, they nevertheless felt angry and frustrated as they criticised both their demented spouses and also the disease itself. The following extracts from the verbalisations of four caregivers are typical of the anger expressed by many caregiving husbands and wives:

**75 year old male nursing home caregiver**

You've got every right to be angry. I think God would expect you to be angry in a situation like this. If I do get angry about it I don't kick myself and say I shouldn't have got angry. I've got every right to be angry and I tell other people that - you've got every right to be angry ... it's an angry situation that you're in ... it's like a bereavement - even when you accept it there's still a little bit of anger - a tinge of anger maybe still remains.

**58 year old female nursing home caregiver**

I had to leave the marital bed last year. I'd come to realise that having sex with somebody that really doesn't know who you are is a great turn-off ... and he would often make absurd comments in the middle of
it such as you don’t have to worry about having any children because I can’t have children. I got knocked by a pipe when I was 17 and I can’t have any! ... I felt so angry, but leaving the marital bed was the turning point ... I’m now able to give him my fullest attention without resentment. ... I’ve lost out in many areas of personal experience because of what I now know is the Alzheimer’s. I hate it.

58 year old male home caregiver (from Turkey)

She’s not very clean now ... I get ready for love, you know, kiss to her but she’s not respond to me, you know, she’s different - like a stone, like something else. A very strange person, like not a person, something else. ... I feel angry. I get mad, you know. ... It’s not normal. I’m normal. I get frustrated. ... This is short life, so I feel anger.

59 year old female home caregiver

I’m the caregiver and he’s the caretaker. It was a reciprocal relationship but now it’s not. ... All I seem to do is work ... I feel angry and resentful. I get very angry. I get angry at my husband sometimes and I think why are you just sitting there watching me; you should be helping me. But then I bring myself back and think he’s got an illess.

Much of the anger expressed by the caregivers in this study stemmed from the negative changes to their spouses’ personalities and behaviours - they were no longer relating to the spouses they once knew. As one woman said: “It’s just a thing lying there alongside me”; while the Turkish caregiver above referred to his wife as being unclean and strange and “different - like a stone”. Most caregivers reported that their demented spouses were previously loving, affectionate and supportive, and that their relationships were reciprocal. It seems that when their attempts to secure validation of this belief had failed, they became angry, frustrated and resentful.

Cognitive Anxiety

It seems that the caregivers in this study were aware of the inadequacy of their construct systems to deal with their new situations and their “new” spouses, and therefore displayed significantly higher levels of cognitive anxiety than the comparisons. The following extracts from the verbalisations of four caregivers are
typical of the cognitive anxiety expressed by many caregiving husbands and wives. These extracts highlight the fact that the spousal caregivers were unable to anticipate and integrate their experiences meaningfully (Viney & Westbrook, 1976):

53 year old male nursing home caregiver

She’s just not the person she was; she’s a totally different person. I don’t know who she is. Sometimes I think she’s a child. Sometimes actually she talks about babies and cats. I don’t know - I don’t know which babies. The only baby is a sister’s baby. I don’t understand her at all.

69 year old female nursing home caregiver

He’s never been very demonstrative until now. It’s sort of a new - it’s as if it’s a new person that’s doing these things. He’s being different to what he was. It’s very strange. I don’t say he never loved me before but he’s showing it in different ways now. ... but he gets that vacant look sometimes and you don’t know whether he’s listening to what you’re saying. ... He’s in a little world of his own and I don’t really know him any more.

64 year old male home caregiver

What worries me most is that she seems to have these turns and it seems as though she thinks I’m two persons ... When she does have these turns I don’t know what to make of it ... Initially I was extremely upset ... What worries us the most is the language, the swearing. ... you’d nearly think she was two persons. ... She doesn’t know who I am ... and I don’t know who she thinks I am. I’ve got no idea.

67 year old female home caregiver

It’s very hard; very very confusing and very very hard to understand. It’s very difficult sometimes. That’s the only way I can describe it. ... I wish things were different. ... it’s very distressing because I can’t think - I’m thinking for two people ... I’m tired, I’m mentally tired ... I can’t work out what I’m to do next ... I don’t know ... I just don’t understand, he’s exactly the opposite to how he was, exactly - in everything. ... I can’t believe that it’s happened to the two of us ... I just can’t see what’s ahead.

The major source of anxiety for the caregivers was that they were aware that they could no longer accurately understand or predict their demented spouses’ “different” behaviours, and were finding it difficult to make sense of their “new”
relationships. Or, as Kelly (1955) would express it, the events they were experiencing were beyond the range of convenience of their personal construct systems.

**Guilt Anxiety**

Even though the caregivers experienced significantly more guilt anxiety than the comparisons, surprisingly only 32 out of 61 caregivers made references to feelings of guilt in their verbalisations (see Table 9.9). The following extracts from the verbalisations of four caregivers are typical of the guilt anxiety articulated by the caregiving husbands and wives:

**74 year old male nursing home caregiver**

I’m still sexual ... I still wake up - to put it in common terms - I wake up and have starched the sheets sort of thing ... My mind has even at different times wandered to other women. ... There was one nurse ... I got close to her, we’d become very friendly ... it could have become a sexual relation but I’d run into that wall again - probably guilt.

**69 year old female nursing home caregiver**

I think, oh I’ve put him in a home ... I feel very guilty that I put him into a home, very guilty.

**58 year old male home caregiver**

She thinks I am doing something strange and thinks someone is watching us. She says, “rude, rude, don’t do that”. She thinks it’s something rude. ... I get angry but I don’t blame my wife ... I put on some video cassette ... I get orgasm myself, okay.

**56 year old female home caregiver**

The quality of my love for him has deteriorated because of the Alzheimer’s. That makes me feel guilty ... The deterioration of intimacy affects my willingness to participate in a sexual role with him and then I feel guilty. ... I feel as though I’m failing in my role.

The caregivers’ feelings of guilt were mostly due to the invalidation of their core constructs following placement of their spouse in a nursing home, looking for sexual
gratification elsewhere, or their guilt about not wanting an intimate relationship with their demented spouse. In other words, the spousal caregivers experienced feelings of guilt because they did not live up to their expectations of themselves.

Interestingly, although seven caregivers (five males; two females) said that they were currently involved in another intimate relationship and 21 (11 males; 10 females) reported that they would like, or had been in, another relationship, this did not appear to cause feelings of guilt. They were able to validate their need for another intimate relationship by indicating that they no longer regarded themselves as in a marital relationship. Their demented spouses were still “number one” but they now thought of them as “a baby”, “a child”, “a dependent parent” and so on.

**Death Anxiety**

Surprisingly, the comparison group scored significantly higher than the caregiver group on death anxiety. However, only 15 out of 63 comparisons and 7 out of 61 caregivers made references to death anxiety in their verbalisations (see Table 9.9). Due to these small numbers, I shall not focus on this result. Nevertheless, it is interesting to note that although the caregivers were the same age and had the same types of physical problems as the comparisons, the focus of their attention was the dementia. It is as though they were currently dealing with the death of their spouses, not their own situations. Conversely, the comparisons focused on their age and physical health and feared the *future* death of either themselves or their spouses; and, hence, the loss of their marital relationship. It is the anticipation of death that is scored on this scale. The following are examples of the comparisons references to death anxiety:
56 year old female

I have wondered sometimes, being in a new place here, what I would do if anything happened to him ... I'd be devastated but, knowing me, I would cope ... I couldn’t think of anything worse than losing him.

62 year old female

There is an awareness of age ... we have friends who are older and if someone has a stroke or a heart attack and you’re thinking perhaps of your own vulnerability. You can look at your partner and think, how long have we got?

73 year old female

We walk together and go to different things together and our life is just a togetherness and for either of us if we became a widow or widower its going to be pretty awful. But you can’t think about that, you just have to live every day as you can.

82 year old male

This is the best stage of my life ... we at least have one another. I don’t know what would happen if one of us died.

84 year old male

She’s everything to me ... if she were to go, I’d really be right down low again.

When one considers the results overall for the content analysis scales, what is clearly indicated is that the husbands and wives in the caregiver group were experiencing significantly more negative affect than the comparisons. It could therefore be suggested that these negative emotions followed invalidation of construing for the caregivers (McCoy, 1980).
Life Satisfaction

The relationship between marital satisfaction and life satisfaction generally has been an important theme in the literature (Peplau & Gordon, 1985; Morrissey et al., 1990; Marshall 2001). The Derogatis Affects Balance Scale (DABS) (1975) assessed the research participants' general psychological well-being, which in turn could be construed as their satisfaction with life in general. Derogatis (1975) believed that the accurate measurement of mood and well-being required the assessment of both positive and negative affective states and the balance between them. As discussed in Chapter 7, the participants were asked to rate the degree to which they felt the eight emotions during the past seven days, focusing on their life in general.

The results of the analyses showed that with regard to the positive affect dimensions of Affection, Contentment, Joy and Vigour, the comparison group experienced significantly more contentment and joy than the caregiver group, while the female comparisons felt significantly more affection than the female caregivers, but there was no significant difference on affection between the male comparisons and male caregivers. As expected, the results also showed that the comparison group experienced significantly higher overall positive affect than the caregiver group.

With regard to the negative affect dimensions of Anxiety, Depression, Guilt and Hostility, the caregiver group experienced significantly more of these emotions than the comparison group, whereas the females experienced significantly more anxiety and depression than the males. This latter finding is in line with findings reported by Argyle (1987). The results further indicated that the caregiver group and cohort of females experienced higher overall negative affect than the comparison group and cohort of males respectively.
The Affects Balance Index (which is a difference score between positive and negative totals) assessed overall well-being and the results showed that the comparison group experienced significantly higher well-being than the caregiver group; while the cohort of males experienced significantly higher well-being than the cohort of females. This latter result is in line with findings reported by Peplau and Gordon (1985).

Most caregivers indicated that “during the past 7 days” they had experienced some positive affect, particularly affection (which was their highest mean score - see Table 9.7). Many caregivers attributed this to spending time with their grandchildren. Nevertheless, the results clearly indicated that the caregivers in this study had a mood balance that was overwhelmingly negative, indicating low well-being and dissatisfaction with their lives in general. This high level of psychological distress experienced by the spousal caregivers is in keeping with the findings of other studies discussed in Chapter 5 (George & Gwyther, 1986; Pruchno & Potashnik, 1989; Owens, 2001). On the other hand, the results indicated that the spouses in the comparison group were highly satisfied with their lives. This latter result is in line with Argyle’s (1987) notion that “those who are married, especially those who are happily married, have a higher level of life satisfaction” (p.143). It will again be noted that the caregivers denied having a “marital relationship” at all.

It is also of interest to note that the mean Affects Balance Index score (0.80) of the caregivers in this study (see Table 9.7) is substantially lower than the mean score (1.27) of long-term metastatic breast cancer survivors, who themselves showed significantly poorer adjustment to their illnesses than short-term survivors (Derogatis et al., 1979). This again illustrates just how “low” the caregivers in this study were feeling about their lives.

Although Argyle (1987) has found that there is little gender difference in life satisfaction generally, the population of males in this study experienced significantly
higher overall well-being than the population of females. This could be explained by
the fact that men get more out of marriage than women (Pearlin & Johnson, 1977;
Gove, 1979), are more satisfied with themselves, and feel more in control of their lives.
Men also get more satisfaction out of their work and leisure (Argyle, 1987).
Furthermore, it is common for married men to score higher on measures of
psychological well-being than married women (Peplau & Gordon, 1985).

Patterns of Marital Relationships

Sternberg’s Kinds of Love

As can be seen from Table 9.6, and following Sternberg’s (1988a) validation
study for typically high, low and average scores (stated in Chapter 7), the comparison
group in this study appears to be high on intimacy and commitment and lower (average)
on passion, while the caregiver group appears to be low on intimacy and passion and
high on commitment. (As stated in Chapter 7, Sternberg’s validation sample consisted
of 101 men and women aged between 18 and 71 years with a mean age of 31 years,
who were either married or currently involved in a close heterosexual relationship. The
length of the relationships ranged from one to 42 years, with a mean of 6.3 years.)

With regard to the overall samples of males and females in the current study, the
scores of these men and women are generally similar to each other and, compared to
Sternberg’s validation sample, indicate lower (below average) scores on intimacy and
passion and high scores on commitment. However, the male and female caregivers
have skewed these scores and therefore when discussing kinds of love it is preferable to
only concentrate on the caregiver and comparison groups.

Sternberg (1988b) argued that in most loving relationships the three components
occur in varying degrees, rather than one or more being present or absent. As stated
above, in comparison to Sternberg’s (1988a) typical scores, the comparison group in this study appears to be high on the intimacy and commitment components and lower on the passion component. This is what Sternberg (1986; 1988b) described as companionate love and is the kind of love that might be expected in long-term marriages.

Sternberg (1986) described companionate love as “... essentially a long-term, committed friendship, the kind that frequently occurs in marriages in which the physical attraction (a major source of passion) has died down” (p.124). According to Sternberg (1986), Duck (1983) captured this view in the title of his book Friends for Life. Furthermore, this view of companionate love is similar to that described by Berscheid and Walster (1978) and discussed in Chapter 4.

The caregiver group in this study was low on the intimacy and passion components and high on the commitment component in comparison to Sternberg’s (1988a) typical scores. Sternberg (1986; 1988b) described this kind of love as empty love. According to Sternberg (1986), it is the kind of love that is sometimes found in stagnant long-term relationships that have lost both the mutual emotional involvement and the physical attraction. Furthermore, unless commitment is very strong, such love can be close to none at all. Sternberg’s empty love is similar to Adams and Jones’ (1999) “empty shells”: marriages that endure in the absence of happiness.

In summary, the kind of love experienced by the husbands and wives in the comparison group correspond to Sternberg’s notion of companionate love, while that experienced by the husbands and wives in the caregiver group he would describe as empty love. It is evident that, although the caregivers were endeavouring to cope with spouses with dementia, they were highly committed to their spouses.
From the results set out in Chapter 9 and discussed in this chapter, it is obvious that there are vast differences between the perceptions of the husbands and wives in the comparison and caregiver groups as far as their present intimate marital relationships are concerned. As indicated in the Results section, the demographic and psychosocial characteristics of both groups are very similar, and there was no significant difference between the groups with regard to their perception of the quality of their past marital relationships. (This was measured by the question in the demographic survey that asked the participants to rate the quality of their past marital relationship as either fair, good or excellent.) Furthermore, as previously mentioned, both groups had husbands and wives with physical problems and illnesses. However, only the caregiver group had spouses with cognitive impairment. Therefore, it could be assumed that dementia is the factor that has radically changed the nature of the intimate marital relationships of the spousal caregivers. In other words, if their spouses did not have a dementing illness, it is more than likely that the spousal caregivers’ marriages would be similar to the marriages of the men and women in the comparison group.

In the next chapter I will commence to unravel the conundrum as my journey progresses. Then, in Chapter 12, I shall attempt to evaluate the findings of this amended study, using PCT (Kelly, 1955) as a theoretical framework.
CHAPTER ELEVEN

JOURNEY PROGRESSES
UNRAVELLING THE CONUNDRUM
Although the following may first appear tangential to this thesis, I ask the reader to persevere, as it was this part of my journey which enabled me to unravel the conundrum; that is, to really understand what the spousal caregivers were experiencing.

* * * * * *

During my 18 months leave of absence from this Ph.D research (mentioned in Chapter 8), my husband, daughter and I began investigations to gain some understanding as to why my son’s personality and behaviour had changed so rapidly and radically, and why we could no longer relate to him. Why had he become a stranger? A psychology colleague and friend, who had known my son for many years, thought he was behaving as though he was in a cult. This comment set us off on a journey into, what was previously, an unknown world. We contacted cult “experts” both in Australia and overseas, by phone, e-mail and in person. We read books and started to gain knowledge. In time we even joined a support group.

Some people thought I was crazy. But I was just a mother who had lost her son - but not through death. So, initially, I received very little support or understanding. I felt so alone in my grief. My son did not have dementia, but I was experiencing similar feelings to those I experienced over the loss of my mother. Again, my identity and existence were being threatened and invalidated. Again, I could not mourn decently. Again, it was (and still is) a long, painful bereavement (Forsythe, 1990).
Then, by a personal communication from cult expert, Giambalvo (2000), responding to my plea for help, I began to understand how people are recruited into destructive cults and "cultic" relationships. After months of delving into this complex area, it appeared that my friend was right. The changes in my son's personality and behaviour were very similar to those that take place in a person recruited into a cult. When that recruitment happened, psychologist and cult expert Steven Hassan said, it could turn "an intelligent, educated person with a strong family background into a stranger" (cover of Releasing the Bonds, Hassan, 2000).

In order to explain the complex phenomenon of mind control used by cults, Hassan (2000) has extended Festinger's cognitive dissonance theory. According to Hassan, by manipulating a person's behaviour, thoughts, emotions, and the information they receive, cults can gain control over a person's identity. Furthermore, as well as being associated with cults, the concept of mind control has been linked to the psychological maltreatment of partners (Andersen, Boulette & Schwartz, 1991; Schwartz, Andersen, Strasser & Boulette, 2000) and the phenomenon of wife battering (Boulette & Andersen, 1986).

After several months of reading the literature and talking to the "experts" (e.g., Hodgkins, 2000), I began to understand what seemed to have happened to my son. It appeared that mind control techniques - that is, "a system of influence that is designed to disrupt a person's authentic identity and replace it with a new identity" (Hassan, 2000, p. 5) - may have been used to change his personality and behaviour and, in turn, his belief system. According to Hassan (2000):
By immersing people in a tightly controlled, high-pressure social environment, destructive cults gain control of their members' behaviour, thoughts, emotions, and access to information. They take over their minds (p. 5).

But then I saw a connection - dementing illnesses also take over minds! I shall not focus further on the phenomenon of mind control, except to say that it was now apparent to me that there are other factors that can cause identity (and hence relationship) changes other than dementia. Like the spousal caregivers, I could also say with regard to my son: “It’s like he’s a different person now”, or “We don’t know him anymore”; “He’s a stranger” (Hassan, 2000). As the years have gone by, most people who knew my son in the past - family, friends, colleagues, from whom he is also estranged - now see what has probably happened to him in a similar fashion to me.

The decade before I had lost my relationship with my mother because she had Alzheimer’s disease. She became a stranger to me and I had lost my role as a daughter. Now I had lost my relationship with my son; the wonderful mother-son relationship we had was dead. He also became a stranger to me and I had lost my role as a mother. My whole system was in turmoil, and the striking similarities between my current experiences and those of the spousal caregivers suddenly became apparent. I finally began to understand a little of what the spousal caregivers were experiencing and why they had denied that they were in a “marital relationship”. But why did it take this experience to make me aware? After all, I had already lost my relationship with my mother because of dementia!
The only way I could answer that question would be to suggest that I did not have awareness at that time because no-one had specifically asked me questions about the nature of my relationship with my mother. Furthermore, when I collected data from the spousal caregivers for my prior study (Rudd, 1993; Rudd, Viney & Preston, 1999), I was focusing on their grief and consequently asked them about their life in general. The open-ended question was: "I'd like you to talk to me for approximately five minutes about your life at the moment, the good things and the bad, what it's like for you now ...". In this current study, not only did I administer standardised instruments that focused on the marital relationship but I also asked open-ended questions that focused specifically on their marital intimacy and hence role relationship (see Chapter 7).

If I was questioned today about my relationship with my son, I would have to say that for almost four years we have not had a mother-son or parent-child relationship, in any way, shape, or form. Explaining what kind of relationship we do have would be challenging. I do not know him anymore; he seems to be a clone of someone else. He is a stranger.

Hence, it seems that in certain close relationships, when the identity of one person in the dyad changes (perhaps because of an organic brain disease like Alzheimer's disease; mind control indoctrination practised by destructive cults or psychological abusers; some head injuries; or perhaps even schizophrenia), then the nature of that relationship changes as well. With regard to personality changes caused by head injuries, in a personal communication (Hodgkins, 2003), I was informed of
the plight of a wife whose husband suffered extensive frontal lobe damage caused by a head injury. The wife said: “it was as though I was living with another person”. Furthermore, the head injured husband was incapable of having any compassion for his wife and had no understanding of her situation. I thought in some ways this was similar to the experiences of the spousal caregivers of dementia sufferers.

I then came across Doka and Aber’s (1989) paper on psychosocial loss and grief, which seemed to confirm my thoughts that there are conditions, besides dementia, that “can lead to abrupt personality changes that might adversely affect relationships with others” (p. 189). These authors state:

We can refer to psychosocial death in those cases in which the psychological essence, individual personality, or self is perceived as dead, though the person physically remains alive. Psychosocial death can occur under many different conditions and in many different circumstances. ... [as well as Alzheimer’s] other conditions such as mental illness or substance abuse can also create a sense of psychosocial death. ... Religious conversion or membership in a cult may also cause sudden and significant personality change ... In each of these cases there is a significant change from the person who he or she once was. Those who related to and were committed to that person’s earlier self will notice this change, for though that person is still physically alive, his or her personality is markedly altered. The qualities of the person to whom one was attached are no longer present. As one spouse of an Alzheimer’s victim once said, ‘All you have is a shell mocking what once was.’ The person is psychologically dead. There is loss, there is grief (Doka & Aber, 1989, p. 189, italics for emphasis).

I need to say that while dementia is irreversible and progressive, and the spousal caregivers’ situations will not change with regard to their “marital relationships”, some people do come out of cults and “cultic” relationships and, in time, regain their authentic identities. People can also recover, to some extent, from some head injuries, although it is unlikely that they will fully regain their former “self”
(Hodgkins, 2003), and medication can help those with schizophrenia. However, the initial change in identity, and hence the relationship change at that stage, remains the same in all these situations, and is an issue that needs to be understood and addressed.

By this time I had resumed my study and this bizarre and difficult experience of losing my son gave me a greater understanding of what the spousal caregivers were experiencing. The identity (or personality) of their partners had changed because of a dementing illness and, because of this identity change, the dementia sufferer became a stranger to the spousal caregiver. This changed the type of relationship they had. Despite the fact that the spousal caregivers were adamant that they no longer had "marital relationships", and many of them were pursuing other intimate relationships, they still loved, idealised, and remained highly committed to, their spouses.

Again, I could relate to this. As at today, the situation with my son remains unchanged but I still love him, remember and perhaps idealise what a wonderful son he was, and remain highly committed to him. Clearly this is not how we would feel about a "real" stranger, which The New Collins Dictionary describes as "any person whom one does not know" (McLeod, 1987, p. 991)!

So what is the nature of the spousal caregivers' current relationships with their demented spouses? Although they all said that they were in a "caregiving relationship", the analyses that I have carried out, and their own words, tell me that it is much more than that. It seems that these spousal caregivers have been forced to reconstrue not only their marital relationships, but also their spouses and themselves.
This is certainly not an issue that will affect everyone's life. However, as I have now experienced with the loss of my son, and confirmed by Doka and Aber (1989), these changes in relationships can be caused by factors other than dementia, and yet the outcome can be just as invalidating, threatening, and bewildering for the people who have not changed.

* * * * *

In the next chapter, I shall attempt to evaluate the findings of this study, using Kelly's (1955) PCT as a theoretical framework. As differences between the caregiver and comparison groups have already been discussed, I shall no longer labour this point. Instead, I shall evaluate the findings for each of these groups separately. I shall also present the findings on overall gender differences.
CHAPTER TWELVE

EVALUATION OF THE FINDINGS
In this chapter I shall evaluate the findings of my amended study. First, the findings of overall gender differences will be presented. This will be followed by an evaluation of the findings for the middle-aged and elderly husbands and wives in the comparison group. Next, I shall present the findings for the caregiver group, and attempt to explain the type of relationship these caregiving husbands and wives were experiencing, using PCT (Kelly, 1955) and, if necessary, by extending this theory.

**Overall Gender Differences**

**Summary of the Findings**

*Meanings of “Intimacy” and “Love”*

Although my main interest was overall gender differences, I also examined gender differences within each group. However, there were surprisingly few gender differences in either case. With regard to the meaning of the terms “intimacy” and “love”, the only noticeable difference was in relation to the term “intimacy”. In line with Duck (1988) and Riessman (1990), discussed in Chapter 4, the majority of all the men in this study (85 percent) defined “intimacy” mainly in terms of sexual relations, while considerably more women than men referred to closeness, communication, sharing and mutual understanding as well as sexual relations. Males and females were very similar in their definitions of “love”.

*Components of Marital Love*

In line with Sternberg (1988a; 1988b), there were no significant differences between males and females on the Intimacy or Commitment components of Sternberg’s Triangular Love Scale. However, contrary to Sternberg, the males in this study scored significantly higher than the females on the Passion component of love. Despite this finding, there was no significant difference in reported sexual activity between the males and females in this study.
Although there were no gender differences in relation to past and present commitment, both populations of males and females reported a decrease in their commitment to their spouses over the course of their marriages, from commitment to the unique person to commitment to both the unique person and the institution of marriage. There were no gender differences with regard to future commitment. Furthermore, there were no gender differences in relation to another important aspect of marital relationships, reciprocity.

**Marital and Life Satisfaction (Affect)**

*Marital Satisfaction*

Although considerably more caregiving husbands than caregiving wives rated their past marital relationships as “excellent” (indicating idealisation), there were no significant differences between the overall populations of males and females on their perceptions of the quality of either their past or present marital relationships. Furthermore, there were no significant differences between the males and females with regard to satisfaction with their interpersonal spousal relationships, or on any of the measures of positive affect or negative affect.

*Life Satisfaction*

With regard to life satisfaction (overall psychological well-being), in line with Peplau and Gordon (1985), the males experienced significantly higher overall well-being than the females. With regard to the positive affect dimension of Affection (Derogatis Affects Balance Scale, 1975), the female comparisons reported feeling significantly more affectionate than the female caregivers, but there was no significant difference on affection between the male comparisons and male caregivers. With regard to the negative affect dimensions, in line with past studies (Argyle, 1987; Rudd, 1993; Rudd, Viney & Preston, 1999), the females in this study experienced significantly more anxiety and depression than the males. Furthermore, the overall population of females
experienced higher overall negative affect than the population of males (Stacey & Gatz, 1991).

In summary, although gender differences were examined in this study, very few differences were found. In fact, the only significant differences were males scoring higher than females on the Passion component of love and overall psychological well-being (life satisfaction), while the females scored significantly higher than males on anxiety, depression and overall negative affect with regard to life satisfaction. The only other significant difference was between the female groups, with the female comparisons scoring higher than the female caregivers on affection.
Comparison Group

Summary of Findings

Below is a summary of the findings for the 63 middle-aged and elderly long-term married husbands and wives in the comparison group. These have been organised in terms of the components of marital love, marital and life satisfaction, and the resulting overall pattern of the marital relationship.

Components of Marital Love

**Intimacy**
High intimacy component of love.

**Passion/Sex**
Lower (average) passion component of love.

70% still engaged in sexual relations, 16% of these stating sexual relationship *better* now than in the past.

Most common reasons for decline or change in sexual relationship:

- health of spouse; health of self; age.

**Commitment**
High commitment component of love.

Past commitment: to unique person and institution of marriage.

Present commitment: to unique person and institution of marriage.

High future commitment.

**Reciprocity**
High reciprocity.

Marital and Life Satisfaction (Affect)

**Marital Satisfaction**

Past marital relationship - majority rated “good”.

Present marital relationship - majority rated “excellent”.

Increased marital satisfaction during later years of life. 79.4% indicating *better* now than in the past.

High satisfaction with interpersonal spousal relationship.
High positive affect regarding intimate marital relationship.
High marital happiness.
Low sadness, anger, cognitive anxiety, separation anxiety, guilt anxiety, death anxiety.

**Life Satisfaction**

High overall positive affect.
Low overall negative affect.
High overall psychological well-being.

**Pattern of Marital Relationship**

Companionate love - high intimacy and commitment, lower passion.

**Comparison Group: Type of Relationship?**

*Grow old along with me!*
*The best is yet to be,*
*The last of life, for which the first was made.*

(Robert Browning, cited in Wright, 1993, p. 7)

From the above summary of findings, it appears that, on average, the husbands and wives in the comparison group perceived themselves as experiencing highly intimate, highly committed, reciprocal marital relationships with their spouses. The arousal of passion and frequency of sexual relations were perhaps lower than in their earlier years of marriage, but most of these husbands and wives reported high levels of marital happiness and satisfaction. Even spouses who were not sexually active reported feelings of high positive affect regarding their intimate marital relationships. Indeed, almost 80 percent of the comparison group indicated that they were experiencing increased marital happiness and satisfaction during their later years. This finding is in line with past research (Roberts, 1979; Gilford, 1984; Weishaus & Field, 1988).
Furthermore, it has been argued by Argyle (1987) that overall marital satisfaction depends on both positive and negative emotions, and the results indicated that the comparison group were experiencing some low negative affect. However, it was interesting to note that the score for this group on death anxiety, although low, was significantly higher than that for the caregiver group. As mentioned previously, only a quarter of the comparisons made reference to death anxiety in their verbalisations, but for these men and women their advancing age and physical health led them to anticipate (and perhaps fear) the future death of either themselves or their spouses.

Unlike Wright’s (1993) well group, whose commitment to their spouses as unique persons was reported to have increased significantly over the course of their marriages, the spouses in the comparison group in this study decreased very slightly in their commitment from past to present. Nevertheless, the results indicated that the comparisons still remained committed to both the unique person and the institution of marriage. In fact, the results of this study are more in line with Swensen and Trahaug (1985), who found that for most older spouses there is a decline in commitment to their spouse as a unique person over the course of their marriage. However, in line with Wright (1993), the scores for the spouses in the comparison group indicated that they were highly committed to the future of their marital relationships. To use Wright’s (1993) words, “the best was yet to be” (p. 104).

In line with findings reported by other researchers (Roberts, 1979; Marshall, 2001), the overall affects balance score for the husbands and wives in the comparison group indicated that they were experiencing high life satisfaction/psychological well-being. Their positive affect scores in relation to their lives in general were very high, while their negative affect scores were very low. This finding is also in line with Argyle’s (1987) notion that happily married people have higher levels of general life satisfaction.
Although this amended study did not measure “satisfactory” or “unsatisfactory” marital relationships (as has been done in most marriage research), it could be argued from the above findings that the spouses in the comparison group were satisfied with their intimate marital relationships with their partners. In PCP terms, as mentioned previously by Neimeyer and Hudson (1985): “satisfying marital relationships involve a continuous and reciprocal process of personal elaboration” (p. 129), which requires spouses to both support and extend their partner’s way of viewing the world. As well as involving the process of validation, interpersonal understanding represents a mechanism for this personal elaboration. Hence, according to Neimeyer and Hudson (1985), satisfactory marital relationships require both validation and mutual understanding.

As mentioned previously, Kelly (1955) emphasised the importance of interpersonal understanding in PCT by calling our most important constructs, core role constructs. Leitner (1988) stated: “If you validate my core ROLE constructs, I may experience emotions such as love and happiness” (p. 254). Here, Leitner was citing McCoy (1980), as I did when I suggested (in Chapter 6) that spouses who have more satisfying intimate marital relationships experience validation of their core role construing, which may be evidenced by them experiencing positive emotions such as love, happiness and satisfaction. Hence, in view of the comparisons’ feelings of high positive affect and low negative affect with regard to their marital intimacy, in line with McCoy (1980), this could indicate that the husbands and wives in this group were experiencing more validation and less invalidation.

It will also be remembered that mutual understanding was a theme in the research participants’ definitions of both “intimacy” and “love”. This is in keeping with other authors’ definitions. For example, as discussed previously, Giddens (1999) included in his definition of intimacy, the notion of understanding the other person’s point of view; while Sternberg and Grajek (1984) proposed that intimacy in a loving
relationship included mutual understanding (among other things). Reis and Shaver (1988) proposed that intimacy involved feeling "understood, validated, and cared for" (p. 367). Whereas, Beck (1988, cited in Noller, 1996) included understanding as one of the characteristics of mature love. Furthermore, Maxwell (1985) found satisfaction with mutual understanding to be one of the best four predictors of overall marital satisfaction. Therefore, when the spouses in the comparison group responded to questions about their intimate marital relationships, it is presumed that they would have been thinking about mutual understanding as well as the other themes which meant "intimacy" and "love" to this cohort.

Hence, in view of all the above findings, together with the comparisons' own words, it is argued that the majority of spouses in the comparison group perceived that they were experiencing validation and mutual understanding in their marital relationships. It is further argued that these spouses had arrived at those understandings which permitted them to experience the deep role relationship of marriage referred to by Kelly (1955).

**Companionate Love**

*Companionate love is essentially a long-term committed friendship, the kind that frequently occurs in marriages in which the physical attraction (a major source of passion) has died down.*

(Sternberg, 1986, p. 124)

As might be expected in long-term marriages, the middle-aged and elderly spouses in the comparison group seemed to be experiencing what love researchers Berscheid and Walster (1978) and Sternberg (1986; 1988b) referred to as a companionate kind of love. The passion in their marriages had died down but intimacy and commitment were still very high, and their lives with their partners were deeply intertwined. The comparisons were still committed to their spouses as unique persons
as well as to the institution of marriage, and future commitment was very high. They were indeed *friends for life* (Duck, 1983 cited in Sternberg, 1986). In fact, many comparisons made reference to this when they made statements such as: “She’s my best friend, my main companion”; “we’re mates”; “we’re good pals and good companions”. However, this notion of friendship was summed up by a 65 year old wife who said:

> We’re both very satisfied. And we care for each other and share everything. And friendship is most important because unless you have a friend there is no love there, and you must value that friend because to that friend you will tell your most intimate thoughts and your sorrow, and you share that sorrow ... he is my best friend.

In summary, there was obviously variety in the experiences of each of the spouses in the comparison group and, indeed, some were even dissatisfied and unhappy with their marriages. However, as indicated by the results, the majority of comparisons were very happy and contented with their intimate marital relationships, and looking forward to the future with their partners. The spouses in the comparison group appeared to be similar (in their relationships with their partners) to the well couples in Wright’s (1993) study, who she described as “two people moving together in harmony” (p. 67).

Furthermore, none of the husbands and wives in the comparison group indicated that they were *presently* involved in an extra-marital relationship. However, one 74 year old man reported that he had previously been in such a relationship for 12 years. He commented:

> I had a relationship with another lady because she found me sexually attractive but at no stage did she or I have any desire to break up a home. We had common interests. Apart from the sexual relationship at that stage - well all through my life I was a boating person and she was a lady who loved boats. So we used to disappear away on boats - about 15 or 16 years ago. My wife knew about it; it went on for something like 12 years. In fact in the early stages they were good friends. My wife was quite happy with the idea in the beginning but not towards the end, and she asked would I come back and behave myself like an old grandfather ... I don’t think from day one my wife was ever sexually attracted to me so I found it in someone else, who also had common interests.
Despite his infidelity, he and his wife continued on with their marriage, re-negotiating the “terms” of their relationship. He said: “It’s purely a partnership. We get on quite well and we’re friendly to one another. There is no sexual contact so it’s purely a platonic state but fairly comfortable ... we get on well; we’re building a new house together”. They also decided to pursue their independent activities and take separate holidays - he liked outback Australia and she liked Europe! This man was “happy” with his marital relationship and highly committed to his wife. He said: “Our relationship is probably a little bit better now than it was in the past because of age. You become more understanding and adjust more and are more forgiving”.

On the surface, his reasons for having an extra-marital relationship seem to be very straightforward (and perhaps could be construed as selfish). However, by allowing him to speak freely about his situation, this husband also disclosed that he had a heart attack at age 42 and was told he would probably not live long because his father and brothers all died before age 60 with heart attacks. He said his heart attack upset his wife more than it upset him (“death isn’t something that bothers me - not an easy death”), because she became his “carer” and, as he had to retire early, she found it difficult having him around the place all the time. It appears that the extra-marital relationship developed some time after his heart attack.

I believe that having this additional information helps us to understand a little more about this man’s situation. It also confirms that if older couples are mutually understanding, forgiving, and willing to make adjustments, then their marriages can go on and increase in satisfaction. I could have never gleaned all this rich information from a standardised measure (which I shall discuss in Chapter 13).

The above comments illustrated a unique situation among my sample of comparisons. However, I believe the following excerpt aptly reflects the feelings of a
typical spouse in the comparison group in this study, who could be described as experiencing a *companionate* kind of love. The comments are made by a 73 year old husband who had been married for 50 years. He had a heart condition and his wife was diagnosed with lymphoma a year before the interview. He and his wife had recently moved from their home into a retirement village.

We are able to support each other completely in all the things that come up, whether it’s to do with our medical conditions, our spiritual conditions or our just living together generally. It’s a complete oneness that binds us. We have a very loving relationship physically and emotionally. This is constant; it doesn’t fluctuate. I can’t say it’s increased in physical passion because you’re getting older but - for example, when we came to live here it was in a sense a new beginning and we had freshness about our, you know, relationship, which was quite amazing. ... It was just the nice surroundings and the fact that we were happy in the decision that we made. Well, it was almost in a sense a sort of type of honeymoon - you know, a new beginning even at this stage of life. ... I guess it’s two people who have their separate personalities and their separate thinking and their separate likes and dislikes working together ... you do things in a home which help each other. I mean I help with the housework and it’s a case of just a joint relationship and it’s jointly in everything.
Caregiver Group

Summary of Findings

Below is a summary of the findings for the 61 middle-aged and elderly long-term married spousal caregivers of dementia sufferers.

Components of Marital Love

Intimacy
Very low intimacy component of love.

Passion/Sex
Very low passion component of love.

82% not engaged in sexual relations.

Most common reasons for decline or change in sexual relationship:
- dementia; general health of spouse.

Commitment
High commitment component of love.

Past commitment: to spouse as a unique person.

Present commitment: to unique person and institution of marriage.

Lower future commitment.

Reciprocity
Virtually no reciprocity.

Marital and Life Satisfaction (Affect)

Marital Satisfaction

Past marital relationship - majority rated “excellent”. (80% of caregiving husbands rated past as “excellent”).

Present marital relationship - majority rated “fair”.

Decreased marital satisfaction during later years of life. 90.2% indicating worse now than in the past. (4 out of 61 reported better).

Very low satisfaction with interpersonal spousal relationship.

Low positive affect regarding intimate marital relationship.

Low marital happiness. 70% less than happy.
High sadness, anger, cognitive anxiety, separation anxiety.
Low guilt anxiety (but significantly higher than comparisons).
Low death anxiety.

**Life Satisfaction**

Low overall positive affect.
High overall negative affect.
Very low overall psychological well-being.

**Pattern of Marital Relationship**

Empty love - low intimacy and passion; high commitment.

**Caregiver Group: Type of Relationship?**

_The person may be married and have a family yet is existing in a house full of strangers rather than living in a home filled with friends since there are no ROLE relationships._

(Leitner, 1985, p. 89)

From the above summary of findings, it appears that, on average, the husbands and wives in the caregiver group perceived themselves as experiencing very unhappy, virtually non-reciprocal “relationships” with their demented spouses, involving very little intimacy and even less passion. Eighty two percent reported that they had no sexual relationship with their spouse, which they reported was mainly due to the dementia.

These spousal caregivers were experiencing very low satisfaction with their interpersonal spousal relationships. In fact, any reported positive interaction between the spousal caregivers and their demented spouses seemed to be in relation to the caregivers supporting and nurturing the dementia sufferers, while receiving virtually nothing in return. The spousal caregivers were also experiencing low positive affect...
regarding their marital intimacy. When they did make reference to positive emotions, these were more subdued than those of the comparison group; for example, the caregivers used phrases such as: "I like to do things for him". Moreover, 70 percent of the spousal caregivers reported that they were less than happy with their marriages. These findings are in line with other studies which have found that spousal caregivers of dementia sufferers experience significantly lower levels of marital closeness and satisfaction than control groups or spousal caregivers of partners with non-dementing illnesses, such as Parkinson's disease (Owens, 2001), or spousal caregivers of partners who are physically impaired (Barusch & Spaid, 1996).

Furthermore, the majority of caregivers in this study verbalised feelings of profound sadness, intense anger, high cognitive anxiety, and the fears and threat associated with separation anxiety. According to Neimeyer and Hudson (1985), both threat and anxiety can result from misunderstanding. Threat normally occurs following misconstructions at relatively superordinate levels of the system. For example, if a spousal caregiver's core structure involved the belief that their partner's identity would remain the same, then they are likely to be seriously threatened when they are required to relate to a stranger. As mentioned previously, this would jeopardise their most central constructions of their marital relationship and force massive reconstruction of their own personal construct system (Neimeyer & Hudson, 1985).

The spousal caregivers also expressed high cognitive anxiety which indicated that the events they were experiencing were beyond the range of convenience of their personal construct systems (Kelly, 1955). Moreover, due to the progressive nature of dementing illnesses, it is likely that the stranger would also be unpredictable, and the caregiver may be forced to relate to many different strangers over the course of their spouse's illness (Preston, 2003, personal communication). I imagine that this would engender more intense feelings of threat and anxiety in the spousal caregiver.
Although the caregivers were experiencing significantly more guilt anxiety than the comparison group, their levels of guilt were relatively low despite many of them pursuing new intimate relationships. As mentioned in Chapter 10, it appeared that the caregivers in this study were able to justify their need for another intimate relationship because they no longer regarded themselves as being in a "marital relationship". The feelings of guilt experienced by the caregivers were mostly due to the invalidation of their core constructs following the institutionalisation of their spouse or their need for sexual gratification.

Furthermore, only seven out of the 61 caregivers made reference to death anxiety in their verbalisations. As mentioned previously, rather than anticipating and fearing the future death of their spouses, as may be normal for older people, it was as though they thought of their spouses as already dead and were already grieving for their losses. Many referred to themselves as "married widows or widowers".

The negative affect emotions of sadness, anger, cognitive anxiety and guilt used in this study were the same as the four psychological states of grief used in my prior research (Rudd, 1993; Rudd, Viney & Preston, 1999). The emotional reactions in regard to these states experienced by the spousal caregivers in this study were of similar intensity to those experienced by the spousal caregivers in my prior work. However in the present study, where I was focusing only on their intimate marital relationships, the spousal caregivers expressed even higher levels of sadness than the high levels reported in my previous study, in which I was focusing on their lives in general.

This overwhelming sadness could partly be explained as follows. From a personal construct perspective, each spousal caregiver can be seen as an active participant in his or her bereavement reaction (Rudd, 1993). However, the adaptability of each person's construct system determines the efficacy of his or her adjustment to bereavement (Woodfield & Viney, 1985). When core constructs are invalidated,
reconstruction of a person’s construct system may be more difficult. Hence, as suggested by Woodfield and Viney (1985), and in line with the findings of Rudd (1993), the spousal caregivers, who had defined their own identities “inflexibly” in terms of their partners and their marital relationships, became “prisoners” of their own construct systems, and experienced overwhelming sadness. Whereas, a person whose prior convictions about themselves and their marital relationships may have “flexibly” encompassed a broader perspective is more likely to discover those choices which will eventually lead to their “freedom” (Woodfield & Viney, 1985, p. 17). Furthermore, when a loved one dies and their identity has not changed, then we do not have to reconstrue that person. We can remember and grieve for the person we knew and loved. In other words, it is easier to make sense of the loss and go through a normal grieving process.

In line with past research (Knop et al., 1998), the majority of the spousal caregivers in this study rated their present marital relationship as “fair”; whereas they rated their past as “excellent”. In my prior study (Rudd, 1993), I also found that the majority of the spousal caregivers described the quality of their past marital relationships as “excellent”. From these findings, it could be argued that spousal caregivers of dementia sufferers idealise their past marital relationships, the same as a person may idealise their spouse who has died. According to Parkes (1972), idealisation is a common component of bereavement. In line with the findings from my prior study (Rudd, 1993), but contrary to other researchers (Morris et al., 1988; Knop et al., 1998), the caregivers in this study were experiencing very high levels of sadness (depression) and other negative emotions, despite perceiving their past relationships as “excellent”.

In contrast to the comparison group, over 90 percent of the spousal caregivers indicated that their marital satisfaction was worse at the present time than in the past. Despite this finding, four out of the 61 caregivers reported it was better than previously,
mainly because their demented spouses were now dependent on them and they felt that they had more control, while one spousal caregiver appeared to be in denial. Denial and idealisation are two processes of assimilation, which is itself a process of adaptation (or adjustment to a loss). As stated by Woodfield and Viney (1985):

Assimilation through denial implies that some of the widow’s [sic] constructs which are associated with the death of her husband are impermeable. Because of this impermeability, elements associated with the death will not be construed realistically (p. 11).

As explained in Chapter 6, in PCT terms, a construct which can embrace new elements within its range of convenience is called a permeable construct; whereas impermeable constructs are not open to such inclusions (Kelly, 1955). In the case of the spousal caregiver above, who was in denial, he tried to assimilate or change the confronting event (that is, the deterioration of his wife’s condition, which in turn would mean the “loss” of his wife) by denying that it would happen. Interestingly, in the same verbalisation he said “we must adapt to change”!

The overall affects balance score for the husbands and wives in the caregiver group indicated that they were experiencing very low psychological well-being and dissatisfaction with their lives in general. This finding is in keeping with findings of other studies of spousal caregivers (George & Gwyther, 1986; Pruchno & Potashnik, 1989; Owens, 2001). However, it is contrary to reports in the literature relating to the psychological well-being of older married men and women in general (Peplau & Gordon, 1985; Morrissey et al., 1990; Stacey & Gatz, 1991; Marshall, 2001). As Baikie (2002) commented: “Although being married conveys many health and social benefits in later life, it can be stressful when it involves caregiving” (p. 293). Furthermore, while the caregivers reported more positive affect towards their lives in general than they expressed in their verbalisations regarding their intimate marital relationships, the positive affect relating to life satisfaction was mainly attributed to the time spent with grandchildren.
Despite their overwhelming unhappiness, verbally reported loneliness, isolation and anguish, and the fact that almost 50 percent were either currently involved in, or said they would like, another intimate relationship, it is striking that the caregivers were still so highly committed to their spouses. Although the comparison group scored significantly higher than the caregiver group on the commitment component of Sternberg’s Triangular Love Scale, the caregivers’ mean score was very high. In fact, it was higher than that in Sternberg’s (1988a) validation study and more in line with his typically high scores (see Chapter 7).

Furthermore, the caregiver group scored significantly higher than the comparison group on past commitment, with the caregivers’ results indicating that their past commitment was solely to their spouses as unique persons. However, the caregivers were again possibly idealising their past perceptions of their spouses. With regard to present commitment, like the comparisons, the caregivers indicated commitment to both the unique person and the institution of marriage. For the caregivers there was a decrease in their commitment from past to present. However, as stated in Chapter 10, despite regarding their demented spouse as a “stranger” and denying that they were presently in a “marital relationship”, most caregivers reported that they still valued their demented spouses as unique persons as well as being committed to their marriage vows. Perhaps the spousal caregivers needed to idealise their spouse and embellish their past marital happiness, as well as blame the disease, in order to validate their reasons for remaining in an intolerable situation, which could endure for many years. Although their identities and existence were being threatened and invalidated by the stranger who now confronted them, the spousal caregivers could at least give meaning to their commitment to stay.

However, in line with Wright’s (1993) caregiver spouses, the spousal caregivers in this study reported lower commitment to the future. Most of the caregivers indicated that they could not do much more than they were presenting doing
to preserve their marriages. Wright put this down to the fact that commitment to the future required energy, and if the caregiver’s own physical health and emotional well-being were failing, then commitment to the future would be affected (Wright, 1993).

*Empty Love*

*Marriages that endure in the absence of happiness are considered to be “empty shells”.*

(Adams & Jones, 1999, p. 10)

According to Sternberg (1986, 1988b) a relationship where there is commitment in the absence of intimacy and passion is called *empty love*. This could very well describe the kind of love that the spousal caregivers were experiencing; they were very high on commitment and very low on intimacy and passion. However, I believe that their situation is a lot more complex than that. As Sternberg (1986) goes on to say:

>[Empty love] is the kind of love one sometimes finds in stagnant relationships that have been going on for years but that have lost both the mutual emotional involvement and physical attraction that once characterised them. Unless the commitment to the love is very strong, such love can be close to none at all, because commitment can be so susceptible to conscious modification (p. 124).

Duck (1979) remarked that “relationships are dynamic and developing things” (p. 291). Although the “relationships” of the spousal caregivers and their demented partners were certainly not as Duck described, I do not believe that they could simply be referred to as “stagnant”, as stated in Sternberg’s description of empty love. Taking into account the caregivers’ reports of valuing their spouses as unique persons, both in the past and present, as well as rating the quality of their past marital relationships as “excellent”, it is very likely that the caregiver group would be similar to the comparison group if it was not for the dementia.
Furthermore, I would argue that people in stagnant, unhappy marriages would not bother to idealise the past, nor have a need to adjust to their “loss”. Also, the caregivers’ motives for staying committed to their marriages were different from a spouse who stays in an abusive marriage hoping to change the perpetrator, or an “empty shell” marriage that continues for religious or financial reasons (Adams & Jones, 1999). For most of the long-term married spousal caregivers in this study, the changes in their intimate marital relationships coincided with their demented spouses’ personality and behaviour (identity) shifts caused by the dementia. It was not due to the fact that their relationships were “stale”, “static” or “dull from inaction” (McLeod, 1987, p. 974).

In keeping with the themes emerging from Baikie’s (2002) ongoing study, despite the devastating changes in their demented spouses, many caregivers in this study reported that they still loved their partner and acknowledged that it was the dementia, not the person, that was the cause of the changes. Hence, I acknowledge that these caregivers were experiencing an empty kind of love; however, this concept is insufficient to explain the type of relationship they were having with their spouses.

If Not Just Empty Love, Then What Type of Relationship Is It?

Before I present my opinion regarding the type of relationship experienced by the spousal caregivers in this study, I need to make a further distinction between the caregivers and the spouses in the comparison group. I believe that the findings for the comparison group, discussed previously, convincingly portrayed a group of older spouses who felt validated and understood and, in turn, happy and satisfied with their intimate marital relationships. However, among the comparison group there were, of course, a few spouses who felt invalidated, misunderstood and, in turn, dissatisfied and unhappy with their marital intimacy. It is important to point out that these dissatisfied spouses were different to the spousal caregivers. The main difference was that the dissatisfied spouses did not deny they were in a “marital relationship” - it was
simply a “bad”, “unhappy”, or “unsatisfactory” marital relationship. They were also still able to have reciprocal relationships - albeit negative reciprocity - with their spouses (Pike & Sillars, 1985).

In order to explore, and attempt to explain in PCP terms, the type of relationship being experienced by the spousal caregivers in this study, I shall focus on the two concepts which, according to Neimeyer and Hudson (1985), depict either “satisfactory” or “unsatisfactory” marital relationships: that is, validation-invalidation and interpersonal understanding-misunderstanding. Kelly’s (1955) Sociality Corollary, as set out in Chapter 6, relates to interpersonal understanding. I shall also illustrate how some spousal caregivers re-wrote identities (Perry, 2002) for themselves and their demented partners, perhaps as a way of overcoming nonvalidation (Walker et al., 2000; Walker, 2002).

**Validation-Invalidation: Or is it Nonvalidation?**

I have mentioned the terms “validation” and “invalidation” throughout this thesis but have not, as yet, given Kelly’s definition of these terms. Kelly (1955) stated:

A person commits himself [sic] to anticipating a particular event. If it takes place, his anticipation is validated. If it fails to take place, his anticipation is invalidated. Validation represents the compatibility (subjectively construed) between one’s prediction and the outcome he observes.Invalidation represents incompatibility (subjectively construed) between one’s prediction and the outcome he observes (p. 158).

Button (1996) elaborated Kelly’s (1955) theory regarding these concepts by first pointing out that the word “validation” is derived from the Latin words *validus-valere (to be strong)*. Button took this to imply that validation-invalidation has to do with strengthening or weakening of one’s predictions, rather than Kelly’s more absolute notion of the prediction being either confirmed or disconfirmed. Therefore,
from Button's (1996) perspective, “constructs are more or less validated/invalidated” (p. 145).

Walker et al. (2000) and Walker (2002) have also attempted to extend Kelly’s (1955) concept of validation. These authors agreed that Button’s elaboration made sense, as it is likely that, over time, our theories about the world have been validated in a cumulative way, particularly our core constructs. As Walker et al. (2000) point out: “It may be rare to have a decisive, absolute confirmation or disconfirmation of a construct or process” (p. 100).

According to Walker et al. (2000) and Walker (2002), Kelly used the construct “validation-invalidation” in two ways. First he linked it to the metaphor of the scientist, whereby a person formulates an hypothesis, conducts an experiment to test the hypothesis, and evaluates the outcome. That is, has the prediction been confirmed or disconfirmed? The second usage applies to one of the possible outcomes of the experiment: that is, when the hypothesis is validated (confirmed); or when the experiment is invalidated (disconfirmed). In order to discuss the apparent “invalidation” experienced by the spousal caregivers in this study, I shall focus on Walker’s (2002) argument regarding the first usage of the construct - the validation cycle, the process whereby a person’s construing is tested.

Walker (2002) stated that Kelly saw people as “incipient” potential scientists, which suggests that the process of construing can go awry. Indeed, Kelly (1955) noted: “... there are times when a person hesitates to experiment because he [sic] dreads the outcome. He may fear that the conclusion of the experiment will place him in an ambiguous position where he will no longer be able to predict and control” (p. 14). Moreover, Leitner (1999) pointed out that in severe cases of trauma, people can shut down their meaning making altogether. Walker et al. (2000) and Walker (2002) used the term nonvalidation to refer to those times when people do not, or can not,
effectively test their construing. This is opposite to the process of validation. With nonvalidation there is no opportunity for constructs to be revised.

Walker et al. (2000) cited other theorists whose views are consistent with theirs. For example, Landfield’s (1988) literalist and circumspectionist represent different strategies of nonvalidation. The literalist no longer needs validational evidence, the truth is known so there is no need for revision; while the circumspectionist “remains trapped in circumspection, avoiding anticipations, showing ‘reluctance in defining situations, person, or validating evidence’” (Landfield, 1988, p. 241, cited in Walker et al., 2000, p. 104). Another illustration of a nonvalidation strategy is Bannister’s (1965) arguments regarding the impact of serial invalidation. According to Walker et al. (2000), Bannister proposed that “those who find themselves in situations where their construing is repeatedly invalidated may develop a coping strategy which entails loosening the relationships between constructs. The result is that specific predictions can no longer be made and invalidation is thereby avoided” (p. 104).

On numerous occasions I have mentioned the spousal caregivers’ experiences of invalidation, and I would suggest that Bannister’s argument regarding the impact of serial invalidation could have resulted in the “preponderance of negative emotions” experienced by these caregivers (Walker et al., 2000, p. 102). Nevertheless, I suggest that what was really going on for many of the spousal caregivers is an example of nonvalidation (Walker et al., 2000; Walker, 2002). A number of caregivers appeared to be so devastated, grief-stricken, and unable to make sense of their experiences, that they were almost immobilised. Indeed, I would argue that for some caregivers, their meaning making had shut down altogether (Leitner, 1999). The situations they were experiencing did not provide the validation necessary to usefully revise their construing (Walker et al., 2000).
For example, a spousal caregiver may have formerly construed his or her "marital relationship" as an intimate, loving relationship with a long-term partner, whose personality and behaviour were mostly predictable. Early in the illness, when their demented partner's identity changed and he or she became a stranger, the spousal caregiver could no longer make such predictions. They knew the eventual outcome would be the physical death of their spouse, but they were forced to live with the uncertainty of when this would occur, and also the uncertainty of which stranger they would be forced to relate to tomorrow! Rather than taking the risk of testing out their construing, they grasped on to the past but were unable to move to the future. As Walker (2002) pointed out, situations such as these are fraught with fear, anxiety, and threat. It was perhaps at this stage, that some spousal caregivers dehumanised their demented partners and re-construed them as a "thing" or a "stone" etc., while others took on their new roles, developed "new identities" for themselves and their spouses and began to find new understandings of their current situations (Perry, 2002).

**Identities Re-Written**

As mentioned in Chapter 8, the majority (if not all) of the spousal caregivers thought of themselves in a "caregiving relationship" rather than a "marital relationship", and many resented their role as "caregiver". One 79 year old husband said: "She's not a partner as she used to be, but a dependant - a sick person who I have to care for". While a 67 year old wife complained that she was her demented husband's "servant". She said: "He's exactly the opposite to how he was, exactly the opposite in everything ... very selfish, very demanding. I'm his servant". Another caregiver, a 57 year old husband, was angry that his wife had "gone", angry he was "celibate", angry he had erotic dreams which resulted in a cold shower, and he resented his caregiving role. He referred to himself as a "social worker" and his demented wife as "a strange person that I've taken upon myself to look after".
Similarly to Perry’s (2002) process of re-writing identities, some spousal caregivers seemed to unwittingly develop “new identities” for both their demented spouses and themselves. Perhaps they did this in an endeavour to make sense of their new experiences, or to relate to their demented spouse, or even to alleviate guilt while having another intimate relationship. However, in most cases, this seemed to be a positive experience for these caregivers. Similar themes came through many of the spousal caregivers’ verbalisations as they re-construed (or re-identified) their demented spouse as a “baby” or “child” and themselves as a “mother”, “father” or “parent”. For example, a 71 year old wife, whose husband had dementia for only two years, said: “... he’s more like my son now, more like a little baby, than a husband”. By describing her husband as “more like my son” indicates that she had re-construed herself as his “mother”. Another 67 year old wife commented:

I always try to get him what he likes, like oysters, his steak rare, and things like this. I feel like his mother giving him what she didn’t. He’s like the child now and he loves it because he often talked about how his mother ill-treated him. I’d rather be his mother now, it suits me fine.

Other metaphors were also used. A 57 year old wife re-construed her demented husband as a “dependent father” and herself as an “adult child”. This allowed her to “let go” of her husband and helped validate her need to pursue other intimate relationships. While, a 56 year old wife re-construed both herself and her demented spouse as “children”. She described how they sang and danced around the kitchen, and acted in “childish” ways because “we’re savouring every moment because I know it will change”.

For the spousal caregivers in this study, it seemed that more wives than husbands re-wrote identities. However, the following comments are those of a 75 year old male caregiver, whose wife had dementia for 13 years. She resided in a nursing home and could no longer speak. The caregiver had recently “fallen in love again” but, due to him having prostate cancer, he and his new companion did not have a sexual
relationship. Instead, they had a “very loving, intimate relationship”. This man still
loved his wife and was committed to looking after her. He re-wrote his wife’s identity
as “baby” and his as “parent”.

I haven’t got my wife any more ... My wife can’t talk to me, she
doesn’t know what I’m saying; she’s not aware I’m there ... she’s like a young baby and I’m like her parent. ... I give her the things that
I know would have made her happy as a child and that’s the way that I
can live with it. Yes, I’ve got a little child and I’ve got to look after
her. Give her an occasional chocolate and you can see the smile come
on her face - you know she’s enjoying it because it’s only sensations
that are left - that’s all. ... You’re not expecting anything in return.
That’s the difference - it’s one way. Instead of being a shared
relationship, it’s one way, ... You do get little things back like a smile
to say, look it’s worth it, it’s worth it. ... When I met [his new lady],
it was just like falling in love as a teenager, silly isn’t it? ... I don’t
feel guilty about having deserted my wife. As I’ve said to [his new
lady], my wife will always come first, you’re second best in a sense.

This caregiver’s wife of almost 50 years had “gone”, as had his “marital
relationship”, and he was left to deal with an unpredictable person, about whom he
commented: “I don’t know anything about what’s going on in her mind”. Hence,
nonvalidation was forced upon him (Walker, 2002). However, by re-writing both his
wife’s and his own identity, perhaps he was able to once again test his construing.
After all, how risky could it be to make predictions about a baby? As he said: “You
know if a baby is wet - it cries; if it’s not fed - it screams ... I give her the things that I
know would have made her happy as a child”. He knew that by giving her an
“occasional chocolate” he would be rewarded with a smile! He felt validated as a
“parent”. Furthermore, like most parents, he was committed to looking after his child
without expecting anything in return. Because of his marriage vows, past memories
and present commitment, despite having fallen in love again, his new companion was
relegated to “second best”.

In fact, most caregivers who had other intimate relationships remarked that the
new relationship was on their terms, and their demented spouse was “number one”.
Furthermore, it was interesting to note that many of the spousal caregivers who re-wrote identities were having, or pursuing, other intimate relationships.

**Sociality (Interpersonal Understanding-Misunderstanding)**

As mentioned in Chapter 6, Neimeyer and Hudson (1985) suggested that interpersonal understanding, or sociality (Kelly, 1955) represented one vehicle for personal elaboration. They went on to say:

> the sociality corollary stipulates that genuine role relations are limited by the interactants' degree of understanding; that is, by their ability to subsume one another's constructions. This suggests that a major factor in the development of interpersonal relationships is the amount of understanding between interactants (Neimeyer & Hudson, 1985, p. 133).

In other words, an important factor in the development of successful role relations “lies in the ability of one or both participants in a dyadic relationship to subsume the points of view of the other person” (Landfield, 1971, cited in Neimeyer & Hudson, 1985, p. 134).

Before proceeding, it is important to mention that, according to Kelly (1955), there are different levels at which we attempt to construe another person’s construing. For example, when driving in traffic we are constantly attempting to predict what the other driver will do. As Kelly (1955) said, here we are endeavouring to predict another’s behaviour by subsuming each other’s perception of the situation, yet each driver knows very little about the “higher motives and the complex aspirations of the oncoming drivers, upon whose behaviour our own lives depend” (pp. 95-96). Kelly suggested that to understand these drivers at higher levels we must first get out of our cars and talk to them. When we can accurately predict another person’s behaviour, then we are able to adjust ourselves to their behaviour, and vice versa. Moreover, understanding can be mutual, but in some role relationships this is not necessary or appropriate, for example, the therapist-client relationship. Nevertheless, when it comes
to the deep role relationship of marriage, Neimeyer and Hudson (1985) found that more satisfied spouses showed more mutual understanding, although it is acknowledged that in many marriages one partner may understand the other partner better than they are understood (Kelly, 1955).

In contrast, Neimeyer and Hudson (1985) proposed that ineffective understandings, or misunderstanding, jeopardized successful relationship development, and two mechanisms which relate to this misunderstanding are threat and anxiety (defined in Chapter 6). In the amended study, I did not specifically measure threat and anxiety. However, it could be argued from the analyses, as well as the spousal caregivers’ verbalisations, that they were indeed feeling threatened and anxious. The events they were experiencing were certainly beyond the range of convenience of their personal construct systems, resulting in high levels of anxiety (Kelly, 1955). Moreover, being confronted by the fact that their demented spouses were no longer the same people they had married would have produced threat, and forced massive reconstruction of their construct systems (Neimeyer & Hudson, 1985).

However, merely feeling threatened and anxious and, in turn, misunderstood does not make the spousal caregivers any different from other dissatisfied spouses. As I have previously argued, their relationships are more than simply “unsatisfactory”. In the previous section, it was argued that they were experiencing nonvalidation; that is, they could not, or would not, effectively test their construing (Walker et al., 2000; Walker, 2002). Now I shall attempt to explain their apparent lack of sociality with their demented spouses. I will be primarily focusing on the deep role relationship of marriage, and the spouses’ ability to arrive at those understandings which permit this kind of role relationship (Kelly, 1955, p. 100). Furthermore, I shall be following Leitner’s (1985) elaboration of Kelly’s theory in relation to “true intimacy”, which he defined as “a reciprocity of extensive ROLE relationships” (p. 85). In other words, “as you try to construe my construing process, I am trying to construe your construing
process" (Leitner, 1985, p. 85). However, I shall also attempt to address any form of role relationship that might exist between a spousal caregiver and their demented partner.

Despite there being virtually no reciprocity between the spousal caregivers and their demented spouses, it could still be asked, to what extent can a dementia sufferer construe the construction process of his or her wife or husband? In a personal communication responding to some questions I posed, Leitner (2001) stressed the need to remember Kelly's (1955) careful phrase at the start of his Sociality Corollary, "To the extent..." (p. 95) (see Chapter 6), so as to avoid getting caught up in a "complete black and white, all or none, understanding". Hence, Leitner suggested that a person (say a husband) in the early stages of dementia may still be able to construe limited parts of his wife's construction process and therefore have a somewhat limited role relationship with her. However, as the dementia progressed, the sufferer might become totally incapable of construing his wife's construing and at that point would be incapable of having a role relationship with her at all. Leitner (2001) proposed that some other type of relationship may then develop (e.g., "baby" to "mother" or "dependant" to "stranger") but it would not be a role relationship.

I understand Leitner's logic, however, we can only surmise what a dementia sufferer can, or can not, construe, even if they can still talk. I suggest that it is almost impossible, at any stage, to truly gain access into a dementia sufferer's world in order to make assumptions about their construing. Do dementia sufferers themselves know what is real or what is an hallucination? We may never know in order to present an informed argument. I acknowledge that there are some dementia sufferers who have some insight, but I agree with Mullan (cited in McGowin, 1993) who wrote: "Most commonly in the early stages of dementia (especially Alzheimer's), insight is mercifully lost and the victim drifts without self-awareness into the depths of the illness" (p. 147).
I would imagine that most dementia sufferers would be incapable of construing, or even attempting to construe, their spouses' construction processes and, hence, could not have role relationships with them, even in the early stages of dementia. Indeed, most spousal caregivers in this study mentioned that their demented partners were not aware who the caregiver was (e.g., "he no longer sees me as his wife") but referred to them as "mummy", or "daddy", or "that man", and so on. Others said that the dementia sufferer gave the same answer to every question (e.g., "she just says 'yes' to everything, whether it's negative or positive, it's 'yes', so I know I'm not getting across there"). Others remarked that their demented spouses just smiled or chuckled as a way of responding to the food the caregiver was giving them.

The following excerpt from the verbalisation of a 64 year old home caregiving husband is a good example, from a caregiver's perspective, of the confusion that a dementia sufferer must be experiencing as their personality and intellect are eroded by this devastating illness. This caregiver's 68 year old wife was in the early stages of dementia and did not know the caregiver.

She's gone back that far that she thinks she's only 20 years old and she doesn't know who I am. If I do make those advances to her she says, I'm going to tell my father. ... She seems to have these turns and it seems as though I'm two persons. ... she wants to go home and I'll say well this is where you live, and maybe half an hour later she'll come back out and say where's that other fellow gone, you know the one that was here before? And I'll say there was nobody here before, I've been here all the time. But as far as I can see how she sees it, is that I'm two persons ... when she quietens down she comes out and I'm still here and she'll say I'm glad he's gone ... When it first started to happen I didn't know what to make of it ... but now I know it's just the illness she has. ... Before I knew what was wrong, I rang the daughter and said I think our marriage has finished ... she has changed from a very loving, happy person to one who is very irritable all the time ... it's the language, the cursing and swearing ...You could nearly say she was two persons too! She doesn't know who I am ... we've had to put locks on the mail box because any mail that comes for me, well there's no way I'd get it ... I showed her my driver's licence and she said: 'how come you've got that name on there when you're not him?' ... Every time I ask her who I am she says: 'Joe Blow'.
It could be assumed from the above comments, that the caregiver’s demented wife thought he, too, was a stranger. It also appears that, at times, she was unaware that she was married. I would imagine that this was typical of most dementia sufferers. In a grounded theory study, Wuest, Ericson and Stem (1994) explored the “reciprocal process of becoming strangers” in which family caregivers and dementia sufferers progressed along a continuum from intimacy to alienation, until the caregiver, “ultimately estranged”, relinquished care (pp. 437-438). Although the authors referred to the “reciprocal process”, and 11 interviews involved the dementia sufferer as well, the study focused on the experiences of the 15 primary caregivers (one son, three husbands, one sister, five daughters and five wives). With regard to the dementia sufferers, the authors said: “... we could only guess at the perception of the affected family member, but it was clear that at times they had no idea whom their former intimate was” (Wuest et al., 1994, p. 438).

The caregivers in this study told me over and over again that their spouses had become totally egocentric. They gave and their demented spouses took. They made statements such as: “There’s no relationship now, I’m the caregiver and he’s the caretaker. It was a reciprocal relationship, but now it’s not”; and “He always worries about how it’s going to affect his world - everything is taking and there’s no giving back”. Perhaps, as Leitner (2001) proposed, if the demented spouse was totally incapable of having a role relationship with his or her partner, then some other type of “relationship” may develop from the demented spouse’s perspective, but it certainly would not be a role relationship.

Furthermore, if a dementia sufferer has regressed to the state of being dependent, like a child (and I would argue that this happens quite early in the disease process for many dementia sufferers), then it is most unlikely that they would be able “to do the subsuming which is an essential feature of role construction” (Kelly, 1955, p. 669). As McGowin (1993) commented:
The Alzheimer's patient asks nothing more than a hand to hold, a heart to care, and a mind to think for them when they cannot; someone to protect them as they travel through the dangerous twists and turns of the labyrinth (p.viii).

Turning to the experiences of the spousal caregivers, Leitner (personal communication, 2001) suggested that, as far as, say, a caregiving wife was concerned, in the early stages she may well continue to construe the construction process of her demented husband, and may even continue to construe his construing as he slipped further into dementia. Hence, she may have a more extensive role relationship with him than he has with her. According to Leitner, this is similar to the difference in the role relationships between therapist and client or parent and child.

I partially agree with Leitner on this point. It will be noted that in this study I was focusing on the intimate marital relationship and most spousal caregivers admitted that they had completely lost their marital intimacy. Indeed, they said they no longer had a "marital relationship". As Leitner (2001) said, if a wife cannot both see her husband's construing process and allow him to see hers (and vice versa), they are not intimate. Furthermore, the majority of spousal caregivers said that they no longer knew their demented spouses, making statements such as: "she's gone, completely gone, she isn't the person I married"; or "I don't know him anymore. I suppose you would say he's a living 'thing'". In one way or another, most spousal caregivers in this study referred to their demented spouse as a different person, a stranger. They could no longer relate to them on any predictable level. And as Kelly (1955) said:

For the more complicated interplay of roles - for example, for the husband-and-wife interplay - the understanding must cover the range of domestic activities at least, and must reach at least a level of generality which will enable the participants to predict each other's behaviour in situations not covered by mere household traffic rules (p. 96).
Hence, I must ask, can a spousal caregiver ever really predict their demented partner's behaviour? I suggest not, in that they are not only dealing with a stranger, but, as the dementia progresses, a stranger who is continually changing. I realise that Kelly does not view people as static, but in motion, and we attempt to understand a person who is changing, evolving, and growing. However, change can be threatening. As Leitner (1985) said: "If I change, you have to be willing to risk the threat of change also" (p. 85). In my personal situation with my mother, I found my constant efforts to predict and understand the continual changes in this "new" person were so threatening and bewildering, that I reached the stage that I could no longer cope. I became hysterical. My meaning making stopped. I became immobilised and she had to go into a nursing home. We had no kind of role relationship whatsoever. I could not even attempt to construe her construing, even at the most basic levels. I did not want to - I was overwrought.

If I felt that way about my mother, I would assume - judging by the analyses and verbalisations - that many of the spousal caregivers were experiencing similar feelings. Some attempted to describe their demented spouses using metaphors, which is perhaps a further indication that they could not construe the dementia sufferers' construction processes. Moreover, most metaphors were of inanimate objects, which allows for no form of intimacy at all. Perhaps resorting to labelling their demented partners as "a thing" or "a stone" indicated that these caregivers' meaning making had broken down (Leitner, 1999). Or maybe their demented spouses were so "lifeless" that the spousal caregivers needed to equate them with something devoid of any sign of life! A 52 year old caregiving wife of an early onset sufferer used an unusual analogy, which I believe aptly reflects the lack of sociality, with regard to the deep role relationship of marriage, between spousal caregivers and their demented partners:
We were previously like two halves of a loaf of bread who were baked together; we were fused ... it was like those old-fashioned loaves that were joined in the middle ... since the disease process, something was slowly pulling the loaf apart. ... The strands of white bread were just pulling apart, and each time it moved, it tore, and it was really very painful. But I think the two halves are finally cleanly apart and you can see them as two separate small loaves and that’s where we are now. So there’s no connection anymore, there’s no sense of reciprocity ... He’s physically and intellectually incapable of recognising any of my qualities anymore and he doesn’t have those qualities anymore that I recognise, so the thing that attracted us originally - mutual respect and admiration, they’re gone, they’re not there, so it’s down to a really primal level now.

Considering all of the above, when focusing on the deep role relationship of marriage, I believe a very strong argument exists for the lack of sociality between the spousal caregivers and their demented partners. However, it should be acknowledged that the spousal caregivers who re-wrote their demented partner’s identity as a “baby” or “dependent child” may have been attempting to relate to their demented partner on a more primal level. However, as Leitner (2001) argued, if a spousal caregiver has re-construed their demented spouse as a “baby”, then they are not seeing their spouse’s inner world very well at all. This point was also highlighted by a caregiver in Wuest et al.’s (1994) study who stated:

It’s just losing this person who was here, my best friend and companion, into a world that only they know, that you don’t know anything about (p. 440).

Furthermore, how predictable is the “baby” going to be for the spousal caregiver? For most of us, our understanding of babies is that they develop and grow and, indeed, we can usually predict the various stages of their development. We expect babies to learn to feed themselves, become toilet trained, learn to walk, talk and so on. However, the “baby” dementia sufferer will regress, and that regression will be unpredictable. Sometimes deterioration is slow, sometimes it is rapid. Like the long bereavement, it will be unpredictable. Therefore, I would imagine that the spousal caregivers who re-construe their demented partners as a “baby” or “child” do so because it allows them to start construing again and perhaps make meaning of their
current roles. Perhaps, for some, at this primal level it also allows them to rekindle some of the love and tenderness they once felt for their demented spouse (Forsythe, 1990).

Hence, I conclude that for spousal caregivers and their demented partners the deep role relationship of marriage does not exist. They no longer have those intimate understandings necessary for a deep ROLE relationship (Leitner, 1985). In fact, they are virtually strangers to each other. As strangers do not usually get to know each other's unique construing processes, I would therefore suggest that these spousal caregivers are experiencing a “non-ROLE relationship” with their demented spouses (Leitner, Begley & Faidley, 1996, p.327).

New Type of Relationship

In summary, then, the majority of the 61 spousal caregivers in this study were experiencing profound grief reactions over the loss of their demented partners and loss of their intimate marital relationships. As is common with bereavement, the majority of spousal caregivers had idealised their perceptions of the quality of their past marital relationships (Parkes, 1972). They labelled themselves “married widows or widowers”, and half of the caregivers were either involved in, or pursuing, other intimate relationships. Some said they had “fallen in love again”. However, their new “love” was second best; their demented spouse was still “number one”.

Due to the dementia sufferers' personality and behaviour (and hence identity) changes early in the disease process, they became strangers to the spousal caregivers. Despite being confronted with, and having to care for, this stranger, the caregivers' commitment was very high - being committed to both the unique person as well as the institution of marriage. The physical death of their spouse was imminent, but they were
forced to live with the uncertainty of when this would occur, and also the unpredictability of the *stranger*.

The spousal caregivers were overwhelmed with sadness, anxiety, loneliness and despair. Many were shattered, and cried uncontrollably as waves of grief enveloped them. They attempted to articulate their experiences but most failed to arrive at any adequate understandings. However, they did realise that it was the *disease*, not the person, that was the cause of their nightmare. Many expressed love for their spouses but seemed to be hanging onto their memories of "what was". However, for some caregivers, even memories were too painful and they tried to block them out. Many were in conflict as, on the one hand, they “hated” the *stranger* who confronted them but, on the other, they were “trapped” as they knew that they could not abandon them. As one distraught husband said: "I owe her something and well she’s still there, isn’t she? She’s still mine and that’s it. It’s not like you can take a dog over the road and shoot it ... you can’t, this is to the end".

Because of their uncertainty, and repeated invalidation, many spousal caregivers reached the point of becoming frozen, immobilised - their situations were fraught with fear, anxiety and threat (Walker, 2002). They were long-term married men and women whose spouses had become *strangers*. In order to function, some were forced to shut down their meaning making altogether (Leitner, 1999), and to avoid invalidation they engaged in *nonvalidation*. (Walker et al., 2000; Walker, 2002). Furthermore, with no reciprocity or true intimacy, as well as the fact that they “no longer knew” their demented spouses, and therefore could no longer construe their construing, *no* role relationships were possible. Hence, there was *no sociality*.

They were forced to relinquish the Kellian notion of the deep role relationship of marriage, and many resorted to using metaphors of inanimate objects to describe their “lifeless” spouses. In response to my description of the plight of the spousal caregivers
in my study, Leitner (personal communication, 2001) remarked: “Think of the horrors associated with experiencing a person you might have had the deepest of connections with as a ‘thing’”. Others took on their new roles, developed “new identities” for themselves and their spouses and began to find new understandings of their current situations (Perry, 2002). Once again, they were able to test their construing, but in a more basic way. However, they would still not be seeing their demented spouse's inner world, as is highlighted hereunder.

Some caregivers were suspicious of the stranger, commenting that they had been “lied to” or “manipulated”. A 49 year old wife said: “He really rapes me mentally because he’s so smart in some ways ... even though his dementia may grow worse, his ability to manipulate and play mind games is there most definitely”.

This young caregiver was angry that she had been “robbed of her husband and their hopes and dreams for the future”. She felt rejected, abandoned, and “sexually and emotionally frustrated and starving for affection”. She said: “I don’t think anyone could really understand what it’s like not to have had sex since you were 40”. She classed herself as a “widow”, and was obsessed with finding another intimate relationship, and having some romance and love in her life. She commented:

I would be totally a 100 percent modern woman and just do it on the quiet, if I could find the right person. But I’m not interested in just going to the club and just picking up garbage because I have a lot of tickets on myself and I think I’m a prestigious woman. And if the opportunity presented itself I most definitely would go for it, but I definitely would keep it very quiet and discreet. I’d be the ideal other woman type I think. But how do you find that?

In order to alleviate her feelings of guilt, and perhaps to enable her to test her construing, I suggest that this woman re-wrote her demented husband’s “identity” as a “manipulator” and hers as a “victim”. She could easily make predictions about a manipulator, and her husband’s behaviour was validating those predictions. This helped her cope with an intolerable situation. However, she had misconstrued her
husband - she was still not seeing his inner world! It is impossible for a dementia sufferer to intentionally "play mind games". Due to their confusion, memory loss, lack of comprehension, disorientation, paranoia and so on, they would be incapable of such calculating behaviour. It is more likely that her husband was being demanding and self-centred like a child might be (Mace & Rabins, 1991). Nevertheless, this spousal caregiver did not see him as a child and, hence, did not use the "child-mother" metaphor.

Taking all the above into account, what type of relationship are these spousal caregivers experiencing? They said it was no longer a "marital relationship". However, it was not simply an empty love relationship or an "unsatisfactory" or "unhappy" relationship. Furthermore, it was more than a "caregiving relationship". I do not believe any one label can sufficiently explain this complex new type of relationship. As stated by Walker (personal communication, 2002), this type of relationship would be outside of the range of convenience that we have of relationships. After all, what do you call:

a relationship that involves loving and being highly committed to a stranger, with whom you can not effectively test your construing, and vice versa, or have a role relationship, but whose physical appearance reminds you of your idealised "dead" loved one, who abandoned you, but over whom you are experiencing overwhelming grief, while [if a spouse] perhaps also having another intimate relationship?

Could this non-ROLE relationship (Leitner et al., 1996) which involves two strangers, one of whom is deeply committed to the other, be called a "committed stranger-to-stranger" non-ROLE relationship? Although this does not completely capture the asymmetry of this complex relationship, I cannot think of a more appropriate label at this stage. Hence, I invite the reader to offer suggestions! However, I suspect that no label could aptly describe this type of relationship.
In this chapter I presented an evaluation of the findings of the amended study, commencing with a brief discussion regarding overall gender differences. An evaluation of the findings for the comparison and caregiver groups were then presented separately, and concluded with a discussion about the new type of relationship that has emerged from this research. In the next chapter the implications and limitations of this research will be presented, including a critique of the standardised instruments I attempted to use. I shall then discuss the sample, implications of my findings and make recommendations for future research.
CHAPTER THIRTEEN

IMPLICATIONS AND LIMITATIONS
OF THE STUDY
In this chapter I shall present the implications and limitations of this study. In particular, the methodological implications of trying to use standardised measures, determined a priori, that did not and could not elicit the information needed to test the hypotheses originally formulated. I shall also discuss the usefulness of content analysis scales, the sample of research participants, implications of the findings and make recommendations for future research.

**Methodological Implications**

**Critique of Standardised Measures**

As mentioned previously, in this study I attempted to use two subscales of the Dyadic Adjustment Scale (DAS) (Spanier, 1976; Spanier & Thompson, 1982). They were the Dyadic Satisfaction subscale and Affectional Expression subscale, the latter needing to be revised (Wright, 1991; 1993 - see Chapter 7). My reasons for using this scale have also been previously discussed.

In presenting the limitations of her study, Wright admitted that the usefulness of the DAS may be questioned, as “it had to be supplemented with many open-ended questions in order to ferret out the essence of the relationships” (Wright, 1991, p. 236). However, she did not report any problems with data collection, but stated that the DAS allowed for group comparisons. Unlike Wright, I could not successfully use the DAS with the spousal caregivers in my study. As discussed in Chapter 8, when I administered the two subscales of the DAS, many spousal caregivers became upset and refused to answer the items that asked about their current marital relationships. They said that the items were “not applicable” to them, or “did not capture” their situations, because they no longer had a “marital relationship” with their spouse. Hence, unlike Wright, I had missing data. I did not have any problems administering the subscales to the husbands and wives in the comparison group and was able to collect data for this group.
It could be argued that the dementia sufferers in Wright’s (1991; 1993) study were not as severely impaired as those in my study. However, other than one or two caregivers whose spouses were in the very early stages, I found severity of dementia did not make any substantial difference as to how the caregivers viewed their marriages. Indeed, one 51 year old caregiver, whose wife was in the very early stages when I interviewed him, was adamant that they had “not allowed the dementia to impede our relationship at all and we’ve just continued with it as it was before”. However, about six months after the interview this man rang me for help as his wife had “changed” and they could no longer relate to one another. Had I interviewed him later on in my study then his responses may have been different, even though his wife was still in the early stages of dementia. Furthermore, some caregivers reported that they had noticed obvious negative changes to their spouse’s personality, which had an impact on their intimate marital relationship, even before a definite diagnosis of dementia was made. This is in keeping with my own experience with my mother as well as what is reported in the literature (see Chapter 3).

Also, as mentioned previously, a few of the caregivers commented that some of the statements in Sternberg’s Triangular Love Scale (1988b) were “not applicable” to them, although they did not object to completing this measure, as the 9 point scale seemed to give them scope. The results of this instrument have been valuable to my amended study, and formed the basis on which I examined the components of marital love.

I had no trouble administering the Derogatis Affects Balance Scale (DABS) (1975), which assessed overall psychological well-being and satisfaction with life in general. In fact, this mood scale proved to be a useful instrument, as it was in my prior study (Rudd, 1993; Rudd, Viney & Preston, 1999). However, such transparent self-rating scales are susceptible to socially desirable responding (Viney, 1983).
It was because of the spousal caregivers' refusal to complete the DAS, insisting that they did not have a "marital relationship", that almost led me to discard my doctoral study. Furthermore, had I not used a constructivist approach (i.e., including many open-ended questions to allow the participants to freely tell their own stories), I would have had no choice but to discard the study (Rudd & Walker, 2002). Fortunately, I had no problems with the open-ended questions, even though I asked the research participants about their intimate marital relationships. This was because the spousal caregivers were able to articulate that they did not have a "marital relationship", and had the freedom to go on and describe their unique experiences in their own words, as well as to express their emotions. Swensen and Trahaug's (1985) two open-ended "commitment to the spouse" questions also proved useful in assessing any changes in commitment from the start of the participants' marriages to the present.

The spousal caregivers could not explain the nature of their present "relationships" but knew that they did not have a "marital relationship" in the sense that the scales measured. This experience has made me realise the danger of depending on the "most psychometrically sound" measure of marital satisfaction (Follette & Jacobson, 1985), or any other valid and reliable standardised measures for that matter. In this study, the DAS, which I chose a priori, did not and could not elicit the information I needed from the spousal caregivers to make meaningful comparisons with the comparison group. Despite being used, apparently successfully, by Wright (1991; 1993), the DAS was simply not suitable to use with the spousal caregivers in this study.

I was trying too hard to rigidly follow other marriage researchers, particularly Wright, but the spousal caregivers were refusing to allow that to happen. Without the qualitative data, I would have never been able to make sense of what was going on for this cohort. However, by adopting a constructive methodology, I could tell the
caregivers’ stories using their own words. This qualitative data gave further meaning to the quantitative analyses which I was able to carry out.

The Usefulness of the Content Analysis Scales

The application of content analysis scales to the research participants’ verbalisations provided a great deal of understanding of the positive and negative feelings, reciprocity and interpersonal spousal relationships experienced by the husbands and wives in the comparison and caregiver groups. The use of the scales enabled a quantitative analysis of several psychological states and proved to be a strong research tool. Again, if I had adopted the practice, as many researchers do, of only using questionnaires and rating scales relating specifically to the subject of interest, then I would have missed a lot of the rich material which came through the participants’ free verbalisations. Unlike questionnaires and rating scales, the content analysis scale technique has no predetermined specificity (Viney, 1983).

Walker (personal communication, 2001) argued that there was a need for extending the usual way of scoring the content analysis scales. She suggested that it would be useful to record the number of transcripts that included scorable content for each scale (not the number of times it was included in each transcript), in order to discern whether significant findings were of real importance to the study. For example, a significant difference between groups might be found on a particular scale, but this finding might be due to one or two transcripts containing a large amount of scorable material, while the majority contained none. Therefore, for each content analysis scale and subscale used in this study, I have provided a table (see Results, Chapter 9) containing the number of transcripts that contained scorable content on that particular scale. This extension of the usual way of scoring content analysis scales proved invaluable, especially when I found a significant difference on Death Anxiety, with the comparison group scoring significantly higher than the caregiver group. An
examination of the frequencies indicated that only a small number of research participants mentioned Death Anxiety in their verbalisations, the majority making no mention of it at all. Hence, this surprising finding was not of vital importance to the study. I would strongly recommend this information be included by other researchers who utilise the content analysis scales.

Sample

I carried out in-depth interviews with 124 research participants for this study; 61 spousal caregivers and 63 comparisons. I feel that this number was adequate to carry out powerful statistical analyses. Of course, increasing the number of subjects would have further increased the power of the tests, but given the time-consuming nature of this, having already taken two years, this was not practicable. The design also had almost equal numbers of subjects in each cohort, which increased the accuracy of the results.

With regard to the external validity of the study, I believe the characteristics of both the caregiver and comparison groups (see Chapter 9), with respect to age, duration of marriage, education and income, are representative of English-speaking middle-aged and elderly spousal caregivers of dementia sufferers, and middle-aged and elderly married men and women in general, living in Australia at the present time. Hence, I am reasonably confident that the results could be generalised to those populations. However, I am not confident that they could be generalised to the non-English-speaking middle-aged and elderly spousal caregivers and middle-aged and elderly married men and women, mainly because of cultural and religious differences. I was not able to interview research participants from these latter groups because interpreters would have been required, and this would have introduced an extraneous variable. In fact, with regard to internal validity, I made every effort to control for the effects of any factors that may have confounded the results. That is why I conducted all the interviews
myself, as well as typing up all the verbalisations, and scoring all the instruments (using co-raters where necessary for inter-rater reliability).

Nevertheless, my selection of research participants may be open to some criticism in that I only interviewed those spouses for the caregiver and comparison groups, who agreed to participate in the study, after they were approached in the various ways described in Chapter 7. All research participants were fully informed about the focus of the research (although they were not aware of the specific questions I would ask). This may have introduced some bias in the findings. However, despite the problems of bias associated with collecting data only from volunteers, it is equally important to take into consideration that the research participants I interviewed were willing to talk about their lives. Furthermore, because the caregivers were willing participants, and showed an interest in the study, perhaps they felt it was an opportunity to make researchers and health professionals aware of their real experiences, instead of simply complying with a researcher’s request for them to respond to all the statements in the standardised instruments!

As the topic of this research is extremely sensitive, some research participants were difficult to obtain. As I discussed previously, it was particularly difficult to recruit long-term married men for the comparison group. Also, as discussed previously (see Chapters 7 and 9), due to the availability of research participants, the comparison group included 18 married couples, which meant that the data for this group were not independent. However, as shown in Chapter 9, appropriate tests were carried out and it was found that the inclusion of these couples did not affect the analyses.

Statistical Problems

As the original hypotheses became redundant, and the amended study focused largely on the qualitative data collected, the statistical analyses did not need to be as
sophisticated as they might have been had this been a purely quantitative study. Hence, as well as many multivariate and univariate analyses, I have included some simple t-tests of differences. However, because of the number of tests carried out, a correction factor should be applied. The alpha level set for this study was .05 (see Chapter 7) but the majority of the differences were highly significant at the .001 level (in fact, they were .000 and I brought them back to .001). Therefore, I would argue that this was not an issue for this study.

Implications of the Present Findings

Comparison Group

I believe the findings for the comparison group in this study advance our understanding of the intimate marital relationships of middle-aged and elderly long-term married men and women in general. These qualitative and quantitative findings will also be a valuable addition to the research literature on the marital satisfaction of older spouses. Although this was only a cross-sectional study, in line with other studies (Roberts, 1979; Gilford, 1984; Weishaus & Field, 1988), the majority of these older husbands and wives reported an increase in marital happiness and satisfaction during the later years of life, especially after children left home. This was even the case for an elderly husband who had previously been involved in a 12 year extra-marital relationship! (see discussion in Chapter 12).

In fact, from the comparisons' verbalisations it could be suggested that the pattern of their marriages was curvilinear or “U”-shaped (Coleman, 1988; Weishaus & Field, 1988; Brubaker, 1990). That is, they started at a high level of happiness and satisfaction, dipped in the middle years, especially after the arrival of children, and increased in later years, after children left home.
Also of value to the research literature, are the following findings for the comparison group:

(1) These middle-aged and elderly spouses were experiencing a companionate kind of love as suggested by Sternberg (1986; 1988b). Furthermore, the results confirmed the validity of Sternberg’s Triangular Love Scale (1988b) in that they were able to appropriately discriminate between groups.

(2) The finding that the spouses in the comparison group were highly satisfied with their lives in general, is in keeping with other authors (e.g., Argyle, 1987) who found that spouses who are happily married have a higher level of life satisfaction.

**Caregiver Group**

The findings for the caregiver group in this study suggest that many spousal caregivers of dementia sufferers no longer believe that they have a “marital relationship”. This fact may only have been acknowledged (or indeed realised) by the caregivers in this study because they were specifically questioned about their present intimate marital relationships. Despite this denial of a “marital relationship”, the findings suggest that these spouses are mourning the loss of their demented partners as surely as if they had died. They are experiencing pre-death grief over the loss of their demented partner’s personality (identity) and, in turn, the loss of their marital intimacy and “marital relationship”. However, they are not receiving from society the comfort and support given to those who are bereaved by physical death of a loved one (Lezak, 1978; Doka, 1989). As Doka and Aber (1989) stated:

The bodies of victims are invaded by what seem to be mind snatchers, and as a result family and significant others suffer a profound sense of loss. But since the person is still physically alive, grief may not be recognized or considered appropriate (p. 188).
Furthermore, as marital intimacy is a taboo subject for older people, they do not readily talk about their emotional and sexual problems and losses, but stoically battle on with their caregiving, endeavouring to relate to their demented spouse who is now a stranger to them. In addition, as health professionals often feel uncomfortable and incompetent in raising these issues with spousal caregivers, they suffer their burden alone. I think Hanks (1992) captured the caregivers' feelings when she stated: "The identity and character of the patient are forever altered and obliterated ... the physical presence of the spouse endures, but the caregiver feels emotionally and sexually abandoned on the one hand, and trapped on the other (p. 141). Therefore, lonely and longing to be touched, hugged and comforted, many spousal caregivers actively pursue intimate (often sexual) relationships elsewhere (Wright, 1991; Hanks, 1992; Rudd, 1993). With the fear, anxiety and threat they are experiencing, it is no wonder that they are suffering very poor psychological well-being, with scores substantially lower than the very low scores of long-term breast cancer survivors (Derogatis et al., 1979).

Therefore, I hope that this research will increase the awareness and understanding of researchers, educators and health care professionals regarding the emotional, sexual, and "relationship" problems and losses faced by spousal caregivers of dementia sufferers, as well as their grief reactions to these losses. Counsellors and other health professionals need to become competent and comfortable in relation to the intimacy-related concerns of spousal caregivers. They will then be able to provide the necessary counselling and related support services to help these caregivers understand their grief responses and help them adjust to their losses, especially the loss of their "marital relationship". Furthermore, health professionals need to allow, encourage, and validate the spousal caregivers' emotional expressions. According to Doka and Aber (1989):

[Spousal caregivers] can feel constrained in recognizing and expressing their emotions. Since the victim is alive, living in the same environment, and defined as not responsible for his or her state, [caregivers] may lack the opportunity for emotional expression, feel personally inhibited from expressing negative emotions, or even face
social sanction from friends and relatives who consider such expression disloyal or unfeeling (p. 194).

As well as providing help for the spousal caregivers, I believe this research is important for the psychological research literature in general. Although it has previously been recognised that personality changes have an adverse impact on relationships, the "new" type of relationship that is being experienced has, as far as I am aware, never before been addressed. Furthermore, the notion of a "committed stranger-to-stranger" non-ROLE relationship (or whatever label it is given) is difficult to understand. As human beings we try to make sense of our world by interpreting what has happened in the past as well as the present, and anticipating what is going to happen in the future. When something is outside our range of convenience we become anxious (Kelly, 1955) and may feel threatened.

When we are confronted with something new, we often try to understand it from our own past experience. When my son "changed" and left us, I became immobilised from shock, depression, and grief - I completely broke down. Many people could not understand and they thought I was over-reacting. Some labelled me a controlling mother who could not let go of her son. However, over time, as other family members, his friends, colleagues etc. had first-hand experience of his "out of character" behaviour, and he estranged himself from them as well, they construed the situation differently. Nevertheless, although their relationships with him have also changed, it may not have the same impact on them as it does on a mother losing her child, or in the case of the dementia caregivers - a spouse losing his or her life partner.

People with dementia may have all sorts of difficulties but, in the early stages, they are very skilful at concealing them. As Mace and Rabins (1991) said: "Some vehemently deny that anything is wrong or blame their problems on others" (p. 8). I have heard many spousal caregivers complain that their adult children, who no longer live at home, refuse to believe that there is anything wrong with their mother or father.
These spousal caregivers are therefore denied the help, support and understanding they so desperately need, and are forced to carry the emotional and physical burden of care on their own. That is, they bear this burden until the dementia has progressed to such a stage that the sufferer can no longer conceal his or her difficulties.

All the above highlights the need for further education and awareness about the effects of dementing illnesses, and the impact on spousal caregivers, particularly in relation to the loss of their "marital relationships". This education and awareness should not only be directed at researchers, educators and health professionals, but also the general public. As I said in Chapter 3, at present, in Australia, dementia ranks as the fourth leading cause of death for those aged 65 years and over, and as the population ages, and the incidence of Alzheimer's disease and other dementing illnesses increases, it is going to be one of the top public health issues of the 21st century (Alzheimer's Australia NSW, 2002).

**Extension of Personal Construct Theory**

Another implication of this study, is that it has highlighted the concept of nonvalidation (Walker et al., 2000; Walker, 2002). I believe that many spousal caregivers shut down their meaning making altogether (Leitner, 1999), and nonvalidation was forced upon them (Walker, 2002). Those who could rewrite identities for their demented spouses and themselves appeared to begin testing their construing again. Although they were still not seeing their demented spouse's inner world (Leitner, 2001), re-construing their spouse as a "baby" or "child" may have helped them to cope with their world shattering situation.

With regard to Kelly's (1955) concept of sociality, I would argue that neither the dementia sufferers nor the spousal caregivers could construe the other's construction processes as, I believe, they were strangers to each other. Therefore, there
was no sociality in the Kellian sense, as far as the deep role relationship of marriage was concerned. There were no intimate understandings that are necessary for ROLE relationships, and therefore I would argue that they were in a non-ROLE relationship (Leitner et al., 1996). Some spousal caregivers who had re-written identities for themselves and their demented partners, may have attempted to relate to their spouses on a more primal level. However, no matter whether the dementia sufferer is construed as a stranger or as a baby, I believe it would still be threatening and anxiety provoking for the spousal caregiver, as dementia is progressive and the changes to the sufferer are very unpredictable.

Hence, perhaps Kelly’s concept of sociality needs elaborating to incorporate situations where there has been identity change in one person in a formerly intimate dyad (spousal relationship, parent-child relationship), resulting in the new type of relationship revealed in this study.

Suggestions for Future Research

This seems to be the second empirical study which has examined the marriages of spousal caregivers of dementia sufferers with the inclusion of a comparison group; and it is the first such study to focus specifically on their intimate marital relationships. As I had problems collecting data with some standardised instruments, I was not able to test the model and hypotheses. Therefore, the original study could not be replicated. However, I believe that the problems I encountered with this study, and my interesting findings, have given a great deal of scope for future research.

First and foremost, Kelly’s concept of sociality needs to be elaborated as I have indicated in the last section. Furthermore, a study should be carried out focusing specifically on the re-writing of identities. Does this process allow spousal caregivers to once again test their construing, following the nonvalidation that is forced upon
them? Does the fact that they can make predictions, even at the most basic level, allow them to come to some kind of acceptance of their losses and therefore get on with their lives?

Furthermore, I think it would be a shame to limit this new type of relationship to dementia research only. Hence, I would suggest that both qualitative and quantitative studies are carried out to perhaps examine the nature of the relationships of parents with adult children in cults; or spouses who are caregivers of partners with frontal lobe damage due to head injuries; or parents with young adult children who have become schizophrenic or have changed due to substance abuse. Although all these situations are perceived as reversible, and there is hope of eventual recovery, reconciliation and resolution, Doka and Aber (1989) believe that “there may also be increased impatience with the slow pace of recovery and intensified feelings of anger toward a victim who is perceived still to have some sense of control” (p. 191).

Perhaps this could also be extended to parents whose young children have been diagnosed with autism. Although autism is apparent in some children from birth, clinicians have observed that symptoms are not recognised in other children until they are “several years old” (Bootzin & Acocella, 1988, p. 449). By this time it is probable that a strong parent-child bond has developed, with the parents recognising the unique qualities that make up their child’s personality. I would imagine that once the symptoms of autism became apparent, these unique characteristics would have changed, and the child may have become a stranger to his or her parents. Furthermore, it is well known that autistic children cannot see the world from another person’s point of view (Bootzin & Acocella, 1988) and, hence, the type of relationship experienced by the parents and their autistic child could also become “committed stranger-to-stranger”.

In this chapter, the implications and limitations of this study were discussed, including a critique of the standardised measures that were used. The usefulness of the
content analysis scales, the sample of research participants, implications of the findings, and suggestions for future research were also discussed. In the next chapter I conclude my journey with spousal caregivers of dementia sufferers.
CHAPTER FOURTEEN

THE END OF MY JOURNEY WITH SPOUSAL CAREGIVERS OF DEMENTIA SUFFERERS
JOURNEY ENDS . . .

After eight years I have now completed this research. As I mentioned at the Tenth Australasian Conference on Personal Construct Psychology in Sydney last year (Rudd & Walker, 2002), a person asked me how long I had been working on my Ph.D. When I told her since 1995, she commented: “Oh you’ve taken the scenic route”. I liked this person’s analogy, but I assured her that it has not been scenic at all - it has been an arduous trek! It has been a research project that has been fraught with difficulties, and on many occasions I have felt like abandoning it. Indeed, at one stage, I thought I had no option but to discard it. However, I did persist, thanks to my supervisor, my determination, and my duty to my research participants, particularly the spousal caregivers. I believe I had a duty to tell their story, especially after the painful hours they willingly spent sharing their devastating losses with me.

Furthermore, this is a doctoral study that did not turn out as anticipated (Rudd & Walker, 2002). My journey was interrupted when the spousal caregivers vehemently denied that they were presently having a “marital relationship”, and refused to respond to statements and questions in the standardised instruments which asked about their current marital relationships. Hence, the conceptual model and hypotheses became redundant. To continue, I had to amend my aims and then attempt to unravel the nature of the intimate marital relationships of the spousal caregivers.

Nevertheless, I trust I have done Denicolo (2002) proud by documenting my disaster to success story, and describing the “warts and all” of this research. By
sharing the distresses I have encountered during the course of this study, I hope other researchers can be alerted to any methodological problems they, too, may experience, especially in relation to standardised instruments. Had I not used a constructivist methodology, I would have had no choice but to discard this study.

The constructivist methodology has allowed the husbands and wives in both the comparison and caregiver groups to tell their own story, and not simply what a researcher may want to hear. Indeed, I was quite bewildered when confronted by the spousal caregivers' refusal to complete the two subscales of the DAS. However, it has shown that we cannot simply rely on standardised instruments, no matter how good their reliability and validity. It was the rich material that I obtained from my open-ended questions that allowed me to proceed with this study, and I would recommend the content analysis technique (duly extended as suggested by Walker, 2001) as a rigorous but flexible research tool.

I have still not been able to reconcile Wright's (1991; 1993) experiences with my own. I commend this researcher on her valuable contribution to the area of Alzheimer's disease and marriage; however, some of my findings differ considerably from hers. I am at a loss to understand why she argued that researchers were "arrogant" for ignoring the perceptions of dementia sufferers, when she could not use their data when comparing groups. Indeed, she acknowledged that "distorted perceptions" were exposed in her study when the dementia sufferers' responses were compared to those of their caregivers, yet she went on to suggest that it may be the caregivers who were distorting the facts!
Taking into account the verbalisations of the spousal caregivers in this study (many excerpts of which are set out in this thesis), the research literature, and my own first-hand experiences, I would argue that it would be almost impossible to gain true access into a dementia sufferer's phenomenological world. As Forsythe (1990) said: "I know, as a doctor, that someone with Alzheimer's disease could not write his [or her] own story" (p. 1). According to Forsythe, words are confused or forgotten early in the disease process. It is quite common for dementia sufferers to be unable to comprehend both verbal and written words. Even though some dementia sufferers can read, they may not understand the written information (Mace & Rabins, 1991). A confused person may be able to speak in what seems to be an articulate manner, however, the information they give is likely to be distorted, as Wright obviously discovered! I think the following passage aptly sums up the situation of a person diagnosed with dementia:

His doctor told him, “I wish I could tell you that it’s cancer...” By the time that sentence was finished, Bob Davis was introduced to a new world of loneliness, rejection, terror, confusion, misinformation, and termination. It was like walking through the looking glass - suddenly seeing just about everything and everybody from a different viewpoint. (Haden cited in Davis, 1989, p. 9 - italics for emphasis).

Just as dementia sufferers are not able to understand their spouses’ inner worlds, the spousal caregivers in my study indicated that they were not able to construe their demented partners’ construing and, in fact, commonly re-construed them as a “baby”, “thing”, “stone” etc. The caregivers and their demented spouses were strangers to each other. They no longer had a “marital relationship” but a stranger to stranger relationship. However, one of the strangers (the spousal
caregiver) was deeply committed to the relationship. Hence, I have labelled this new type of relationship, a “committed stranger-to-stranger” relationship. The deep role relationship of marriage was gone - it was now a non-ROLE relationship (Leitner et al., 1996).

Some spousal caregivers re-wrote identities for themselves and their demented partners (e.g., parent-baby) and these caregivers seemed to be able to begin testing their construing again. Although they were still not seeing their demented spouse’s inner world, re-construing their spouse as a “baby” released them from nonvalidation (Walker et al., 2000; Walker, 2002). However, their construing was tested at a more primal level. Furthermore, in searching for reciprocal role relationships to compensate for the loss of their intimate marital relationships, many spousal caregivers pursued extra-marital relationships, and did not feel guilty for doing so.

It is vital that spousal caregivers of dementia sufferers are helped to understand why their “marital relationships” have disintegrated. It is vital that health care professionals, especially general practitioners and counsellors, understand the nature of spousal caregivers’ new type of relationships with their demented partners. As Forsythe (1990), who was both a medical doctor and a spousal caregiver of a dementia sufferer, said:

By the first anniversary of his death all the ‘if onlys’ were flooding back in and I began to understand more about the difficulties of recovering from the long bereavement that is Alzheimer’s disease ... I am now more able to understand the damage that was done to John, to me, to our family and friends through ignorance about dementia and the very real problems of diagnosing it. This ignorance includes my own but also that of John’s general practitioner. ... Ignorance
perpetuated my own confusion, feelings of inadequacy, guilt and disbelief that I was capable of doing anything positive. John’s disintegration was a very frightening threat to my own integrity: in accepting that this was so, has come the opportunity to understand very much more about myself and in so doing to be able to change and improve my relationships with those around me. Watching the disintegration of somebody close to you and experiencing it within yourself is painful, but in the end all the anguish need not be a waste (pp. 19-20).

I realise that Forsythe’s words were written over a decade ago, but even today most people do not really try to understand dementia unless they are confronted by it. And even then, as I have noticed from my counselling experience, there is still a great deal of ignorance.

As I said previously, not everyone will be confronted by the loss of their relationship with a loved one because of a dementing illness. And only a minority of people will lose their relationship with a loved one because of any of the other factors that appear to change a person’s identity (e.g., mind control indoctrination; frontal lobe damage caused by head injury; schizophrenia; substance abuse, and perhaps autism). However, I have experienced this type of loss twice: once with my mother from Alzheimer’s disease, and now with my son, whose identity changes are very similar to those that take place in a person recruited into a destructive cult or “cultic” relationship. My son is now a stranger to me. However, I believe I must also be a stranger to him. People in cults and “cultic” relationships have a distorted sense of reality (Hassan, 2000).

If I had to describe my present “relationship” with my son, I would have to say that I am the “committed stranger” and he is the “stranger”. Nevertheless, this thesis
is about dementia, not about mind control indoctrination. However, as Forsythe (1990) suggested, our experiences need not be wasted. I admit that it seems quite bizarre that I started this research focusing on the impact of dementia on the intimate marital relationship, and yet used my experience with the loss of my son to unravel the true nature of their relationships.

Finally, although I commenced this research in 1995, as at today, dementia is still topical in Australia and around the world. This past week, a leading Australian newspaper, The Australian, had a headline: “Dementia: curse of the new aged”. This article predicted that as “Australia’s population lurches towards an epidemic ... neurodegenerative disorders [will] become the major cause of death and disability” of Australians (Legge, 2003, p. 5). On the same day, in another article in the same newspaper, dementing illnesses were described as “fast becoming the grim reaper of ageing populations around the world” (Legge, 2003, p. 5). However, the story of an early onset dementia sufferer, and the tragic words of his caregiving wife, made me aware of the ongoing relevance of my Ph.D research. The spousal caregiver said:

One day you've got a husband, a salary and a company car, and the next you're living with a personality you do not recognise and getting by on a disability pension (Legge, 2003, p. 5).
REFERENCES


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APPENDICES
APPENDIX A

TWO CONCEPTUAL MODELS
Model (A.1).

A Personal Construct Model of Intimate Marital Relationships

General propositions about intimate marital relationships [following, in part, Neimeyer and Hudson's (1985) model about marital relationships in general]

Satisfaction with the Intimate Marital Relationship

Spouses who have more satisfying intimate marital relationships experience validation of their core role construing; while dissatisfied spouses experience invalidation of their core role construing. Validation may be evidenced by them experiencing positive emotions such as love, happiness and satisfaction; while invalidation may be evidenced by them experiencing negative emotions such as sadness, anger and guilt (McCoy, 1980).

Spouses who have more satisfying intimate marital relationships experience extension of their construct systems, or personal elaboration. This may be obtained by interpersonal understanding, especially in connection with more important (or superordinate) constructs (Neimeyer & Hudson, 1985). Dissatisfied spouses, on the other hand, experience ineffective understandings. Two reactions to misunderstandings are threat and anxiety (Neimeyer & Hudson, 1985).

Spouses who have the most satisfying intimate marital relationships contribute to the process of personal elaboration in a continuous and reciprocal way. That is, they show mutual understanding (Neimeyer & Hudson, 1985).

Gender Differences in the Meaning of Marital Intimacy

Spouses develop their constructs by interpreting their individual past experiences. For husbands and wives looking back for intimacy-related constructs, this often means that their most relevant set of constructs may have developed through their own socialisation and experience. Hence, husbands and wives may differ in their meanings of marital intimacy. For example, women often place greater
importance on emotional intimacy and verbal self-disclosure; whereas, men often place more importance on sexual intimacy (Duck, 1988).

**Coping**

Spouses may feel competent and in control when they are coping with changes that occur to their intimate marital relationships (Westbrook & Viney, 1980). However, husbands and wives may differ in the ways they cope with these changes.

Spouses may feel helpless and lacking control when they are not coping well with changes to their intimate marital relationships (Westbrook & Viney, 1980). These spouses may need to go outside their marriages for support; for example, they may seek advice from family, friends, or health professionals. Others may seek comfort from another partner, prayer or giving their love to grandchildren or pets. Husbands and wives may differ in what means of support and comfort they seek (Rudd, 1993).

**Specific propositions about long-term married spouses**

The following propositions derive largely from the literature reviewed in Chapters 4 and 5.

*People's construct systems are not static; they are continually being altered and amended.* As people are in a constant state of change (Kelly, 1955) so, too, is the intimate marital relationship. Older spouses who have more satisfying intimate marital relationships adapt and change; they adjust to one another's changing needs. For example, increasing age and physical limitations (e.g., prostate problems) may decrease a husband's sexual performance; however, in long-term successful marital relationships both spouses adapt to this change and look to other expressions of intimacy (Wright, 1993).
Life Satisfaction

Older spouses who have more satisfying intimate marital relationships should also enjoy higher life satisfaction (Roberts, 1979). That is, they should have significantly higher positive affect (e.g., joy, contentment) and significantly lower negative affect (e.g., depression, hostility).

Components of Marital Love

The "kind of love" experienced by long-term married couples might be described as "companionate". That is, their scores are higher on intimacy and commitment and lower on passion (Sternberg, 1986; 1988b). Furthermore, spouses can increase their commitment to their partners over the course of their marriages, especially if there is a reciprocity in their commitment to each other. Those spouses who remain married because they value their partners as unique persons, rather than being committed to the institution of marriage, are more in love with their partners and have fewer marriage problems (Swensen & Trahaug, 1985).
Model (A.2).

**A Personal Construct Model of the Impact of Dementia on the Intimate Marital Relationship**

General propositions [following Kelly, 1955; Viney, 1990; Rudd, 1993]

*Spousal caregivers who are experiencing changes to their intimate marital relationships because of their partners' dementing illnesses try to make sense of the changes that are happening to them.* For this purpose they try to interpret their current experiences in terms of their past experiences. These interpretations (or constructs) enable spousal caregivers to attempt to effectively anticipate their future experiences.

*Anticipation through the use of a construct system of already proven effectiveness may not be possible for these spousal caregivers.* Such anticipation may not be possible if these types of changes in marital intimacy are new to these caregivers, necessitating the development of new constructs.

*The constructs held by spousal caregivers about the changes in marital intimacy that they are experiencing may appear inappropriate to others, yet these constructs determine how these caregivers act.* They influence the way they relate to their demented partners, particularly emotionally and sexually.

**Propositions about the construing of spousal caregivers who are experiencing changes in marital intimacy**

Based on concepts from Kelly (1955).

*Spousal caregivers develop their constructs by interpreting their own past experiences.* For spouses looking back for constructs relating to disruptions and losses in marital intimacy, this often means looking back to other crises in their marriages when intimacy was affected; for example, other times when one partner was ill
or when children were young. Caregiving husbands and wives may differ in their meanings of marital intimacy.

**Spousal caregivers who are experiencing changes to their intimate marital relationships because of their partners’ dementing illnesses differ in:**

(a) *how they construe their current experiences.* It cannot be assumed that any two people are using the same constructs, even if they are dealing with the same changes in intimacy. The content and structure of their individual construct systems must be assessed;

(b) *the permeability of their construct systems.* The extent to which they can use them to make sense of changes in intimacy (such as being rejected by their demented partners) varies.

**Spousal caregivers who are experiencing these changes to marital intimacy can change their constructs by reinterpreting their experiences.** They can do this themselves, but may find it very difficult while their demented partners are still alive. Support groups and health professionals may help.

**Propositions about the emotional reactions and experiences of spousal caregivers following changes to their marital intimacy**

**Satisfaction with the Intimate Marital Relationship**

*When spousal caregivers’ construct systems do not enable them to effectively interpret and anticipate the events with which they have to deal, they will experience negative emotions following this invalidation of their core role construing.* Examples of some negative emotions follow.

**Spousal caregivers experience sadness when they become aware of the invalidation of implications of a portion or all of their core structures (McCoy, 1977).** Sadness is a feeling of loss and can vary in intensity from pensiveness to extreme grief depending on the range of implications of their core role structures which have
been invalidated. For example, a caregiving wife may experience extreme sadness when she realises her husband of fifty years no longer recognises her, nor remembers her name.

**Spousal caregivers become angry when they are trying to secure validation for a construct that has failed them in their attempts at anticipation** (Viney, 1990). Anger may be expressed by the spousal caregivers in terms of frustration, irritation or annoyance. Anger can stem from caregiving spouses feeling that they are continually giving and making sacrifices, while their demented spouses take but do not reciprocate in any way.

**Spousal caregivers experience guilt when they are aware of their dislodgement from their core role structures** (Kelly, 1955). This happens when they do or think something that they normally would not see themselves as doing or thinking, such as having another intimate relationship while their demented partner is still alive.

**Spousal caregivers of dementia sufferers may also experience some positive emotions, such as love, happiness, and satisfaction following validation of their construing** (McCoy, 1980).

**Spousal caregivers of dementia sufferers will experience misunderstanding.** Thus, they may:

(a) *feel threatened when they become aware of imminent comprehensive changes in their core role structures* (Kelly, 1955). For example, a caregiving wife whose core role structure involves the belief that an intimate marital relationship is characterised by love and affection may feel threatened when her demented husband abuses and hits her.

(b) *become anxious when the events they experience are beyond the range of convenience of their construct systems* (Kelly, 1955). This happens when
spouses are aware that they can no longer accurately understand or predict one another. For example, a caregiving husband may become anxious when he cannot predict when his formerly prudish wife will make offensive remarks or behave sexually inappropriately in public.

**Spousal caregivers of dementia sufferers may experience emotional and sexual intimacy with their spouses when they are interacting in a positive and reciprocal way. However, spousal caregivers are more likely not to have reciprocal relationships with their demented partners.** It is more likely that the spousal caregivers will give, while the dementia sufferers will take (Rudd, 1993).

**Components of Marital Love**

Spousal caregivers of dementia sufferers will be experiencing less intimacy, less passion and be less committed to their demented partners than long-term married men and women not married to dementia sufferers. This may happen, despite their past marital happiness and despite still valuing their spouse as a unique person (Wright, 1993).

Spousal caregivers of dementia sufferers may still be experiencing the same 'companionate' kind of love as is experienced by most long-term married couples (Sternberg, 1986; 1988b). That is, their individual scores will be higher on intimacy and commitment and lower on passion.

**Coping**

*Spousal caregivers of dementia sufferers will feel helpless and lacking control.* These spouses may need to go outside their marriages for comfort and support. Caregiving husbands and wives may differ in what means of comfort and support they seek.
Differences between Spousal Caregivers

Caregiving husbands will experience similar changes to their marital intimacy as caregiving wives. Because of the impact of their demented spouses’ early personality changes on their marital intimacy, caregiving husbands and wives will be experiencing similar problems and losses. However, males and females will differ in their meanings of marital intimacy.

Spousal caregivers whose demented partners are in nursing homes will experience similar changes to their marital intimacy as those spousal caregivers who provide home care. This is because dementia sufferers’ personality changes most often occur in the early stages of dementia (Forsythe, 1990; Alzheimer’s Association, 1995), and long before nursing home placement.

Spousal caregivers of early onset dementia sufferers will experience similar changes to their marital intimacy as those experienced by spousal caregivers of late onset dementia sufferers. With the loss of their demented spouse’s personality (identity), middle-aged spousal caregivers may contend with similar problems and losses to those experienced by elderly spousal caregivers (Austrom & Hendrie, 1990).
APPENDIX B

TWO TABLES OF DEMOGRAPHIC AND PSYCHOSOCIAL CHARACTERISTICS
Table B.1. Frequencies ($f$) and percentages (%) of the demographic and psychosocial characteristics of the caregiver and comparison groups by ordinal¹ or categorical (nominal)² measurement.

<table>
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<th>Comparison group (n=63)</th>
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Table B.2. Frequencies (f) and percentages (%) of the demographic and psychosocial characteristics of the husbands and wives in the caregiver and comparison groups by ordinal¹ or categorical (nominal)² measurement.

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<td>f    %</td>
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<td>%</td>
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<td>16.1</td>
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APPENDIX C

RESEARCH PROJECT INFORMATION SHEET

Research participants required:

Spousal Caregivers of Dementia Sufferers

AND

Healthy Married Couples aged 50+ (as a comparison group)

Research topic: How the intimate relationship between married couples is affected when one of the partners has dementia.

My name is Marilyn Rudd and I am conducting this research in fulfilment of a Doctor of Philosophy by Research degree supervised by Associate Professor Linda Viney in the Department of Psychology at the University of Wollongong, NSW, Australia. I am also a former family carer; my mother died of Alzheimer’s disease three years ago.

The aim of the study is to increase awareness and understanding of the impact of a dementing illness on the intimate relationships of married couples. The information provided may assist to educate both health professionals and the families of dementia sufferers about the sexual and emotional problems and losses faced by spousal caregivers, and to highlight the need for counsellors (and other health professionals) to become competent in raising and addressing the intimacy-related concerns of these caregivers.

I am interested in talking to both husbands and wives who either care for a demented spouse at home or who are providing on-going care now their spouse has been placed in a nursing home. I am also interested in talking to healthy married couples aged 50+ (where dementia is not present in either spouse).

Participation in the project will involve only one interview lasting approximately one and a half hours. Interviews can be at your home at a time convenient to you. Data will mainly be collected by conducting an open-ended interview with you, but you will also be asked to complete various scales, including some questions relating to the emotional and sexual aspects of your relationship. You are assured that any information you provide will be strictly confidential and you are not obliged to answer any question if you do not wish to do so. The healthy married couples will be interviewed individually.

If you are willing to be interviewed, please contact me on (042) 725757 to obtain further information and to arrange a suitable time to meet with me. If you have any concerns regarding the research project please ring my supervisor, Associate Professor Linda Viney, on (042) 213693.

Your participation in this project will be greatly appreciated by me as well as the carers of dementia sufferers who will benefit from this research.

Marilyn Rudd (Mrs)
BSc. (Hons) in Psychology
APPENDIX D

CONSENT FORM

THE IMPACT OF DEMENTIA ON MARITAL INTIMACY

MARILYN RUDD

This research project is being conducted in fulfilment of a Doctor of Philosophy by Research degree supervised by Associate Professor Linda Viney in the Department of Psychology at the University of Wollongong.

The aim of the study is to increase awareness and understanding of the impact of a dementing illness (in one partner) on the intimate relationship of married couples, as experienced by spousal caregivers. The information provided may assist to educate both health professionals and the families of dementia sufferers about the sexual and emotional problems and losses faced by spousal caregivers, and to highlight the need for counsellors (and other health professionals) to become competent in raising and addressing the intimacy-related concerns of these caregivers.

Data will mainly be collected by conducting an open-ended interview with you. You will first be asked to respond to four unstructured questions; and your permission will be obtained to tape record your responses. You will also be asked to complete a self-rating adjective mood scale, two scales measuring important aspects of your present relationship, and a questionnaire relating to demographic characteristics and the emotional and sexual aspects of your relationship. The interview will be conducted in your home and will last approximately one and a half hours. You are assured that any information you provide will be strictly confidential.

You are not obliged to answer any question if you do not wish to do so, and if at any time you choose to discontinue participation in the study, you are free to do so without question.

If you have any enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (042) 214457.

If you wish to take part in this research please sign below.

***************

I have read the above and understand that the data collected will be used by Marilyn Rudd for her Doctor of Philosophy by Research degree investigating the impact of dementia on marital intimacy, and I consent for the data to be used for that purpose. I also give my permission for the interview to be tape-recorded.

.................................      .... / .... / ....
APPENDIX E

CLINICAL DEMENTIA RATING SCALE
<table>
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<td><strong>Memory</strong></td>
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<tr>
<td><strong>Orientation</strong></td>
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<td><strong>Judgment — problem solving</strong></td>
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<td><strong>Community affairs</strong></td>
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<td><strong>Home + hobbies</strong></td>
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<td><strong>Personal care</strong></td>
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CLINICAL DEMENTIA RATING (CDR)

MEMORY
- NO LOSS: OR ONLY SLIGHT FORGETFULNESS
- MILD LOSS: PARTIAL RECOLLECTION OF EVENTS
- MODERATE LOSS: INTERFERES DAILY LIFE
- SEVERE LOSS: NEW MATERIAL RAPIDLY LOST
- VERY SEVERE LOSS: ONLY FRAGMENTS REMAIN

ORIENTATION
- FULLY ORIENTED
- SOME DIFFICULTY TIME AND PLACE
- USUALLY DISORIENTED IN TIME, OFTEN TO PLACE
- SEVERELY DISORIENTED IN TIME AND PLACE

JUDGMENT - PROBLEM SOLVING
- SOLVES EVERYDAY PROBLEMS WELL
- ONLY DOUBTFUL IMPAIRMENT WITH PROBLEMS
- MODERATE DIFFICULTY OF COMPLEX PROBLEMS
- SEVERE IMPAIRMENT PROBLEMS/SOCIAL JUDGE.
- UNABLE TO MAKE JUDGEMENTS/SOLVE PROBLEMS

COMMUNITY AFFAIRS
- OPERATES INDEPENDENTLY
- DOUBTFUL OR MILD IMPAIRMENT
- UNABLE TO FUNCTION INDEPENDENTLY BUT MAY APPEAR NORMAL
- NO PRETENSE OF INDEPENDENT FUNCTIONING

HOME AND HOBBIES
- HOME & HOBBIES WELL MAINTAINED
- ONLY SLIGHT IMPAIRMENT OF HOME/HOBBIES
- MILD BUT DEFINITE IMPAIRMENT OF FUNCTION
- DEFINITE IMPAIRMENT: SIMPLE CHORES ONLY
- NO SIGNIFICANT FUNCTION OF HOME/HOBBIES

PERSONAL CARE
- FULLY CAPABLE OF SELF CARE
- NEEDS OCCASIONAL PROMPTING
- REQUIRES ASSISTANCE IN DRESSING/HYGIENE
- REQUIRES MUCH HELP WITH PERSONAL CARE; OFTEN INCONTINENT
**APPENDIX F**

**DYADIC ADJUSTMENT SCALE**

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each of the following items.

<table>
<thead>
<tr>
<th></th>
<th>Always Agree</th>
<th>Almost Agree</th>
<th>Occasionally Agree</th>
<th>Frequently Agree</th>
<th>Almost Disagree</th>
<th>Always Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demonstrations of affection</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex relations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>All the time</th>
<th>Most of the time</th>
<th>More often than not</th>
<th>Occasionally</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you discuss or have you considered divorce, separation or terminating your marriage?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>How often do you or your mate leave each other after a fight?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>In general, how often do you think that things between you and your mate are going well?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Do you confide in your mate?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you ever regret that you married?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>How often do you and your mate quarrel?</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>How often do you and your mate &quot;get on each other's nerves&quot;?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Every day</th>
<th>Almost every day</th>
<th>Occasionally</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you kiss your mate?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your mate kiss you?</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Do you lovingly touch your mate?</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Does your mate lovingly touch you?</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Do you put an arm around your mate?</td>
<td></td>
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</tr>
</tbody>
</table>


Does your mate put an arm around you?  
Do you cuddle your mate?  
Does your mate cuddle you?  
Do you and your mate hold hands?

There are some things about which couples sometimes agree and sometimes disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Tick yes or no).

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Being too tired for sex</td>
<td></td>
</tr>
<tr>
<td>Not showing love</td>
<td></td>
</tr>
</tbody>
</table>

The dots on the following line represent different degrees of happiness in your relationship. The middle point, "happy", represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely Unhappy</td>
<td>Fairly Unhappy</td>
<td>A Little Unhappy</td>
<td>Happy</td>
<td>Very Happy</td>
<td>Extremely Happy</td>
<td>Perfect</td>
</tr>
</tbody>
</table>

Which of the following statements best describes how you feel about the future of your relationship?

| | | |
| | | |
| I want desperately for my relationship to succeed, and would go to almost any length to see that it does. | | |
| I want very much for my relationship to succeed, and will do all I can to see that it does. | | |
| I want very much for my relationship to succeed, and will do my fair share to see that it does. | | |
| It would be nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed. | | |
| It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going. | | |
| My relationship can never succeed, and there is no more than I can do to keep the relationship going. | | |
APPENDIX G

THE STERNBERG TRIANGULAR LOVE SCALE
# THE STERNBERG TRIANGULAR LOVE SCALE

## INSTRUCTIONS
The blanks represent the person with whom you are in a relationship. Rate each statement on a 1-to-9 scale, where 1 = "not at all", 5 = "moderately", and 9 = "extremely". Use the intermediate points on the scale to indicate intermediate levels of feelings.

<table>
<thead>
<tr>
<th></th>
<th>1 Not at all</th>
<th>2 Slightly</th>
<th>3 Somewhat</th>
<th>4 Reasonably</th>
<th>5 Moderately</th>
<th>6 Fairly</th>
<th>7 Quite</th>
<th>8 Very</th>
<th>9 Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. There is nothing more important to me than my relationship with ______.</td>
<td></td>
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<td></td>
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<tr>
<td>2. Even when ______ is hard to deal with, I remain committed to our relationship.</td>
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<tr>
<td>3. ______ is able to count on me in times of need.</td>
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<tr>
<td>4. I communicate well with ______.</td>
<td></td>
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<td></td>
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<tr>
<td>5. I am certain of my love for ______.</td>
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<td>6. I would rather be with ______ than with anyone else.</td>
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<tr>
<td>7. I feel that ______ really understands me.</td>
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<tr>
<td>8. I idealize ______.</td>
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<tr>
<td>9. I cannot imagine life without ______.</td>
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<td>10. Just seeing ______ excites me.</td>
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<tr>
<td>11. I value ______ greatly in my life.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 Not at all</td>
<td>2 Slightly</td>
<td>3 Somewhat</td>
<td>4 Reasonably</td>
<td>5 Moderately</td>
<td>6 Fairly</td>
<td>7 Quite</td>
<td>8 Very</td>
<td>9 Extremely</td>
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<tr>
<td>12. I will always feel a strong responsibility for [ ] .</td>
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<tr>
<td>13. There is something almost &quot;magical&quot; about my relationship with [ ] .</td>
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<tr>
<td>15. I view my commitment to [ ] as a solid one.</td>
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<tr>
<td>16. I am actively supportive of [ ] 's well-being.</td>
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<tr>
<td>17. I expect my love for [ ] to last for the rest of my life.</td>
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<tr>
<td>18. I feel that I really understand [ ] .</td>
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<tr>
<td>19. I cannot imagine ending my relationship with [ ] .</td>
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<tr>
<td>20. I plan to continue in my relationship with [ ] .</td>
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<tr>
<td>21. I could not let anything get in the way of my commitment to [ ] .</td>
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<tr>
<td>22. When I see romantic movies or read romantic books I think of [ ] .</td>
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<tr>
<td>23. I view my relationship with [ ] as permanent.</td>
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<tr>
<td>24. I am able to count on [ ] in times of need.</td>
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<tr>
<td>25. I am willing to share myself and my possessions with [ ] .</td>
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</tr>
</tbody>
</table>
26. Because of my commitment to _____, I would not let other people come between us.

27. I adore _____.

28. I especially like physical contact with _____.

29. I receive considerable emotional support from _____.

30. I share deeply personal information about myself with _____.

31. I feel that I really can trust _____.

32. I give considerable emotional support to _____.

33. I know that I care about _____.

34. I cannot imagine another person making me as happy as _____ does.

35. I view my relationship with _____ as a good decision.

36. I find myself thinking about _____ frequently during the day.

37. I have a comfortable relationship with _____.

38. I find _____ to be very personally attractive.

39. I have confidence in the stability of my relationship with _____.
<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>40. I feel close to ______.</td>
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<tr>
<td>41. I have a warm relationship with ______.</td>
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<tr>
<td>42. I am committed to maintaining my relationship with ______.</td>
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<tr>
<td>43. My relationship with ______ is very romantic.</td>
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<tr>
<td>44. I feel a sense of responsibility toward ______.</td>
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</tr>
<tr>
<td>45. My relationship with ______ is passionate.</td>
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</tbody>
</table>
## APPENDIX H

### DABS

Below is a list of words that describes the way people sometimes feel. We would like you to tell us whether you have been having any of these feelings during the past including today. Please indicate the degree to which you have felt each emotion by circling the number that best describes your experience. Circle only one number for each emotion and do not skip any items.

| 1. NERVOUS | 21. CHEERFUL |
| 2. SAD | 22. SATISFIED |
| 3. REGRETFUL | 23. ACTIVE |
| 4. IRRITABLE | 24. FRIENDLY |
| 5. HAPPY | 25. ANXIOUS |
| 6. PLEASED | 26. MISERABLE |
| 7. EXCITED | 27. GUILTY |
| 8. PASSIONATE | 28. ENRAGED |
| 9. TIMID | 29. DELIGHTED |
| 10. HOPELESS | 30. RELAXED |
| 11. BLAMEWORTHY | 31. VIGOROUS |
| 12. RESENTFUL | 32. AFFECTIONATE |
| 13. GLAD | 33. AFRAID |
| 14. CALM | 34. UNHAPPY |
| 15. ENERGETIC | 35. REMOURESEFUL |
| 16. LOVING | 36. BITTER |
| 17. TENSE | 37. JOYOUS |
| 18. WORTHLESS | 38. CONTENTED |
| 19. ASHAMED | 39. LIVELY |
| 20. ANGRY | 40. WARM |

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**D A B S**

### Dimension Scores

<table>
<thead>
<tr>
<th>Jy</th>
<th>Ct</th>
<th>Vg</th>
<th>Af</th>
<th>Ax</th>
<th>Dp</th>
<th>Gl</th>
<th>Ho</th>
</tr>
</thead>
<tbody>
<tr>
<td>T-</td>
<td>T-</td>
<td>T-</td>
<td>T-</td>
<td>T-</td>
<td>T-</td>
<td>T-</td>
<td>T-</td>
</tr>
<tr>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
</tr>
</tbody>
</table>

### Global Scores

<table>
<thead>
<tr>
<th>+Tot</th>
<th>-Tot</th>
<th>ABI</th>
<th>AEI</th>
<th>PAR</th>
</tr>
</thead>
<tbody>
<tr>
<td>T-</td>
<td>T-</td>
<td>T-</td>
<td>T-</td>
<td>T-</td>
</tr>
<tr>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
<td>Raw</td>
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</tbody>
</table>

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**D A B S: Computation of Affect Scores**

#### Positive

<table>
<thead>
<tr>
<th>Jy</th>
<th>Ct</th>
<th>Vg</th>
<th>Af</th>
<th>Ax</th>
<th>Dp</th>
<th>Gl</th>
<th>Ho</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. ( )</td>
<td>6. ( )</td>
<td>7. ( )</td>
<td>8. ( )</td>
<td>1. ( )</td>
<td>2. ( )</td>
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<td>4. ( )</td>
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<tr>
<td>21. ( )</td>
<td>22. ( )</td>
<td>23. ( )</td>
<td>24. ( )</td>
<td>17. ( )</td>
<td>18. ( )</td>
<td>19. ( )</td>
<td>20. ( )</td>
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<tr>
<td>29. ( )</td>
<td>30. ( )</td>
<td>31. ( )</td>
<td>32. ( )</td>
<td>25. ( )</td>
<td>26. ( )</td>
<td>27. ( )</td>
<td>28. ( )</td>
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<tr>
<td>37. ( )</td>
<td>38. ( )</td>
<td>39. ( )</td>
<td>40. ( )</td>
<td>33. ( )</td>
<td>34. ( )</td>
<td>35. ( )</td>
<td>36. ( )</td>
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</table>

#### Negative

<table>
<thead>
<tr>
<th>Ax</th>
<th>Dp</th>
<th>Gl</th>
<th>Ho</th>
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<tbody>
<tr>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

**ABI** = (POSITIVE SCORE TOTAL - NEGATIVE SCORE TOTAL) ÷ 20

**AEI** = (POSITIVE SCORE TOTAL + NEGATIVE SCORE TOTAL)

**PAR** = (POSITIVE SCORE TOTAL) ÷ AEI

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APPENDIX I

RELIABILITY AND VALIDITY OF CONTENT ANALYSIS SCALES
Table I.1. Reported interjudge reliability estimates for content analysis scales

<table>
<thead>
<tr>
<th>Scale</th>
<th>Average coefficient</th>
<th>Range of coefficients</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positively toned scales</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sociality</td>
<td>.96</td>
<td>.95-.97</td>
<td>Viney &amp; Westbrook (1979)</td>
</tr>
<tr>
<td>Positive Affect</td>
<td>.93</td>
<td>-</td>
<td>Westbrook (1976)</td>
</tr>
<tr>
<td><strong>Negatively toned scales</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hostility In</td>
<td>.94</td>
<td>.76-.98</td>
<td>Gottschalk &amp; Gleser (1969)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Viney &amp; Manton (1973)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Schofer, Koch &amp; Balck (1979)</td>
</tr>
<tr>
<td>Hostility Out</td>
<td>.79</td>
<td>.58-.87</td>
<td>Gottschalk &amp; Gleser (1969)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Viney &amp; Manton (1973)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Schofer, Koch &amp; Balck (1979)</td>
</tr>
<tr>
<td>Total Anxiety (which includes</td>
<td>.90</td>
<td>.76-.94</td>
<td>Gottschalk &amp; Gleser (1969)</td>
</tr>
<tr>
<td>the Death, Mutilation, Separat</td>
<td></td>
<td></td>
<td>Viney &amp; Manton (1973)</td>
</tr>
<tr>
<td>ion and Guilt Anxiety Subscales)</td>
<td></td>
<td></td>
<td>Schofer, Koch &amp; Balck (1979)</td>
</tr>
<tr>
<td>Cognitive Anxiety</td>
<td>.96</td>
<td>.71-.99</td>
<td>Viney &amp; Westbrook (1976)</td>
</tr>
</tbody>
</table>

(Adapted from Bell, 1990)
Table I.2. Reported evidence of validity of content analysis scales

<table>
<thead>
<tr>
<th>Scale and reference</th>
<th>Evidence of validity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positively toned scales</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Sociality</strong></td>
<td></td>
</tr>
<tr>
<td>Viney &amp; Westbrook (1979)</td>
<td>Independent of sex, age, occupational status.</td>
</tr>
<tr>
<td>Viney &amp; Westbrook (1979)</td>
<td>Significantly negatively correlated with negatively toned states.</td>
</tr>
<tr>
<td>Viney &amp; Westbrook (1979)</td>
<td>Discriminated informants who were maintaining good relationships from those who were not.</td>
</tr>
<tr>
<td>Preston (1987)</td>
<td>Discriminated religious group from normative group as well as between religious groups.</td>
</tr>
<tr>
<td>Bell (1990)</td>
<td>Discriminated mature age nurse trainees from younger ones.</td>
</tr>
<tr>
<td><strong>Positive Affect</strong></td>
<td></td>
</tr>
<tr>
<td>Westbrook (1976)</td>
<td>Independent of sex, age, education and occupational status.</td>
</tr>
<tr>
<td>Viney &amp; Bazeley (1977)</td>
<td>Discriminated women who were moving to a new home from those who were not.</td>
</tr>
<tr>
<td>Viney (1980)</td>
<td>Discriminated mothers reporting on childbearing from women reporting on other events.</td>
</tr>
<tr>
<td>Bell (1990)</td>
<td>Discriminated mature age nurse trainees from younger ones.</td>
</tr>
<tr>
<td><strong>Negatively toned scales</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Hostility In</strong></td>
<td></td>
</tr>
<tr>
<td>Gottschalk &amp; Gleser (1969)</td>
<td>Independent of sex, age, educational level.</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Description</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Gottschalk (1979)</td>
<td>Significantly correlated with psychiatrists' ratings of depression.</td>
</tr>
<tr>
<td>Bell (1990)</td>
<td>Discriminated mature age nurse trainees from younger ones.</td>
</tr>
<tr>
<td>Viney (1990)</td>
<td>Discriminated the ill from the well.</td>
</tr>
<tr>
<td>Viney, Walker, Bell, Nagy &amp; Tooth (1994)</td>
<td>Discriminated trained palliative care staff from burns nurses or general nurses.</td>
</tr>
<tr>
<td>Rudd, Viney &amp; Preston (1999)</td>
<td>Discriminated male and female spousal caregivers of dementia patients and also home caregivers and nursing home caregivers of dementia patients.</td>
</tr>
<tr>
<td>Hostility Out</td>
<td>Independent of age and educational level.</td>
</tr>
<tr>
<td>Gottschalk (1979)</td>
<td>Significantly correlated with ratings of angry behaviours by observers.</td>
</tr>
<tr>
<td>Preston (1987)</td>
<td>Discriminated religious group from normative group as well as between religious groups.</td>
</tr>
<tr>
<td>Rudd, Viney &amp; Preston (1999)</td>
<td>Discriminated male and female spousal caregivers of dementia patients and also home caregivers and nursing home caregivers of dementia patients.</td>
</tr>
<tr>
<td>Total Anxiety (which includes the Death, Mutilation, Separation and Guilt Anxiety Subscales)</td>
<td>Significantly correlated with psychiatrists' ratings of anxiety.</td>
</tr>
<tr>
<td>Gottschalk (1979)</td>
<td>Significantly correlated with self reports of anxiety.</td>
</tr>
</tbody>
</table>
Gottschalk (1979)  
Significantly correlated with ratings of anxiety-related behaviours by observers.

Viney & Westbrook (1982)  
Independent of sex, age, educational level.

Westbrook & Viney (1982)  
Discriminated chronically ill from others.

Preston (1987)  
Discriminated between religious groups.

Bell (1990)  
Discriminated mature age nurse trainees from younger ones.

Viney, Walker, Bell, Nagy & Tooth (1994)  
Discriminated trained palliative care staff from burns nurses or general nurses.

Viney, Crooks & Walker (1995)  
Discriminated counselled and not counselled voluntary AIDS caregivers.

Nagy (1995)  
Discriminated burns nurses from neonatal nurses.

Rudd, Viney & Preston (1999)  
Discriminated home caregivers and nursing home caregivers of dementia patients.

Cognitive Anxiety

Viney & Westbrook (1976)  
Independent of sex, age, but correlated with occupational status.

Viney & Westbrook (1976)  
Significantly correlated with measures of state anxiety, not trait anxiety.

Viney & Westbrook (1976)  
Discriminated people's accounts of situations which were unpredictable from those which were not.

Bunn & Clarke (1979)  
Discriminated relatives' accounts when waiting for emergency medical patients from those who were not.

Viney (1980)  
Discriminated people in situations which were new to them from those who were not in new situations.

Preston (1987)  
Differentiated construct organisation between religious people.

Rudd, Viney & Preston (1999)  
Discriminated home caregivers and nursing home caregivers of dementia patients.

Weekes (1999)  
Discriminated between parents of children with and without developmental disabilities.

(Adapted, in part, from Bell, 1990)
APPENDIX J

TABLES RELATING TO SEXUAL INTIMACY
Table J.1. Frequencies (f) and percentages (%) of sexual relations per month of the husbands and wives in the caregiver and comparison groups.

<table>
<thead>
<tr>
<th>Sex relations per month</th>
<th>Caregiver group</th>
<th></th>
<th>Comparison group</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Husbands (n=30)</td>
<td>Wives (n=30)</td>
<td>Husbands (n=30)</td>
<td>Wives (n=33)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>f</td>
<td>%</td>
<td>f</td>
<td>%</td>
<td>f</td>
</tr>
<tr>
<td>0</td>
<td>23</td>
<td>76.7</td>
<td>26</td>
<td>86.7</td>
<td>9</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>6.7</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>6.7</td>
<td>2</td>
<td>6.7</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>3.3</td>
<td>0</td>
<td>0</td>
<td>4</td>
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<tr>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
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<tr>
<td>8</td>
<td>1</td>
<td>3.3</td>
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<td>10</td>
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<td>0</td>
<td>3</td>
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<td>12</td>
<td>1</td>
<td>3.3</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>14</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>16</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>20</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3.3</td>
<td>0</td>
</tr>
</tbody>
</table>

* One female caregiver refused to answer the question.
Table J.2. Frequencies \((f)\) and percentages \(\%\) of the reasons attributed to the decline or change in sexual relations by the husbands and wives in the caregiver and comparison groups.

<table>
<thead>
<tr>
<th>Reasons for decline or change in sex relations</th>
<th>Caregiver group</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Comparison group</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caregiver group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Comparison group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td>17</td>
<td>56.7</td>
<td>18</td>
<td>60.0</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing home placement</td>
<td>1</td>
<td>3.3</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health - self</td>
<td>1</td>
<td>3.3</td>
<td>1</td>
<td>3.3</td>
<td>5</td>
<td>16.7</td>
<td>5</td>
<td>15.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health - spouse</td>
<td>3</td>
<td>10.0</td>
<td>7</td>
<td>23.3</td>
<td>2</td>
<td>6.7</td>
<td>13</td>
<td>39.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health - both</td>
<td>1</td>
<td>3.3</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>6.7</td>
<td>1</td>
<td>3.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication - self</td>
<td>1</td>
<td>3.3</td>
<td>1</td>
<td>3.3</td>
<td>3</td>
<td>10.0</td>
<td>1</td>
<td>3.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication - spouse</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>2</td>
<td>6.7</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>26.7</td>
<td>2</td>
<td>6.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of interest</td>
<td>2</td>
<td>6.7</td>
<td>2</td>
<td>6.7</td>
<td>3</td>
<td>10.0</td>
<td>2</td>
<td>6.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No change</td>
<td>2</td>
<td>6.7</td>
<td>1</td>
<td>3.3</td>
<td>5</td>
<td>16.7</td>
<td>3</td>
<td>9.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better than in the past</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>6.7</td>
<td>5</td>
<td>15.2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^1\) One female caregiver refused to answer the question.
APPENDIX K

THREE CORRELATION TABLES
Table K.1. Correlations among the three components of Sternberg Triangular Love Scale - Pearson’s $r$

<table>
<thead>
<tr>
<th></th>
<th>Intimacy</th>
<th>Passion</th>
<th>Commitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intimacy</td>
<td>1.00</td>
<td>.75*</td>
<td>.55*</td>
</tr>
<tr>
<td>Passion</td>
<td>1.00</td>
<td></td>
<td>.62*</td>
</tr>
<tr>
<td>Commitment</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
</tbody>
</table>

*p < .001

Table K.2. Correlations among the four positive affect dimensions and four negative affect dimensions of Derogatis Affects Balance Scale - Pearson’s $r$

<table>
<thead>
<tr>
<th>Positive Affects</th>
<th>Affection</th>
<th>Contentment</th>
<th>Joy</th>
<th>Vigor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affection</td>
<td>1.00</td>
<td>.40*</td>
<td>.48*</td>
<td>.59*</td>
</tr>
<tr>
<td>Contentment</td>
<td>1.00</td>
<td></td>
<td>.78*</td>
<td>.52*</td>
</tr>
<tr>
<td>Joy</td>
<td>1.00</td>
<td></td>
<td></td>
<td>.57*</td>
</tr>
<tr>
<td>Vigor</td>
<td></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Negative Affects</th>
<th>Anxiety</th>
<th>Depression</th>
<th>Hostility</th>
<th>Guilt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>1.00</td>
<td>.53*</td>
<td>.48*</td>
<td>.51*</td>
</tr>
<tr>
<td>Depression</td>
<td>1.00</td>
<td></td>
<td>.61*</td>
<td>.60*</td>
</tr>
<tr>
<td>Hostility</td>
<td>1.00</td>
<td></td>
<td></td>
<td>.62*</td>
</tr>
<tr>
<td>Guilt</td>
<td></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
</tbody>
</table>

*p < .001
Table K.3. Correlations among the nine content analysis scales - Pearson’s $r$

<table>
<thead>
<tr>
<th></th>
<th>Positive Affect</th>
<th>HI</th>
<th>HO</th>
<th>Cognitive Anxiety</th>
<th>Death Anxiety</th>
<th>Mutilation Anxiety</th>
<th>Separation Anxiety</th>
<th>Guilt Anxiety</th>
<th>Sociality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Affect</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>HI</td>
<td>- .43**</td>
<td>- .40**</td>
<td>- .29**</td>
<td>.33**</td>
<td>-.06</td>
<td>- .39**</td>
<td>- .30**</td>
<td>- .76**</td>
<td></td>
</tr>
<tr>
<td>HO</td>
<td>.19*</td>
<td>.28**</td>
<td>-.04</td>
<td>.06</td>
<td>.81**</td>
<td>.29**</td>
<td>-.60**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive Anxiety</td>
<td>1.00</td>
<td>.06</td>
<td>.07</td>
<td>.26*</td>
<td>-.05</td>
<td>.32**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death Anxiety</td>
<td>1.00</td>
<td>.11</td>
<td>.02</td>
<td>-.05</td>
<td>.32**</td>
<td></td>
<td></td>
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<tr>
<td>Mutilation Anxiety</td>
<td>1.00</td>
<td>-.00</td>
<td>-.01</td>
<td>.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separation Anxiety</td>
<td>1.00</td>
<td>.26*</td>
<td>.57**</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guilt Anxiety</td>
<td>1.00</td>
<td>-.39**</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Sociality</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
</tbody>
</table>

* $p < .05$

** $p < .001$
Four groups by gender

Figure 1. Mean Affection scores as a function of group by gender