National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

UNIVERSITY OF ALBERTA

THE EXPERIENCE OF RESPITE FOR CAREGIVERS OF DEMENTIA PERSONS

by

Victoria Rosalind Strang, RN., MN. ©

A thesis submitted to Faculty of Graduate Studies and Research

in partial fulfilment of the requirements

for the degree of Doctor of Philosophy

in

Educational Administration

Department of Educational Policy Studies

Edmonton, Alberta

Fall 1995

National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

ISBN 0-612-06297-X

University of Alberta

Library Release Form

Name of Author: Victoria Rosalind H. Strang

Title of Thesis: The Experience of Respite for Caregivers of Dementia Persons

Degree: Doctor of Philosophy

Year this Degree Granted: Fall, 1995

Viki Strang

Victoria R.H. Strang
3615-113B Street
Edmonton, Alberta.
T6J 1L6

Date Aug 31/95

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **The Experience of Respite for Caregivers of Dementia Persons** submitted by **Victoria Rosalind H. Strang** in partial fulfilment of the requirements for the degree of **Doctor of Philosophy** in Educational Administration.

M Haughey
M. L. Haughey, PhD — Supervisor

D. Wertenberger, RN, PhD — Committee Member

D.A. MacKay, PhD — Committee Member

Janet C. Ross Kerr
J. Ross Kerr, RN, PhD — Committee Member

Anne Neufeld
A. Neufeld, RN, PhD — Committee Member

W. G. M.
D.Pringle, RN, PhD — External Examiner

W. G. Maynes
W. Maynes, PhD — Committee Chair

Date Aug 31/95

This thesis is dedicated to my late husband

ALLEN LESLIE STRANG

The memory of his quiet enduring love and

his strength of spirit sustain me

in my life's work. I will never forget!

ABSTRACT

This thesis explores the experience of respite for caregivers of dementia persons within an interpretivist and exploratory research design. The qualitative methods of narrative development and grounded theory are used for the data collection and analysis processes. The theoretical perspective of the study begins with social support and shifts to a coping orientation as the more appropriate informing theory for exploring the meaning of respite to study caregivers.

The respite experience was seen as a coping strategy by the study informants. They described two experiential spheres: the dominating and energy consuming caregiving world and the smaller world they considered their "own personal world"; with respite being an interval where they were in this "personal world", feeling mentally free to be themselves.

The caregivers identified the respite experience as a cognitive process of moving out of their caregiver world into their personal world away from caregiver responsibilities. This process included three dimensions: recognizing the need to "get out", giving themselves permission to "get out", and the availability of social support resources. Factors influencing the caregivers' ability to leave included: the nature of the pre-illness relationship; personality-based factors; role expectation; attributes of respite help; and the time length of being a caregiver. Being in their personal world, the mental state of feeling free from caregiver duties, was the essence of the respite experience. The time dimensions of length, quality and use influenced how the respite interval was experienced by the caregivers. How they experienced the respite interval and the dementia person condition as they resumed caregiving influenced their re-entry into and their ability to continue in the caregiving world. The process of re-entry was integral to the respite experience. A conceptual model was developed to summarize the components of the caregiver respite experience.

The thesis concludes by challenging practitioners and researchers to consider the experience of respite as a deeply personal caregiver process, different and separate from the use of respite services. Respite as leisure including gender experiential differences are directions outlined for future research.

ACKNOWLEDGEMENTS

Many individuals have assisted in the completion of this research. I acknowledge with sincere thanks the support and guidance of my committee members, Dr. Margaret Haughey, Dr. Dana Wertenberger, and Dr. Al MacKay throughout the research process. I reserve particular appreciation for my supervisor, Dr. Haughey, for her quick mind, prompt feedback, collegial regard, and capacity to effectively straddle two disciplines.

I extend thanks to Dr. Dorothy Pringle, my external examiner and mentor, for her thoughtful comments and advise; to Dr. Janet Ross Kerr and Dr. Anne Neufeld for their continuing support; and Dr. William Maynes for chairing my oral defense. I am grateful to Educational Policy Studies for their flexibility and support in allowing me to pursue my research topic in their department. I also thank the Faculty of Nursing and my many Faculty colleagues for their sustaining encouragment in facilitating the PhD process for me.

I extend acknowledgment and thanks to the Victorian Order of Nurses in Edmonton for their support of this research. They approved the release of NHRDP Community Researcher Award funds for the partial financial support of this project. I offer a special thanks to Jean Pearson, the former VON Edmonton Executive Director, for her continuing encouragement and enthusiastic support of my research work.

My sincere thanks and special gratitude goes to the 10 participants in the study for sharing with me the complexity of their lives. Without their emotional openness and candid answers to my questions this research could not have been done.

Finally, I thank all the members of my immediate and extended family for their support and assistance. I particularly acknowledge my sister, Ruth Enns, for providing through and reliable editing assistance; my elderly mother, Helena Wiebe, for her encouragement and prayers; and my two daughters, Kathryn and Elizabeth (Liz), for cheering me on at each stage of the PhD process.

TABLE OF CONTENTS

Chapter Page

Figures

Chapter 1

INTRODUCTION

My interest in respite evolved from my experience as senior administrator and researcher in community health nursing. Over time, as I worked with staff and families, I came to realize the importance to families of programs focusing on the quality of life for frail elderly persons and their caregivers. I became committed to facilitating quality support services to families.

More specifically, I became involved in the development of an adult day care program and a subsequent evaluation study of it. One of the goals of this day program was to provide respite to the family caregivers of the frail elderly clients of the program. As I attempted to identify the outcome measurement of respite in this evaluation study, I came to realize the difficulty of this process. In my naivete, I thought that if I could demonstrate the decrease of caregiver burden over time and there are numerous instruments available measuring this concept quantitatively, then I would have measured the respite impact of the day program for caregivers. In the evaluation study of the day program, this decrease in caregiver burden, of course, did not happen.

However, in the process of this study, as I listened to the caregiver narratives and analyzed what they told me about how the day program assisted them in their difficult and complex lives, I realized that they did benefit from the program and that they did experience respite. But in the process of linking these caregiver respite benefits to the literature I became increasingly aware of the conceptual confusion in the respite field. There were no clear definitions of respite and there were many diffuse models of respite services. Further, as I listened to the family caregivers, the program staff, other helping practitioners and gerontology experts, I realized the extent of the stress in the caregivers' lives. Also, I began to understand that the lives of caregivers caring for dementia relatives seemed more difficult than that of other caregivers caring for dependent, but cognitively intact, elderly persons.

At the same time, the health care reform movement was escalating. The reform rhetoric was strongly emphasizing the advantages of community care and advocating a shift from institutional to community health care in all health care sectors including care for the elderly. As the directional changes within the system became more evident, the plight of family caregivers and their need for support began to be recognized. Respite was seen as one way to provide this support to caregivers. With the importance of respite increasing in the health care system, a plethora of diverse program and service models supporting caregivers, all labelled respite services, have emerged. To accentuate its present importance in the health care system, respite for family caregivers was specifically named in a recent Edmonton key policy document (Capital Health Authority, 1994) as one service to be enhanced and strengthened.

It is against this background of experience in developing and evaluating a respite program and within the political context of a health care reform movement where emphasis is shifting from institutional to community and home-based care, that I embarked on the process of understanding respite more fully. What was needed, I felt, was research focusing on the conceptual clarification of respite. Because respite services are targeted to family caregivers, I needed to talk to caregivers directly and at length. They are the ones who experience the caregiving and they are the ones who experience respite. I needed to enter into the complexity of that context. It seemed to me that the process of experiencing respite could happen only if the circumstance, the caregiving experience, warranted relief.

Throughout this thesis, I have consistently attempted to portray respite within the context of the caregiving experience. I needed to know the all-encompassing nature of caregiving from within in order to comprehend the actual caregiver experience of respite. This dissertation, therefore, focuses on the development of an experiential understanding of respite for caregivers of dementia persons.

Purpose of the Study

The role of the family caregiver is stressful, especially when associated with caring for persons with dementia (George & Gwyther, 1986; Mace & Rabins, 1984; Novak & Guest, 1989; Skaff & Pearlin, 1992; Zarit, Todd, & Zarit, 1986; Zarit & Zarit, 1983). There is now an extensive body of literature delineating the stress and burden experienced by this group of caregivers (Novak & Guest, 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Chappell, 1992; Rankin, Haut & Keefover, 1992; Knight, Lutsky, & Macofsky-Urban, 1993; Montgomery, 1995). As well, there is growing evidence of the negative consequences to caregivers of providing care to dementia persons, including deterioration of physical health, social isolation, severe time restrictions, and negative emotional responses (Gaynor, 1989; Novak & Guest, 1989; Dillehay & Sands, 1990; Robinson, 1990; Lindgren, 1993).

Although a number of different formal support services and programs are available to assist these family caregivers, respite is seen as one key formal support intervention which mitigates the negative consequences of caregiving (Lawton et al., 1991; Chappell, 1992; Knight, Lutsky, & Macofsky-Urban, 1993; Montgomery, 1995). The literature on the impact of respite on caregivers shows a mixed caregiver response to program effectiveness (Scharlach & Frenzel, 1986; Seltzer et al., 1988; Montgomery, 1992; Hirsch, Davies, Boatwright, & Ochango, 1993; Montgomery, 1995). This response seems related to ambiguity in the conceptualization of respite itself and to an unclear delineation by the family caregivers to the outcomes of respite (Knight, Lutsky, & Macofsky-Urban, 1993; Montgomery, 1995). Caregivers of dementia persons have indicated a great need for respite (Fortinsky & Hathaway, 1990; Chappell, 1992; Homer & Gilleard, 1994). However, in the limited research in this area, rather than enquiring what caregivers mean when they ask for respite, service delivery systems have used their own interpretation of respite. This has resulted in the present hodge-podge of respite programs and services, where the lack of a unified foundational understanding of respite is quite evident. Therefore, it seems that a clearer conceptualization of respite could be achieved if caregivers of dementia persons were asked to share their understandings of their own experiences of respite.

Therefore, the purpose of this study was to explore respite from the perspective of family caregivers of dementia persons and to gain an increased understanding of what respite means to them. The new insights gained in this study should result in a clearer definition of respite. From this conceptual foundation of respite, more specific and appropriate outcome indicators for respite can be identified. These outcome indicators can then be more confidently used to identify the effectiveness of specific respite programs and can be used for respite program development for the caregivers of dementia persons. Additionally, this foundational work on defining respite could provide a conceptual framework which could guide research on the factors which influence caregivers' experiences of respite and from which specific interventions for caregivers could be developed. As well, respite outcome research with caregivers of different care-recipient populations could evolve. It could lay the conceptual groundwork for an ongoing program of respite research.

The Problem

Dementia represents a major public health concern particularly for the elderly (Forbes & Barham, 1991). Insidious in nature, the diseases which result in dementia are characterized by irreversible memory impairment, deterioration in general intellectual ability, personality disorganization and a decreased ability to perform self care tasks (Keating & Gilewich, 1985). The course of these dementia conditions can continue for as long as 14 years with the usual duration being four to seven years. McDaniel (1986) indicates that in Canada the 65 and older segment of the population, which comprised 9.7 percent of the total population in 1981, will have grown to 14 percent by the year 2001 and to 21 percent by 2021. In this growing population segment, the prevalence of moderate to severe dementia is 7.8 percent (Robertson, Rockwood & Stolee, 1989). With no cure or significant treatment in sight, the care of dementia persons and the support of their caregivers present major challenges to the health care system (Binstock, Post, & Whithouse, 1992).

Although surveys indicate that dementia is one of the major causes for institutionalization, about one-half or more of dementia persons are maintained at home by caregiver relatives, sometimes for lengthy periods of time (Keating & Warren, 1988). Further, it is the caregivers' stress and burden together with the behaviours of dementia persons which predict institutionalization (Dillehay & Sandys, 1990; Jerrom, Mian, Rukanyake, & Prother, 1993). Therefore, if over half of the dementia population are being maintained at home and if it is the caregivers' perceptions of stress and burden that predict long-term care placement, then research should focus on caregivers.

Programs to maintain the elderly in their homes as long as possible have been strongly endorsed by governments and are seen as a 'system buffer' to reduce the demand on institutions (Bowen & LaPerriere, 1994; Hyndman, 1989; Mirosh, 1988; Nolan & Grant, 1993). The effect of this policy within the home and within families is that family caregivers are assuming increasing responsibility for the care of their frail elderly family members (McDaniel & Gee, 1993). Families have always been the foundation of care for seniors. However, in today's environment of extreme fiscal restraint, Chappell (1993) states that family caregivers have, in fact, "become a cornerstone in the rhetoric for health reform in virtually all provinces in Canada.... With concerns over increasing costs and possible over medicalization of the health care system, the new found recognition of informal caregivers is embraced as a key element of community care for seniors" (p.3). Indeed, family caregiving has been recognized as a significant and escalating challenge facing Canadian society today (McDaniel & Gee, 1993).

Recent reports have called for more services for family caregivers as they increasingly assume more care for longer periods of time (Health and Welfare, 1992; National Advisory Council on Aging, 1990a; 1990b; Nolan & Grant, 1993). One service frequently requested by caregivers, particularly caregivers of dementia persons, is respite (Chappell, 1992; Kosloski & Montgomery, 1993). In fact, respite is seen as one of the key methods of providing formal support to the caregivers of dementia persons (Lindeman, Corby, Downing, & Sanbourn, 1991; Deimling, 1991; Lingren, 1993). Allen and Wrege (1991) further indicate that increasing numbers of lower functioning dementia persons are being maintained by caregivers in the home. Also, Lindeman et al.(1991) say that most dementia persons can be maintained at home if their caregivers and families are given adequate supportive assistance. They see respite as one way to provide this support. In the Alberta health reform process, local jurisdictions identified specific directional changes in restructuring the health care system. In Edmonton, respite was specifically named as one service for family caregivers which must be enhanced and strengthened (A New Direction for Health, Capital Health Authority, 1994).

However, there seems to be ambiguity in the actual conceptualization of respite itself. Within the health care service sector, many different types of programs and interventions are called respite. Respite can include short term, full-time or part-time, institutional placement of the dementia person to provide the caregiver with vacation relief. Regular attendance at an adult day program by the dementia person for a designated number of hours per day is also identified as respite. Respite can also include health care workers, either professional or para-professional, providing in home services so that caregivers can be relieved temporarily of their caregiving responsibilities. It is readily evident that these respite services differ significantly on a number of different dimensions. For example, the length of stay, the location where the service is provided, and the type of service delivery are different in each type of program. Despite these, and perhaps other variations, all these programs are expected to provide respite to caregivers. According to Knight, Lutsky, and Macofsky-Urban (1993), it is because of this wide range in the conceptualization of respite services that it becomes difficult, if not impossible, to delineate clearly the outcomes of respite for family caregivers.

Therefore, because of the prominence of respite within the health care reform movement and because of the lack of clarity in defining respite, it becomes crucial to clarify the meaning of the term. Respite involves providing relief to caregivers. To achieve a clearer conceptualization of respite, it would seem that exploring the actual experience of respite from the family caregiver perspective would be the most logical research approach. If we can increase our understanding of what gives the caregivers relief from their caregiving responsibilities, we can develop a clearer respite conceptual framework and perhaps, respite services will be more effective.

Significance of the Research

Respite must be explored in greater depth from the caregivers' perspective so that its specific components and elements can be more clearly identified. If this expanded knowledge of respite has the potential to enhance the effectiveness of respite programs then the quality of life for both the caregivers and their dependent family members can be enhanced. If the quality of life is improved for both, then, caregivers might be able to remain in their role for longer periods of time resulting in dementia persons remaining in their homes longer. Maintaining caregivers in their role can contribute specifically to more stable family functioning and to the health care system. Potentially, as caregiver satisfaction increases and guilt decreases, families are more likely to keep their dependent family member at home longer and thus relieve the system of early, inappropriate, and more costly institutional placement (Shapiro & Roos, 1987; Friedman & Newberger, 1993).

A clearer concept of respite will also be significant to the ongoing research in the area. Because of the prominence of respite in health care reform, research clarifying such care is very critical. Having a stronger conceptual foundation of respite can only strengthen the development of respite intervention and outcome research. This research can then ultimately contribute to enhancing respite programs and their effectiveness for caregivers.

The Research Question

Because of the confusion in the concept of respite and the diversity in respite programming, it is important to explore more extensively the phenomenon of respite from the family caregivers' perspective. What seems to be missing from the literature is the caregiver perspective of respite. Therefore, the main research question was: **What is the experience of respite for caregivers of dementia persons?** This question provided the over-arching framework for the inquiry process. Two fundamental components seemed embedded in this question: the all-encompassing caregiving experience itself and how the respite experience fits into this experience. These two components guided the direction of the study and are reflected the following research questions:

1. What is the **caregiving experience** of the family caregiver of a dementia person?
2. What aspects of the **caregiving experience** are the most/least stressful?
3. What events are seen as helpful/not-helpful by the caregiver in their **caregiving situation**?
4. What do caregivers identify as **respite**?
5. How is the provision of **respite** experienced by the caregivers?
6. When caregivers are separated temporarily from their dependent family member, how do they experience **this time interval**?
7. How do caregivers assess the worth of **respite**?

Organization of the Dissertation

This research report is organized into six chapters. The relevant literature on the topic of respite for caregivers of dementia persons is reviewed in the next chapter. The philosophical framework guiding the research methods, the methods used, and the ethical considerations of the study are presented in Chapter 3.

The findings of the study are presented in Chapter 4. The discussion of these findings is in three sections: a summary of the specific stories of the ten caregiver informants concluding with the beginning elements of a respite conceptual framework; a detailed presentation of the common themes from these narratives; and the more detailed outline of the conceptual model emerging from the total body of data.

In chapter 5 these findings, in the context of the conceptual framework and with reference to the relevant literature, are discussed. Additionally, the findings of the study are explored in the context of a secondary literature review based on the concepts and changed understandings gained during the research process. Chapter 6 contains a summary of the processes and findings of the study. The study concludes with a discussion of the implications of the findings for practice and research.

Chapter 2

LITERATURE REVIEW

The research questions reflect two components fundamental to the exploration of the experience of respite; that is, caregiving itself and the caregiver's experience of respite. From the health care system perspective, the provision of respite is generally viewed as a supportive service to caregivers. Juxtaposing the caregiver orientation to respite with the health care delivery system perspective of respite, social support theory seems the most appropriate organizing framework for the literature review and the study. Social support theory addresses the issues of caregiver stress and burden and orients respite services within formal supportive networks. Therefore, the literature review reflects this theoretical orientation. The review starts with an overview of social support theory, including a discussion of the stress and burden of caregiving. Within this framework, respite is presented as a component of formal social support. The chapter concludes with a detailed review of the respite literature.

Overview of Social Support Theory

Social support is referred to as interactions between people and is seen as a multidimensional concept (Chappell, 1992) which has been of interest to researchers from different disciplines (Antonucci, 1990). A review of the major concepts of social support from these various theoretical perspectives follows.

Pearlin (1985) identifies three major distinctions within the social support concept, and differentiates between social network, group affiliation, and interpersonal interaction. According to this author, social network includes all people with whom an individual may have a contact or an exchange. Group affiliation refers only to those relationships of an individual that involve active attachment to a group. Interpersonal interaction is focused even more on relationships and includes only active affiliations that involve relationships of trust and intimacy. House and Kahn (1985), similarly, categorize social relationships in terms of social network, social support, and social integration. From their perspective, social network refers to the structures existing among a set of relationships, such as density or homogeneity. Social support refers to the functional content of social relationships, such as the emotional component or the instrumentality of a relationship. Social integration or isolation refers to the existence or quantity of relationships.

In their conceptualization of social support Cohen and Syme (1985) along with Cobb (1976) include emotional support or the feeling of being loved and cared for, information that leads to the belief of being esteemed and valued, and belongingness or a feeling of being part of a network of communication and mutual obligation. Cohen and Syme define social support more specifically as the resources provided by other people.

However, to use the concept of social support in the context of social network/structure/integration is limiting. According to Antonucci (1990), social networks, support structures, or social integration describe those people who are available to provide support but who do not necessarily do so. In other words, it is the quantity, and not the quality, of relationships that seems to be the important feature of social support.

To achieve the emotional and "belonging" perspective of social support as outlined by Cobb (1976) and Cohen and Syme (1985), a broader more functional definition seems to be needed. As well, the processes and mechanisms through which social support operates are important, particularly for intervention-based programs designed to assist the elderly in remaining as independent as possible.

Social support is important because through interactions with others, individuals develop a sense of self and value (Chappell, 1992). Antonucci (1990) states that it has a positive effect on the general health and well-being of individuals. As well, Cohen and Wills (1985) conclude from their extensive evidence that social support has a buffering effect assisting individuals to cope better, particularly in times of crises.

Therefore, in discussing social support, particularly researching intervention and policy design for the elderly, the more appropriate approaches are the ones outlined by Cohen and Syme (1985) and by House and Kahn (1985). The most salient and operational feature of social support is the giving and receiving of support either in the form of objects, services, or emotional support, be it from family, friends, or service agencies. Within social support theory these authors refer to the assistance coming from kin and friends as informal social support, while they refer to the help coming from services agencies and governments, where payment for services is involved, as formal support.

Informal and Formal Support

A. Informal Support

Support has traditionally been provided within the informal networks of family, friends and neighbours. Increasing age is associated with increases in chronic conditions and functional disability (Chappell, 1992). When health deteriorates, whether physical, mental, or both, the informal network of family and friends tends to be the first line of support (Ward, 1983).

However, with the increasing proportion of seniors in society, particularly the increase in the "old old" sector of this population, there are more demands being placed on these informal networks of family and friends as they seek to provide the support required by these seniors (Chappell, 1992).

There is evidence that the informal network is the primary source of assistance for seniors. Brody (1981) suggests that 80 percent of all care provided to elders in the United States comes from informal sources. It could be argued that this might be the result of a fragmented United States health delivery system and that the informal system is forced to "look after its own". However, Chappell (1992) reports that in Canada, despite the availability of universal health care insurance programs, the informal network continues to provide 75 to 85 percent of the total personal care provided to seniors.

Chappell (1992) indicates that within this informal network, spouses, usually wives, are the primary sources of support particularly when health deteriorates. Spouses, more than any other caregivers, are likely to provide care during periods of greater disability and illness. As well, they continue to provide care even when they themselves become disabled. Caregivers second to the spouse in frequency are children, usually daughters, especially when the spouse is no longer available. Brody (1985) reports strong filial obligations of children towards parents. Further, Chappell (1990) reports that friends and then siblings are the next most frequent source of care after spouses and children.

It is well documented that the role of caregiver can be very stressful, especially when associated with caring for a cognitively impaired person (Clipp & George, 1993; George & Gwyther, 1986; Lawton et al., 1991; Zarit & Zarit, 1983). There is growing evidence of the negative consequences to caregivers of providing care (Dillehay & Sandys, 1990; Gaynor, 1989; Gignac & Gottlieb, 1994; Novak & Guest, 1989; Robinson, 1990). These negative consequences can include deterioration of physical health, mental depression, and social isolation. As these negative aspects of caregiving have become more apparent, agencies have increasingly attempted to provide formal support services to mitigate these negative effects. More attention is being focused on the provision of support services to the informal network of family and friends by formal service agencies (Chappell, 1992). Therefore, the significance of the relationship between formal and informal support is increasingly being discussed.

B. Formal Support

The formal care system refers to governmental and non-governmental service agencies as well as to the professionals and paraprofessionals in health and other services who work for these agencies (Chappell, 1992). Government funded home care, acute and long-term care institutions, and physician services are perhaps the most significant formal support services available at present. Within this broad umbrella of services, a number of new and innovative services are being implemented to provide formal support to families. These include foster care homes for the elderly, supported living arrangements for seniors, and various forms of respite services for caregivers. Respite services are one of the newly emerging and important types of formal assistance which is particularly targeted to aid informal caregivers (Nolan & Grant, 1993).

Caregiver Burden

The recognition by researchers that the role of caregiver is stressful, especially when associated with looking after cognitively impaired persons (George & Gwyther, 1986; Mace & Rabins, 1984; Novak & Guest, 1989; Wallsten, 1993; Zarit, Todd, & Zarit, 1986; Zarit & Zarit, 1983), has resulted in a great deal of research activity focused on differentiating the stress and burden experienced by caregivers (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). This research has resulted in considerable evidence of the negative consequences to caregivers of providing care (Dillehay & Sandys, 1990; Gaynor, 1989; Novak & Guest, 1989; Robinson, 1990). In this section, an overview of the research related to caregiver burden is linked to informal and formal support.

A. Caregiver Burden and Informal Support

Dillehay and Sandys (1990) define burden as the psychological state resulting from combinations of physical work, emotional pressure, social constraints, and financial demand accruing because of patient care requirements. Numerous factors contribute to the burden experienced by caregivers. In a descriptive study of a group of 89 spousal caregivers, Barusch (1988) concluded that the most prevalent problems involved the cognitive aspects of caregiving. Frequently expressed concerns were: grief over the loss of the spouse they once had; worry about their own health; anxiety about the future; depression and loneliness; and physical difficulties of performing certain tasks. Wilson (1989) found, in a constant comparative study of 20 caregivers of Alzheimer persons, that the caregiving experience consisted of coping with negative choices wherein all possible alternatives were undesirable.

In a comparative study of 21 caregivers and 20 non-caregivers, Wallsten and Snyder (1990) found that, even under unusually stressful conditions, a buffering effect from positive experiences was found in the non-caregiver group but not in the caregiving group. They also indicated that the negative impact of caregiving permeated and influenced every aspect of daily life. It even seemed to affect the immunological functioning of the body. This is similar to the findings of Dorian and Garfinkle (1987). In their short-term longitudinal study, family members who care for people with Alzheimer's disease were shown to have reduced total T lymphocytes and higher antibody titre to Epstein-Barr virus than did matched non-caregivers.

Further, caregivers experience stress and burden in a number of different spheres. Schene (1990) differentiates between objective and subjective burden. Objective burden is the symptoms and behaviour of patients within their social environment and the consequences of these behaviours. Subjective burden relates to the psychological consequences of these behaviours to the family and/or caregivers.

However, this differentiation does not seem adequate when the extent of caregiver burden is recognized. The distress that family caregivers experience can manifest itself psychologically, physically, socially, and financially (Brodaty & Hadzi-Pavlovic, 1990; Levine & Lawlor, 1991). Brodaty and Hadzi-Pavlovic (1990) further point out the isolation experienced by the caregivers in their study. These authors suggest that possible explanations for this isolation are: the clinging dependency of patients which inhibits the caregivers' ability to socialize; problems such as incontinence and immobility which impose practical limitations; financial constraints resulting from the illness; demoralization of caregivers; anxiety and guilt in the caregivers; increasing difficulties in transporting the dependent family member; and social stigma and embarrassment from family and friends.

To Pallett (1990), caregiver burden is a multidimensional rather than a unidimensional phenomenon as might be suggested by the works of such authors as Zarit (1980) and Kosberg, Cairl and Kellor (1990). In supporting the multidimensionality of caregiver burden, Novak and Guest (1989) suggest that the measurement of caregiver burden should include such factors as time dependency, developmental burden, physical burden, social burden, and emotional burden. They defined time dependency as burden due to time restrictions; developmental burden as feelings of being out of step in their development compared to their peers; physical burden as feelings of chronic fatigue and damage to their health; social burden as feelings of role conflict; and emotional burden as negative feelings toward their dependent family member. It seems that this broader definition of caregiver burden is a more realistic approach in recognizing the complexity of the caregiver burden concept.

It is suggested by some, that caregiver burden is experienced differently by women and men (Borden & Berlin, 1990; Harper & Lund, 1990; Zarit, Todd, & Zarit, 1986). Men generally report lower levels of psychological distress or burden than do women. Zarit et al. (1986) state that the husbands in their study appeared to have a greater tolerance of memory and behaviour problems than the wives. Harper and Lund (1990) indicate that women are especially influenced by their own general outlook on life (life satisfaction) and the dementia behaviours pertaining to lack of orientation and affect or change in personality. Men seem less burdened with affect but have difficulty with the activities of daily living, lack of orientation, and the conflicting demands on their time.

Borden and Berlin (1990) interpret these differences from a developmental socialization perspective. Women, they say, are encouraged to value intimate relationships and may define themselves in terms of these relationships. Men, on the other hand, are expected to be more self-reliant, independent, and more activity-focused in their relationships. Zarit et al. (1986) also suggest that men might under-report and women might over-report their subjective burden, again following from a developmental socialization perspective. Such patterns of socialization throughout the development of a person, may lead to different perceptions of the family members' illness and the caregivers' situation within the illness experience.

B. Caregiver Burden and Formal Support

An important relationship exists between formal support and the burden experienced by caregivers of dementia persons. According to Zarit et al. (1986), it is the caregivers' feelings of burden that are associated with long term institutional placement. A number of authors have stated that the behavioral and cognitive changes in dementia persons do not have the same impact on all caregivers (Borden & Berlin, 1990; Harper & Lund, 1990; Novak & Guest, 1989). For example, the severity of the demented person's cognitive impairment, their inability to perform daily tasks, or the length of time caregivers have been giving care does not adequately predict the caregivers' sense of burden (Novak & Guest, 1989; Zarit, et al., 1980). Rather, it is the caregivers' social supports, their subjective perceptions of caregiving, and their feelings of life satisfaction which more closely reflect feelings of burden (Grant & Nolan, 1993; Haley, Levine, Brown, & Bartolucci, 1987; Harper & Lund, 1990; Novak & Guest, 1989; Robinson, 1990; Zarit, Todd, & Zarit, 1986). And it is the caregivers' subjective experience of strain or burden together with the behaviour of their demented family member that predicts increased dependence on the formal system or institutionalization of that demented person (Dillehay & Sandys, 1990).

In their study of 109 older caregivers, Brown, Potter and Foster (1990) found that caregiver burden was a major factor in the decision to institutionalize the dementia victim. However, in other studies no statistically significant difference in burden between caregivers of institutionalized and non-institutionalized dementia persons has been found (Harper & Lund, 1990; Pratt, Wright, & Schmall, 1987). Pratt, et al. (1987) also suggested that although the overall burden score was not shown to be significant statistically, the sphere in which the burden was experienced differed. The caregivers who had institutionalized family members scored lower on social burden but higher on guilt and time spent visiting their relative. Stephens, Kinney, and Ogrocki (1991), in attempting to explain this lack of difference in overall burden experienced by the two groups, have suggested that the distress mitigated by the nursing home placement was of a social nature only, whereas, emotional factors played an important part in the overall experience of caregiver burden.

A key issue in the area of formal support mitigating caregiver burden, is the uncertainty about the effectiveness of programs designed to provide support to family caregivers (Oktay & Volland, 1990). The unease in the formal support system seems linked to the fear of uncontrolled and escalating costs, particularly when the perceived outcomes of formal support programs are not clearly understood (Chappell, 1992). And, as will be discussed in the next section, when programs in the formal system designed to assist caregivers, such as respite, have been evaluated, their effectiveness has not been clearly established.

Another concern is that the availability of formal support services will discourage the provision of informal care by family and friends, thus further enhancing the use of expensive formal services by the elderly (Chappell, 1992). Examining the relationship between informal and formal support from a utilization perspective is a useful way of exploring this concern in greater detail. It is recognized that the elderly generally resist the use of formal support, preferring instead their immediate family (Litwak, 1985). For example, respite is one of the services most frequently requested by informal caregivers and caregivers themselves have named it as a top priority (Fortinsky & Hathoway, 1990; Lawton, Brody & Saperstein, 1991; Riggs, 1991). Yet, the utilization of available respite services by caregivers remains low (Kosloski & Montgomery, 1993; Lawton, Brody, & Saperstein, 1991).

There is also much concern that the continuation of caregiving by family and friends is threatened because of caregiver "burn-out," if formal support is not made available (Chappell, 1992). But, there is a continuing concern about the lack of clarity of formal program outcomes and a worry about over-dependence on the formal system by informal caregivers. In attempting to resolve these issues, this author has suggested a complementarity between formal and informal care. The relationship between these two components is not one of substitution but rather one of judicious use of formal services to complement the informal care. The formal services can effectively increase or prolong the caregiving contributions of the informal network. This is both a humane and an economic approach to the families' stresses in caring for their dementia family member.

Linked to this concept of complementarity between formal and informal support services are caregivers' knowledge and understanding of the services available to them. There is some evidence that the caregivers' ability to mobilize formal support services counters institutionalization (Archbold, 1980). Keating and Warren (1988), in their study of 70 caregivers of dementia persons, indicate that the most important predictor of the length of time a dementia family member stays at home, is the number of formal services used by caregivers, particularly home care. This seems to indicate that the use of formal support services does have some influence on the ability of caregivers to continue in that role.

Recently, the issue of providing formal care to informal caregivers has received increasing recognition. Respite is one of the most prominent of such formal services (Nolan & Grant, 1992). As indicated previously, while it has been the most frequently requested by informal caregivers and has been named by caregivers themselves as a top priority (Fortinsky & Hathoway, 1990; Kosloski & Montgomery, 1993; Lawton, Brody & Saperstein, 1991), use of respite services generally remains low (Gonyea, Seltzer, Gertsein, & Young, 1988; Lawton et al. 1991). These authors suggest that the very system providing the service was also a major barrier to the use of that service. For example, Lawton, Brody and Saperstein (1991) state that respite services seem fragmented with each program having its unique features, making it difficult for caregivers to appropriately gain access to the service. Kosloski & Montgomery (1993) also stated that both the caregiver perceptions of the usefulness of respite and the convenience of respite service were found to have significant direct effects on the level of actual respite use. As well, Gottlieb and Johnson (1995) and Strang, Greschuk, McIlveen, and Gadez (1992) suggest that perhaps caregivers use respite services, such as adult day care programs, as a last resort rather than as assistance designed to prevent or alleviate their own stress. The caregivers are therefore not able to experience the full benefit of the service. Chappell (1992) outlines other reasons linked with low utilization. These include the deterioration of some elderly when relocated to respite, the cost associated with respite, and the general lack of information about the availability of the service. From Archbold's (1982) and Keating and Warren's (1988) work, it seems that caregivers might use formal supports more if they were more informed about them.

C. Summary of Caregiver Burden, Informal and Formal Support

It is apparent that caregiver burden and stress is extensive, particularly when associated with the informal caring for dementia family members. There is some suggestion of a gender difference in how caregiver burden is experienced. There is evidence of the destructive influence of ongoing burden and stress on caregivers. Yet the primary caring for family members with dementia continues within the informal networks of family and friends.

As well, there is a recognition of the need to provide formal supportive services to caregivers. Yet, there remain continuing concerns about over-dependence by caregivers on the formal system resulting in high costs to the system, a lack of clarity in formal support program outcomes, and low utilization patterns by caregivers when services are offered. Different authors offer a number of explanations about the persistence of these concerns. These include discontinuous, fragmented, inconvenient and costly service delivery patterns; less than adequate services resulting in the deterioration of dependent family members; lack of caregiver knowledge about gaining access to available services; and using services as a last resort by caregivers so that the full benefit of the service is not experienced.

It is evident that little is known about the formal provision of supportive services to informal family caregivers, although there is agreement that it is required. Although respite is being recognized as one of the most prominent of formal services for caregivers, there remains a confusion about how it should be provided, what its specific benefits are and why caregivers might use it.

Respite

In this section, the literature on respite will be explored in three sections to demonstrate further the confusion in this area. First, the existing definitions of respite will be discussed; second, the various models of respite will be outlined; and third, the impact of respite will be examined from the caregivers' perspectives, the dementia persons' perspective, and their joint perspectives.

Defining Respite

Respite, despite its apparent simplicity, has eluded specific definition. According to Montgomery (1992), the ambiguity associated with it has been related to the almost total lack of agreement on the types of services that are to provide this relief. Crossman, London, & Barry (1981), in very general terms, indicate that respite is any service which provides intervals of rest and relief for caregivers. Berman et al. (1987) and Seltzer et al. (1988) state that respite is the temporary supervision or care provided to disabled or ill persons, specifically to relieve their primary caregivers. Lawton, Brody, and Saperstein (1991) describe respite as a service or group of services that provides caregivers with temporary periods of relief and rest away from the care of their dementia family member. Chappell (1992) simply states that respite is 'time off' from caregiving.

These definitions are oriented to the provision of respite service and include two common themes; short periods of caregiver time away from caregiving related activities and, by implication, short-term separation of caregivers from the care receivers. As well, there is an underlying assumption that 'time away' equals respite. Based on their evaluation studies of adult day care programs, Strang and Neufeld (1990) and Strang et al. (1992) argue that respite needs to be more specifically defined. These authors indicate that the definition of respite should extend beyond the service orientation of these themes and assumptions to include the caregivers' perceptions of what respite means to them. For example, these authors suggest that respite might mean reduced feelings of guilt by caregivers and that if the caregivers do not perceive improvement in their situation as a result of using a respite service, then that experience or that service is not respite to them.

Montgomery (1992) implicitly includes caregiver perception in her brief statement that the essential element of respite is to provide rest for the caregivers. But, Montgomery does not state what this "rest" means to caregivers and when they might be experiencing it. This caregiver orientation to the definition of respite seems to be a step in the right direction. It requires expansion to include the caregivers' perspective more fully.

Models of Respite

Montgomery (1992, 1995) states that there are generally three service models of respite which are linked to the dimensions of time, place, and level of care. The most basic dimension is the location or setting in which the service is provided. Services can be provided in the client's home: examples include sitter services or additional "respite" hours of the home care homemaker's time in the home. Respite can also be provided out of the home in such community group settings as adult day care programs. Institutional group settings, too, can provide respite services with such programs as day hospitals or short-term vacation institutional placement. Respite can also occur in multiple settings with a mixture of different types of services.

In addition to the variation in the location of respite services, there is variability in the intensity/frequency and in the type of the services provided (Montgomery, 1992). The frequency of the service can range from hourly or daily to weekly or monthly. The intensity of the service can range from a few hours per day, week or month to a short period of full time twenty-four hour service. Respite services can include short periods of full-time institutionalization such as the placement of family members while caregivers are on vacation. The various respite services can also provide differing levels of care ranging from the simple provision of custodial care to the provision of sophisticated multi-disciplinary rehabilitative services. The frequency and type of services used usually depend on the family situation, the family's perception of the need for respite, and the resources available to them.

In summary, these models all reflect the formal support service perspective. There seems to be no provision for the inclusion of the caregivers' perspective of their actual experience of respite in these models. There needs to be a differentiation between respite provided as services by the formal support system and how respite is actually experienced by the family caregivers. It would seem more appropriate to develop a model of respite to include the family caregivers' perceptions of that assistance, rather than assuming that what is provided by the formal support system will automatically ensure respite.

The Impact of Respite

Examining the impact of respite services on the caregivers is a relatively new focus of research. Nevertheless, studies can be grouped broadly around the impact of respite on three relationships. These include the impact of respite from the perspectives of caregivers, or dependent family members, or from both.

A. Respite and Caregivers

Research findings have indicated a mixed response to the impact of respite services on caregivers. The most pervasive findings are that caregivers like the service and are generally satisfied with it (Larkin & Hopcroft, 1993; Montgomery, 1995). When more specific measures of caregiver outcomes, such as caregiver burden or depression, are used the impact of respite seems unclear.

Lawton et al. (1989), using a randomized control group experimental design, with a sample size of 632 families, found that a one year program of respite services resulted in families maintaining their dependent relative significantly longer in the community. The treatment subjects stayed at home 22 days longer than did the control subjects in the one year interval of the study. Although this is a statistically significant finding, the clinical and practical impact of this finding seems minimal. Additionally, in the same study, there was no significant difference in such broad outcome indicators as caregiver burden or caregiver mastery. Overall, however, the caregivers' general satisfaction with respite and perception of "improved quality of life" were high.

In another randomized trial of family caregiver support program in the home management of dementia (Mohide, Pringle, Streiner, Gilbert, Muir & Tew, 1990), with a sample size of 60 families, no significant change was demonstrated in depressive symptomatology and anxiety scores as measured by the Centre for Epidemiologic Studies Depression Scale and the State-Trait Anxiety Inventory. However, quality of caregivers' lives, as measured by the Caregiver Quality of Life Instrument, improved in the experimental group receiving supportive interventions to enhance caregiver competence and sense of control in their caregiving role. Quality of life decreased in the control group who were offered conventional community nursing resources (did not include respite services) which focused on the care of persons with dementia rather than on caregivers. Although the 20 percent difference in scores between the two groups could not be shown to be statistically significant due to the size of the initial sample (n=60) and attributes of the subjects, it is considered by these authors to be clinically important. They argue that, considering the changing demographic patterns, aging of the population, the research to date, and no prospects for an imminent cure for Alzheimer's disease, support for caregivers of demented family members continues to warrant considerable attention. If caregivers can feel supported while they maintain their family member at home they might be more inclined to continue in that role. Consequently, they concluded that institutionalization could be postponed which, in turn, could benefit the health care system.

Wells, Jorm, Jordan, and Lefroy (1990), in their study of 219 caregivers of dementia persons using a special day care program, indicated that adult day care did not relieve the considerable psychological distress of caregivers. However, the program did have the effect of providing the caregivers with time for themselves.

Deimling (1991) examined the impact of a respite program by interviewing 78 caregivers of dementia persons twice with a four to six month interval between interviews. This study indicated that the respite program seemed to reduce depression, reported health problems, and family relationship strain in stable caregiver situations. However, in unstable situations, where the dependent family member's cognitive ability was declining rapidly, respite had no stabilizing effect on these same variables.

Skelly, McAdoo, and Ostergard (1993), in an evaluation of a veterans in-hospital respite program, explored whether the program reduced the caregiver burden of caregivers of dementia persons. With a sample size of 16 caregivers, there was some evidence that the program reduced caregiver burden related to the memory and behaviour problems associated with caring for dementia persons. As well, Conlin, Caranasos, and Davidson (1992), in a 10 week study to determine whether providing respite would decrease the stress and mood disturbances of caregivers of dementia persons found, with a sample of 15 caregivers, that there was a downward trend of stress levels. The Relative's Stress Scale and the Profile of Mood States were the measures used in the study. The only change in the mood disturbance measures occurred in the confusion-bewilderment mood category. In both these studies, the respite intervention was not strongly associated with positive caregiver benefits.

B. Respite and the Dementia Person

When the impact of respite services is examined from the dependent family members' perspective using such outcome indicators as delayed institutionalization, use of health services, functional ability, and the dependent family members' quality of life, the results continue to be inconclusive. In a randomized controlled trial of a day hospital program, with a subject sample of 113 elderly clients, Eagle, Guyatt, Patterson, Turpie, Sackett, and Singer (1991) found the care received at the day hospital did not improve the functional status or quality of life of elderly patients as compared to the control group who received regular outpatient geriatric care. The Barthel Index was used to measure the functional status while the Geriatric Quality of Life Questionnaire was use to measure quality of life. In contrast, Hirsch, Davies, Boatwright and Ochango (1993) found a statistically significant decline in self-care and general behavior in 39 dementia clients admitted for about two weeks to a California institutional respite program. Fourteen days after their return home, however, most had regained their pre-respite functioning levels. The clients' self-care behaviour was measured using the Functional and Behavioural Scale for Advanced Dementia. Their mental functioning was measured using the Folstein Mini-Mental State Exam and they received a physical examination by a physician. In both studies, no attempt was made to measure the impact of the respite service on the caregivers.

Further, Seltzer et al. (1988), in their study of 37 dementia clients using a two week in-hospital respite program, found that their cognitive and functional status had changed, depending on their pre-respite functioning status. Clients with the poorest status tended to show slight improved functioning at the end of the respite period while clients with higher initial levels of performance tended to show slight decline in functioning. These authors concluded that the respite program had little effect on client status and that respite is generally a harmless intervention.

In a similar vein, Chappell and Blandford (1987), in a longitudinal study with 562 subjects, examined the impact of adult day care programs on program participants and found that adult day care programs initially made no difference in the utilization of health care services by participants. However, they argued that, after the day program had been operative for some time, it might lead to dramatic decreases in hospital inpatient stays. Harder, Gornick, and Burt (1986), in a United States survey of adult day associations in 19 states, found that these programs seemed to improve the health and functional ability of participants slightly but did not delay their rate of institutionalization. Adult day care programs were seen by these authors as an "add on" to the health care system rather than as a delaying strategy for long-term care placement. In both studies no comment was made on the impact of adult day care programs on family caregivers.

C. Respite, Caregivers and Dementia Persons

In studies focusing on both the dementia person and caregiver outcomes, similar mixed results continue. Panella, Lilliston, Brush, and McDowell (1984), in an evaluation study of an adult day care program for persons with dementia, indicated that respite, or relief, was the greatest benefit derived by caregivers from the day program. The participants in the program, however, continued to show progressive decline in physical and mental functioning. Sands and Suzuki (1983), in examining another adult day care program, indicated that families consistently reported gaining relief and their family member showing marginal improvement in cognitive functioning.

Burdz, Eaton, and Bond (1988), in their study of 55 Manitoba caregivers, found a positive effect for both the caregivers and their dementia family members from a two week institutional respite intervention. The dementia clients showed significant improvement in functioning as reported by their caregivers. The caregivers indicated that they also benefited from the respite program. However, when asked more specifically, they indicated their situation had not changed or, indeed, had worsened. However, in a subsequent longitudinal study of 33 caregivers and their dependent family members examining the impact of nursing home respite on both the caregivers and the dementia persons, Burdz (1991) found no significant improvement in the psychological functioning of the caregivers although the patients' functional status seemingly was unaffected by the nursing home respite intervention.

Scharlach and Frenzel (1986), in their evaluative study of a California institutional respite program, found positive outcomes for both the dementia clients and their family caregivers. In their survey of 99 primary caregivers of dementia persons, the caregivers reported that respite contributed to improved physical and mental health, better relationships, and increased confidence in their ability to continue in the caregiving role. The caregivers also reported that the care recipients did not suffer significantly as a result of the disruption caused by their temporary placement in an institutional setting.

Further, Strang and Neufeld (1990) indicated, in their evaluative study of a small adult day care program, that, although the relief of burden experienced by the caregivers was minimal, it seemed to sustain the caregivers in their role. Client physical and mental functioning was maintained for a three month period and many of the caregivers stated their relative had improved and was easier to care for following admission to the program. The caregivers also indicated a feeling of reduced guilt as a result of having their family member attend the day program.

In the subsequent evaluative study of the same adult day care program, Strang, Greschuk, McIlveen, and Gadacz (1992) again found that participant physical and mental functioning was maintained in a three month time period and that there was some evidence the program provided respite to the caregivers. These authors suggested that the impact of the program seemed to be at the "living from day to day level" of caregiver functioning. The program gave caregivers time to themselves and to do chores they otherwise could not do. And again, it helped to reduce feelings of guilt in relation to their caregiving role. As well, there was a high degree of caregiver satisfaction with the program. These findings are congruent with the findings of other studies (Adler, 1992; Gottlieb & Johnson, 1995). Finally, Strang et al. (1992) found that, rather than delaying institutionalization, the day program in their study seemed to act as a "bridge" to long term care placement. It seemed to reduce caregivers' hesitancy in considering placement as an alterative in their situation. This is congruent with the conclusions drawn by Scharlach and Frenzel (1986) in their evaluative study of an institution-based respite program and by Gottlieb and Johnson (1995) in their evaluative study of 16 Ontario adult day care programs.

Larkin and Hopcroft (1993), in a survey study with 22 caregivers and 21 dementia patients, examined the influence of a hospital respite program in moderating caregiver stress. The caregivers were interviewed three times: first, three days before respite admission; second, three days before respite discharge; and third, 14 days after respite discharge. The respite time interval was a two week stay in a dementia unit of a veterans hospital. There was significant evidence of stress reduction at the second time interval. However, the stress reduction effects did not seem to be sustained. Although overall caregiver stress was lower two weeks post-respite (T3) as compared to pre-respite, the score at T3 was not statistically significant. The respite service, however, seemed to have a negative impact on the dementia persons in the study; the functioning levels of 58 percent of the dementia persons were judged by their family caregivers as having remained the same or had deteriorated. As well, 35 percent of the dementia persons experienced negative health consequences during their time in hospital and within 30 days of their in-hospital respite experience 38 percent had been admitted to a long-term care facility. The overall conclusions drawn by these authors were that the benefits of hospital respite for caregivers was short-lived and that in-hospital respite presented particular risks for patient decline and institutionalization. Again, this is congruent with Strang et al. (1992) and Scharlach and Frenzel (1986).

Gottlieb and Johnson (1995), in an evaluative study of 16 adult day programs in southern Ontario, examined the impact of adult day programs on family caregivers. After an average of five months of day program use, the caregivers reported significantly less global stress and less emotional distress. There was no change in their life satisfaction or self-reported physical health, however. The day programs seemed to provide temporary sanctuary from the tensions and responsibilities of caregiving. Caregivers' satisfaction was highly related to their perception that the program benefited their relatives; that is, their well-being was closely tied to their relatives' well-being. In examining the impact of the day programs on dementia persons, the programs appeared to be a stepping stone to long-term care placement.

Alternatively, Homer and Gilleard (1994), in a prospective study of 58 patient/caregiver pairs using inpatient respite services, examined the immediate effect of respite admission on caregivers and their dependent family member. The disabilities of the patients included non-dementia as well as dementia conditions. These authors found no observable improvement in the caregivers' emotional well-being. The dependent family members, on the other hand, showed improvement in both physical and social functioning. The caregivers, again, felt that the respite had been worthwhile and expressed a wish for more respite services.

D. Summary of the Impact of Respite

In summary, the main benefits of respite programs identified in the research are that of providing caregivers with time for themselves and with helping them feel better and less guilty about their daily situation. It seems to help them manage their daily life a little better. However, even in this area there are discrepant findings. Berry, Zarit, and Rabatin (1991) indicated that women caregivers who used day care respite services spend more time performing caregiving activities on respite days than on non-respite days. Generally, there is evidence that respite reduces caregiver burden or depression only slightly and that this slight effect might not continue. As well, there is inconsistent evidence that respite delays institutionalization. In fact, there seems to be a theme that institutionalization is facilitated by respite services.

For the dependent family members, the benefits are even less clear. Some studies indicate marginal improvement or maintenance in client functioning while others indicate continuing decline. The impact of respite on family caregivers and their dependent family members remain unclear. Such broad indicators as caregiver burden, caregiver depression, and delayed institutionalization have not adequately measured the impact of respite to date. This conclusion is supported by Knight, Lutzky, and Macofsky-Urban (1993) in their meta-analysis of the literature on caregiver intervention programs.

Summary of Literature Review

In summary, social support theory is the most relevant theory and appropriate framework for the review of the literature because it addresses the issues of caregiver stress and burden and it orients respite services within formal support networks. This theory is also appropriate because it includes a differentiation of informal and formal support. Within this framework the discussion of the stress and burden of caregiving becomes incorporated into the informal dimension of social support while respite becomes a component of formal social support. In examining the relationship between caregiver burden and both informal and formal support, the destructive influence of caregiver stress, particularly when associated with the informal caring for a dementia family member, becomes apparent. To counter these destructive influences, the literature recognizes the need to provide formal supportive services to caregivers and identifies respite as a prominent example of this type of service. There is confusion, however, about how this respite should be provided, what its specific benefits are and why caregivers might use it.

The literature on respite reveals the conceptual disorder in the definitions and models of respite and predominantly reflects the formal support service perspective. There is little or no provision for the inclusion of the caregivers' perspective of their actual experience of respite in these definitions and models. Further, in the literature relating to the impact of respite on caregivers, there is only slight evidence that respite reduced caregiver burden or depression and there is inconsistent evidence that respite delays the institutionalization process of the dementia person. The impact of respite on dementia persons is even less clear, with some studies indicating marginal improvement or maintenance in client functioning while others indicate continuing decline. The impact of respite on family caregivers and their dependent family members also seems unclear because the indicators used to date have not adequately measured how respite is experienced by either caregivers or their dependent relatives.

To conclude, the formal system orientation to the phenomenon of respite needs to be countered by a representation of respite as it is actually experienced by the family caregivers. As well, there is a need to clarify the conceptual disarray demonstrated in the literature review. It is essential to develop a conceptualization of respite which includes the family caregivers' perceptions of that service. Continuing research must challenge the assumption that if the formal support system provides respite then caregiver respite will automatically result. Therefore, given the inconclusive results to date, the apparent logical approach is to ask the caregivers themselves how they experience respite. Through the insights gained from listening to their experiences and by the mutual validation, by both the researcher and the caregivers, of the essential components of respite in their stories, a more appropriate conceptualization of respite can be achieved.

Chapter 3

RESEARCH METHODS

As is evident from the literature review, there is confusion and lack of conceptual clarity regarding respite. In particular, the descriptions of caregiver experiences have not been collected to help inform the concept. The purpose of this study, therefore, is to explore the experience of respite from the perspective of family caregivers of dementia persons and to gain an increased understanding of what respite means to them. Through this exploratory process, a third purpose is to formulate a theoretical conceptualization of the experiential understanding of respite from the family caregivers' perspective.

Hence, an exploratory, qualitative study, based on interpretivist principles, was selected as the most appropriate methodology to conduct this research study. This method provides the caregivers with the opportunity to freely describe and interpret their experiences, insights, and understandings about respite. From their descriptions, the experiential components of respite and the relationships within these components were constructed through the use of two methods associated with interpretivist enquiry: grounded theory and narrative study. In the following section, the assumptions underlying this methodology are presented.

The Interpretivist Research Orientation

The interpretivist research orientation has its roots in symbolic interactionism, a theoretical orientation which arose out of the sociological works of Cooley, Mead, and Thomas (Spradley, 1980). According to this author, there are three fundamental assumptions on which this theory rests: human beings act toward things on the basis of the meanings that the things have for them; the meaning of such things is derived from, or arises out of, the social interaction that one has with others; and, meanings are handled and modified through an interpretative process used by persons dealing with things they encounter (pp.8-9).

More recently, Guba and Lincoln (1994) and Schwandt (1994), building on these foundational premises, indicate that within the interpretivism orientation, knowledge is generated from a subjective and dynamic uncovering of individual meanings and the human experience. The aim of this enquiry approach is to understand the actions of individuals and the meaning that they attribute to those actions. Therefore, from this perspective, reality is subjective and multiple. The generation of new understandings are based on the empathic understanding by the researcher of how individuals make sense of their world. These authors further state that the reality of life is seen as value laden and context driven and the process of research cannot be separated from this life reality it is seeking to illuminate. Therefore, from the interpretivist perspective, research is value laden and context driven to include the informants' value orientations and the acknowledgement that the researcher's values also influence and filter perceptions of the research process.

Further, with an interpretivist orientation to the research process, the relationship between the researcher and the informant subject cannot be separated. They are co-dependent and influence each other in the gathering and interpretation of the data. From the interpretivist way of knowing, theory and the reality of practice, in whatever context, are strongly connected; practice is changed, enhanced, and reinforced by gaining new insights and changing the ways in which phenomena are understood.

There are five major reasons why the interpretivist orientation was selected to guide the research methods in this study. As indicated earlier, there is confusion and lack of conceptual clarity in defining respite. Initially, social support theory, the only theory with seeming relevance, provided a broad unifying framework from which to conduct the literature review. However, when the review of the respite literature was completed, the lack of conceptual clarity became readily evident. As well, the formal social support service perspective seemed to dominate this literature. Therefore, to begin the process of illuminating respite more fully and with greater relevance to caregivers of dementia persons, the interpretivist perspective seemed the logical choice to guide the research methods of this study.

Another reason for choosing the interpretivist research orientation was the nature of the research questions being asked in this study (Strauss & Corbin, 1990). All the questions were exploratory in nature. They focused on how caregiving is experienced and how respite is perceived within that experience. They sought the meaning of respite for the caregivers and descriptions about the differing realities within the caregiving experience. They were informed from my perspective, as the researcher, and since I wanted to gain an empathetic understanding of how caregivers experience respite, I needed to become partners with them in the exploratory process of identifying the essential elements of their experience of respite. Together the caregivers and I needed to reflect about the nature of respite and its meaning to them. Given this relational alignment, the interpretivist research orientation seemed the most suitable philosophical stance for the study.

Finally, the study of how caregivers experience respite is highly process oriented. To explore how the process of respite is experienced within the overall context of the caregiving situation requires a method which goes "with the flow". The interpretivist orientation allowed me to engage in this type of fluidity and openness within the data collection process (Guba & Lincoln, 1994). The open ended and in-depth interviewing methods associated with this enquiry orientation, best captured the dynamic nature of how respite is experienced by caregivers of dementia persons.

Within the interpretivist research orientation different methodological approaches can be used. In this study two distinctive approaches were used. These included grounded theory and narrative study.

Methods

Grounded Theory

The methods of grounded theory, while incorporating the basic assumptions of interpretivism with its rich contextual descriptions, direct researchers toward the inductive generation of theories which explain human actions. Therefore, grounded theory methods are directly associated with developing substantive theory (Strauss & Corbin, 1990). It was designed to guide researchers in producing theory conceptually dense, that is, with many conceptual relationships and identifying patterns of action and interaction between and among the various components of the phenomenon under study. Theory evolves during the actual research process and is achieved through the continuous interplay between analysis and data collection, a process referred to as the constant comparative method of grounded theory (Strauss & Corbin, 1994). In this constant comparative method, researchers are engaged in inductive analysis in order to discover the processes and patterns within social interactions and situations. Specifically, researchers search for and examine the reciprocal changes in patterns of social actions and/or interactions and the relationships within and between the changing conditions, either internal or external to the social process itself (Strauss & Corbin, 1994).

Within grounded theory the number of participants or informants in a research study are determined through the process of theoretical sampling (Strauss & Corbin, 1990). With this sampling approach, the actual sample size is not set in advance of the study. Rather, the sample size is determined as the study is being conducted by: the number of data categories emerging from the data, the saturation of these various categories, and the emerging, although primitive theory (Strauss, 1987). Further, the data analysis processes of grounded theory include the procedures of coding, memoing, and integrative diagramming.

Coding is the process of identifying and labeling the properties of a situation, spoken word, or event. Strauss and Corbin (1990) differentiate between substantive and theoretical coding. Substantive codes are the beginning elementary steps toward theory and form the initial conceptual organization to the data. However, as the analysis progresses, and as new ideas and relationships between and among the data become apparent, these beginning codes become obsolete and are replaced by new and more theoretical codes. As subsequent data are collected these more theoretical codes then dominate the analysis. As the analysis continues towards its completion, the theoretical codes become more complex and conceptually dense.

Strauss (1987) states that, in the increasingly complex theoretical coding process, the procedure of memoing becomes a useful analytical tool. Memoing is the process of registering, in some fashion, the ongoing analytical thinking of researchers. Memos include the noting of new ideas, beginning relationships among themes, and glimmering insights as researchers work with the data. As with coding, memoing becomes more complex as larger volumes of data become available and as the density of the theoretical concepts increases. Eventually, the memos focus on the emerging major thematic categories of the data and their relationships with each other.

At this point, says Strauss (1987), researchers start finding integration useful. Integration is the process of bringing all the cumulative analyses together to form an integrated theoretical whole. Similar to coding and memoing, this integrative process starts with the identification of simple conceptual relationships but, as the analysis progresses, there is a gradual but ever-increasing articulation of the components of the emerging theory. The integrative diagram, where researchers outline the tentative conceptual relationships of the theory graphically, is a useful tool in this process. Coding, memoing and integrative diagramming within the constant comparative grounded theory methods evolve the data toward analytic completeness and unity. The conceptually dense theory is the end product of these analytic processes.

The strength of grounded theory methods exists in the specificity of its analytical procedures and its search for relationships between themes and concepts within the data. However, in its constant comparative search for patterns, themes and relationships and with its relentless thrust toward theory generation, the distinctive nature of individual informants and their particular social circumstance are lost. Grounded theory seems to have a formalistic and reductionistic tendency where the experience of the individual seems obliterated (Clandinin & Connelly, 1994). In grounded theory, the search for common themes and the relationships between them seem to be emphasized. In the process of attempting to understand the similarities within the data, it is the collective meaning of informant experiences which seems to be achieved. The uniqueness and the "differentness" of each informant's story is ignored. However, if the interpretivist research orientation is to be maintained, that is, if the subjective and dynamic uncovering of individual caregiver's meanings and experiences of respite are to remain paramount, then additional methods should be used in tandem with grounded theory. The dilemma in this study was to remain true to the uniqueness of the individual caregiver experiences and also to achieve some theoretical wisdom about their respite experiences so that clarification of the confusion in the respite area could be attempted. In this study, the narrative enquiry approach to analysis provided the answer to this dilemma.

Narrative Study

Connelly and Clandinin (1990) state that the processes of narrative inquiry seek to keep the individual experience in the foreground. They state that the fundamental quality of the narrative method is its ability to represent the individual human experience holistically. As well, persons relate their own experiences, not by merely recording the experience over time in a linear manner but by talking about these experiences in story form. The telling of these experiential stories has components of the raw sensation of the experiences themselves, but also includes cultural interpretations. Therefore, state Clandinin and Connelly (1994), because of this blending of raw experience with cultural context, people live stories and in the telling of them reaffirm them, modify them, and create new ones. The story, they say, is the closest proximity the researcher can get to the actual experience of the informants.

One of the most widely used methods of generating the data for narrative enquiry, called field texts by Clandinin and Connelly (1994), is interviews. These interviews are turned into field texts through transcription, note taking, and the selective use of interview segments. Therefore, what is told, as well as the meaning of what is told, is shaped by the relationship between the researcher and the informant within the interview process, state these authors. As well, the focus in this data generation method, as it seeks to illuminate personal experience, can simultaneously be oriented in four directions: inward and outward, backward and forward. The inward focus refers to the exploration of internal conditions of feelings, hopes, and reactions, while the outward focus refers to examination of external or environmental conditions related to the story. In the backward and forward approaches, conditions of temporality related to past, present and future are explored (p. 417). In this inward/outward and backward/forward analyses of the field texts of narrative enquiry, the components and themes within one informant's story are scrutinized and identified. In this way, the integrity of that individual's story is retained within the research process.

The uniqueness of the stories about the informant experiences as caregivers and how respite felt within those experiences was evident throughout this study. Each caregiver story was different and each story was told from within the cultural experience of that caregiver. The distinctiveness of these stories will be specifically demonstrated in Chapter 4. The inclusion of these narrative methods added a richness to the analysis process and gave credence to the individual and unique caregiver stories of this study.

Embedded in the unique stories of the caregivers in this study were many similarities. Including both narrative and grounded theory methods in the study provided a forum to demonstrate the distinctive nature and the contextual richness of the caregiver stories. It also allowed the search for common themes and relational patterns between and among the different caregivers' experiences of respite which was necessary in order to illuminate more clearly, theoretically, the concept of respite.

Procedures

Selection of Participants

The number of participants was determined through the process of theoretical sampling as outlined by Strauss & Corbin (1990) with the actual sample size not set in advance of the study. Rather, the sample size was determined as the study was being conducted by the number of data categories emerging from the data and saturation of these various categories. Sampling was concluded when no new categories emerged from the data and the identified categories in the data analysis were saturated. In this study, ten volunteer caregivers of dementia persons were interviewed.

I made requests for the caregiver volunteers through existing voluntary self-help groups, other informal community connections and various home care agencies in the greater Edmonton region. These included the Edmonton chapter of the Alzheimer's Society, the Edmonton Stroke Club, the Society for Retired and Semi-Retired, the Victorian Order of Nurses, the Edmonton Home Care Program, and the Leduc-Strathcona Home Care Program. The information sheet, which included a brief overview of the purpose, nature, and procedures of the study and found in Appendix A, was handed to the agencies for distribution to prospective informants. Volunteer informants were encouraged to contact me by telephone if they were interested in participating in the study.

In the case of the volunteers from the home care programs, the information sheet was given to the nurses and social workers with dementia clients in their case loads. When a prospective informant volunteered, the nurse or social worker provided me with that person's name and phone number. I then made the initial telephone contact to explain further the study and make arrangements for the first interview.

I established a minimal number of criteria for the selection of volunteer informants to facilitate as broad a recruitment as possible. The selection criteria in the study were: the informants had to be English-speaking, live in the greater Edmonton region, and be the primary caregiver of and living with the dementia person in their care. However, the interviews with one informant whose spouse had died one month prior to the first interview, were also included in the data analysis. This was done because of the recency of his experience and because of the quality of his insight into his experience with respite in the context of his overall caregiver experience.

Characteristics of the Caregiver Participants

The 10 caregiver participants in this study were similar to the traits of caregivers generally (Kuhlman, Wilson, Hutchinson & Wallhagen, 1991), particularly in terms of gender, relationship to dementia person and age. They had the following characteristics:

Age: The age of the caregivers ranged from 47 to 82 years of age with the mean age being 70 years.

Gender: Eight of the volunteers were women and two were men.

Relationship to Dementia Person: Of the 10 caregivers eight were wives, one was a husband, and one a son.

Education of Caregivers: The education of the caregivers ranged as follows: four were university educated, one had completed high school, two had completed Grade 11, one had completed Grade 9 and two had completed Grade 8.

Occupation: All were retired with the exception of the son caregiver. Prior to retirement their occupations ranged from being a college educator, accountant, teacher, and telegraph operator, to being in farm and retail related occupations. The son caregiver was a practicing lawyer.

Type of Dementia: There were two types of dementia conditions represented in these caregiver situations. Six people had dementia of the Alzheimer type and four had multi-infarct dementia associated with the diagnosis of cerebral vascular accident.

Living with the Dementia Person: In addition to the previously mentioned caregiver whose spouse died one month prior to the first interview in this study, the living circumstances changed for some of the remaining caregivers between the first and second interviews. At the time of the first interview, the nine caregivers were living with their dementia person, but by the time of the second interview, while seven caregivers were still living with their dementia person, two caregivers had now institutionalized their dementia relative.

Health Problems of Caregivers and Dementia Persons: For the caregivers, seven reported having no health problems. Of the three reporting health problems, one had diverticulosis and gall bladder problems, one had angina and hypertension, and one had hypertension and hiatus hernia. For the dementia persons the health problems in addition to their dementia were more extensive. Only two reported no health problems. One had recently died. The other seven reported conditions as follows: hypertension, stroke and arthritis; stroke and coronary condition; cancer and muscular pains; stroke and diabetes; cancer of the kidney, stroke and coronary; hypertension, diabetes, and arthritis; cardiac arrythmia; and diabetes, deafness and blindness.

Data Collection

The main data collection method was qualitative, open-ended, in depth interviews. The interviews were semi-structured, open ended, and exploratory in nature, using the interview guide found in Appendix B. Each caregiver was interviewed two times, with each interview lasting approximately 1½ hours. Because of the qualitative and subjective nature of the questions and the emotional content of the topic in general, the repeat interviews were essential so that all the components of the topic could be clarified with each caregiver. Also, in keeping with the methods of narrative enquiry, having two interviews with each caregiver provided the opportunity for the caregiver and me, as researcher, to enter into their experience of respite together. Together, we explored the various layers within the caregiver story itself, so each of us was enriched by the interview itself and by the depth of understanding each of us achieved about respite in the context of the caregiver situation. It was a process of searching for mutual understanding through the method of in depth interviewing.

After the caregiver had signed the consent form (see ethical considerations to follow), an audio tape-recorded interview was conducted in the caregiver's home or in a mutually agreed upon place. Each interview tape was transcribed verbatim as soon after the interview as possible. All the interviews were conducted from April through to September 1994. The interview process was piloted with one caregiver in order to assess its feasibility, the suitability of the open-ended questions, and the caregiver's ease in responding to the various questions. I conducted all the interviews.

Because of the importance of eliciting the caregivers' innermost thoughts and feelings about their caregiving experience and how respite related to it, I attempted to create an atmosphere of trust, authenticity, openness, and sensitivity. The interview usually started with some general social "chit-chat". The demographic data components were collected at the beginning of the interview since it was factual, concrete and a safe place to start. The main thrust of the interview then proceeded.

Through using grounded theory methods in the ongoing analysis of the transcripts of these interviews, themes and relationships between these themes began to emerge. In subsequent interviews with different caregivers, I began to incorporate these newer themes into the interactions with them. For example, one caregiver talked of respite as a mental attitude which she could achieve without outside help. In subsequent interviews I encouraged the caregivers to discuss the relevance of this theme to their particular situation. Strauss and Corbin (1990) suggest the necessity of this approach so that new leads, themes, and categories can be clarified.

Working with families in home settings has been part of my past professional community health nursing experience. This experience as senior administrator of a community health agency, as an educator in community health nursing, and as a researcher in the gerontological area added credibility to my approach with the caregivers. Because of this extensive background in community health nursing, I felt comfortable contacting the caregivers, entering their homes, and conducting the interviews. With all the informants rapport was easily and quickly established. Perhaps, because they were volunteers, the caregivers were willing and even eager to relate their experiences, emotions, and insights to me. One caregiver, in anticipation of the first interview, wrote six pages of experiences and insights for me to read. She wanted to be accurate in what she said. At the time of the second interview this caregiver disclosed that the writing of those six pages had been a very therapeutic process for her. She also said she felt more content with her circumstances even though nothing had changed. In the interviews, the caregivers revealed very emotional information which, for some of them, had never been talked about before. Often the caregivers cried as they talked. At the end of the interview they all stated that they had found the interviews helpful as they continued to struggle with their complex lives. They had the opportunity to talk about their feelings and experiences to a neutral non-judgemental person, they said.

Data Analysis

The methods of data analyses were based on grounded theory (Strauss & Corbin, 1990; Strauss, 1987) and narrative enquiry (Connelly & Clandinin, 1990; Clandinin & Connelly, 1994). These methods focus, to a large extent, on the analysis of data generated by the interview process. They can also include the analysis of data from other sources, such as researcher observations and responses from informants who are seen as expert in the field. In this study, data were generated primarily from caregiver interviews. However, my own observations and responses from expert informants were also included in the data being analyzed.

The objective of the analysis was to determine categories and the relationships among and within the categories embedded in the caregiver interview data. As the categories became evident the recurring patterns, similar themes, and the relationships between the patterns and themes were identified. Since grounded theory was used to generate theoretical constructs to help explain the phenomenon of respite, the analysis proceeded in stages, with each stage representing a higher level of theoretical complexity.

To counter the apparent obliteration of the individual caregiver story in the grounded theory approach to analysis, the narrative analysis approach helped maintain the context and the richness of the individual stories. In many ways, the narrative analysis seemed similar to grounded theory, in the sense that recurring patterns, similar themes, and the relationships between the patterns and themes were identified. However, the narrative analysis remained within each caregiver story so that the sense of the whole of that individual story could be maintained. As Connelly and Clandinin (1990) say of narrative analysis, "...one does not feel lost in minutia but always has a sense of the whole" (p.7). Therefore, I identified the themes, patterns, and relationships within each caregiver story and examined the flow in that particular narrative. Then, moving out of the specific caregiver narrative, the themes, patterns, and relationships within each story were compared to every other story to establish the commonalities and differences among them.

I used the Ethnograph software program for IBM compatible computers to facilitate the general processing and coding of the data. Following each interview, the audio tape was transcribed by a secretary into a format compatible with the Ethnograph program. I then read, reread and coded the transcripts. Often I listened to the audio tapes again as this coding proceeded. In coding the data, the initial guiding scheme was the general orienting framework of the research questions. This initial scheme included such codes as: the caregiving experience, what it involved and why they continued to do it; respite, what it meant to the caregivers, its value to them, and how they achieved it; and coping with the caregiving situation, what did and did not help in their particular situation. As the interviews progressed and the relationships between the various codes and themes started to surface, this initial guiding framework became inadequate. Additional, newer, and more theoretical codes were then used to group and categorize the data. For example, as the theme that the respite experience was a cognitive and personal attitude of being out of the caregiver world began to emerge, 'moving out of the caregiver world' became a theoretical code. As these codes evolved, they were checked and validated by my research supervisor.

Throughout the analysis process I kept notes and made memos about the theorizing process, as ideas about the relationships between the codes, themes, and categories swirled around. These notes and memos alerted me to developing themes and relationships and pointed to areas requiring further clarification, refinement, and verification. Periodically, I took these to my research supervisor for validation and general discussion. In these discussions, we used a process called the flip-flop technique (Strauss & Corbin, 1990), an examination of a central concept under study from the perspective opposite to the dominant view. For example, the dominant view of my study had been to identify respite and respite seeking behaviours by the caregivers from the formal support system perspective. As long as I retained this perspective, the various components and the linkage between them remained muddled. When the term "respite" was identified as "getting out of the caregiver world," the components of respite and the relationships between the component variables became clearer. As well, throughout this process of interviewing, coding, and memoing I would regularly attempt to draw integrative diagrams in an effort to identify the relationships between the various patterns in the data, the theoretical codes, and the embryonic constructs of the emerging theory. As I became more confident in the direction of these analyses, as a result of confirmation interviews with caregivers and discussions with experts in the area, these integrative diagrams became less confusing and more discerning. Gradually, the concept became clearer.

As mentioned earlier, within the narrative analytical processes, the same procedures as grounded theory were used with one exception: the analysis remained within the context of each caregiver story. However, the additional analytical procedure of writing a narrative vignette of each caregiver story was also used. To do this, I reread the original transcripts and identified the themes related to caregiving and the respite experience in each one. In writing the vignettes, the overview of the caregiver experience was outlined and the themes in each story were highlighted. This served to maintain the uniqueness of each story and to identify the themes and their relationships within each story. In this process of maintaining the individual identity and themes of each caregiver text, the common themes across the various stories more readily became evident to me.

Trustworthiness

It is essential that the reliability and validity of research studies using qualitative research methods such as the grounded theory and narrative enquiry methods used in this study, must be addressed with rigor and precision. However, there is considerable debate about the constituents of these review procedures for qualitative studies and what their dominant features might be (Denzin & Lincoln, 1994, p. 479). Lincoln and Guba (1985) and Wolcott (1994) argue that research with an interpretative orientation must use quality criteria which are more appropriate to the fundamental philosophical assumptions of interpretativism. From this perspective, then, these authors state that it is more fitting to translate the positivist concepts of internal and external validity, reliability, and objectivity into interpretativist concepts related to trustworthiness. They identify the criteria of credibility and authenticity as particularly appropriate in evaluating the rigor of the research process. Therefore, since this study is grounded in the interpretivist frame, its methodological rigor was reviewed using the trustworthiness criteria of credibility and fittingness or authenticity (Wolcott, 1994; Lincoln & Guba, 1985).

Credibility

According to Wolcott (1994), the criteria of credibility is linked with determining the truth value, or the worth, of the study. Connelly and Clandinin (1990) use the notions of adequacy and plausibility to determine whether an account of a particular experience rings true. Do the study informants themselves feel the representation of their stories are true? Do experts in the area under investigation view the interpretation as believable? Is the interpretation credible to people who have had similar experiences to those of the study informants?

To maintain credibility within this study, I adhered strictly to the texts of the caregivers as presented in the interviews. I read and reread the original transcriptions of the interviews and I listened to some of the tapes again. The caregiver respite experiences were described as accurately, meticulously, and completely as possible. As the analysis evolved and the meaning of respite began to emerge, I checked the relevance of these interpretations with the caregivers. For example, in one case, as the emerging model of respite was presented at the second interview, the caregiver kept saying "that is exactly right"; it accurately represented that caregiver's experiential perspective of respite. Other caregivers also confirmed, although not as dramatically, my interpretation of their respite experiences.

In addition, I established and verified the data analysis codes with my research supervisor and one other member of my advisory committee. This was done first by me and then by these two advisors reading and coding the initial interviews independently of each other. They then verified with me the coding and the analysis of the themes. These codes were then used to group, analyze and interpret the on-going interview data. As the study progressed, I continued to verify the emerging theoretical themes and the interpretation of the findings with my research supervisor. As well, I pilot tested and refined the procedures of the study before the research project began. These procedures included gaining access to the participants, getting their consent, and the conducting, transcribing, and coding of the interviews.

Authenticity

The authenticity or fittingness refers to the meaningfulness and "fit" of the findings to the participants in the study (Lincoln & Guba, 1985). It is the accuracy of the interpretation of the phenomenon under investigation as it represents the "real" experience that is important. Owens (1982) states that the soundness of the research is embedded in its ability to represent the "close in" experience, the personalized and intimate understandings of the phenomena under investigation.

In this study, to ensure the findings accurately represented the caregivers' perspective on respite, I verified the analysis and the interpretation of the findings with each of them at the second interview. At this time, a summary of the analysis and findings from the preceding interview was shared with the study participants. In this way the participants had the opportunity to validate, confirm, or reinterpret the findings, thereby ensuring that I remained true to the reality of the participants' respite experience (Guba & Lincoln, 1982; Lather, 1986; Lincoln & Guba, 1985). In all these second interviews, the caregivers added contextual richness to the interpretation of the findings by elaborating and expanding their stories of how they understood respite. This established congruence between my analysis and their interpretations and experiences.

Evidence of achieving "in close" and intimate authenticity was demonstrated by the positive caregiver statements at the end of the interview process. They all stated that the interviews had been helpful to them. In fact, some of the caregivers confirmed with me that the interviews had had a strong therapeutic benefit for them.

Additionally, I presented the emerging theoretical model to various groups external to the research study so that further authenticity could be established. First, I presented the findings of this study as a poster session at a national gerontological research conference. At least 25 conference participants, including both experts in the field of respite and family caregivers, discussed the findings and the emerging respite model. This group of people provided confirmation authenticity in that the interpretation of the findings accurately and reasonably represented their experiences with caregivers and with respite. To enhance its representativeness, two of the caregivers suggested additions to certain components of the model.

Second, in presenting the findings to a group of PhD students, the model received further validation when one of the participants in the group indicated that the findings had particular meaning for him in his personal life. He had no experience in caring for a dementia person but was the father of a chronically ill child. The discussions about the model of respite as experienced by the caregivers in this study had assisted him in gaining some meaningful insight into his particular situation. The fact that the model had relevance to an individual from a different experiential background to the caregivers in this study, provided beginning evidence of the "fit" of the model to the experience.

Ethical Considerations

Ethical clearance was sought and obtained from both the Faculty of Nursing, University of Alberta, and the Edmonton Board of Health Ethical Review Committees. See Appendix C for the documentation of these review procedures. Each potential volunteer caregiver participant was contacted by telephone to set up the first meeting. They were informed of the need to sign the consent form. The consent form is also included in Appendix C. They were also informed that, if they provided consent, they would be interviewed, that the interviews would be audio-taped to be transcribed later, and that the interviews would last about 60 minutes. They were informed that a second and possibly a third interview might be requested to clarify and expand on interview content and to validate the interpretation of data from the previous interview. In fact, the interviews usually lasted about 90 minutes and no third interviews were conducted.

The caregivers were informed that: access to the data would be limited to persons directly involved in the study; they had the right to refuse to participate in the study and to discontinue their involvement in it at any time by informing the researcher; and that the study might result in public presentations and publications of findings.

All participants were reassured that the interview information they provided would be kept confidential. This was done by assigning a code number to each caregiver participant and by using fictitious names when the study findings were presented in public. All interview tapes, notes, and transcriptions were identified with the caregiver code number only and are stored in a locked container. The names, addresses, telephone numbers, and corresponding code numbers of the caregiver participants are stored in a separate locked container which is accessible only to me. The caregivers were informed of these procedures. They were informed that the interview data would not be destroyed after the study was completed and that these data might be used for other related research projects in the future, following appropriate ethical review procedures.

Chapter 4

FINDINGS

This chapter is organized into three major components. In the first section, the specific stories of all ten caregiver informants are summarized to provide the narrative context of the diversity of each of their stories. The themes from each of the caregiver narratives are summarized with an illustration of the skeletal components of the emerging model of respite. Additionally, this summary of themes from the narratives provides the contextual backdrop for the subsequent more detailed presentation of the findings in this study in section two. The informant quotes supporting each theme are specifically outlined. In the third section, the conceptual model which emerged from the linking of these themes is presented.

The Stories of the Ten Caregivers

Marilyn's Story

Marilyn is the primary caregiver to her husband, Alex, and has been since he suffered a stroke seven years ago. As a result of this stroke, Alex experienced brain damage and impaired cognitive abilities. Over time, there has been further mental deterioration to the extent that, at present, Marilyn, at the age of 74 years, is a full-time caregiver to a husband with dementia. She is a deeply committed caregiver.

In the interviews, Marilyn talks fondly about the loving nature of their marriage, gives detailed accounts of how she got married to him, and tells extensive tales of the good experiences they have had together in their marriage. She also talks about how dependent Alex was on her for social interaction and companionship throughout their life together. He needed people around him and he wanted her with him; "he was reaching out for somebody all the time....he just didn't want to be alone." In their 48 years of marriage her life has centered on maintaining a quality relationship with her husband. The fact that her identity and purpose in life was entirely focused on her husband is exemplified in the following quote:

> Interviewer (I): But it's difficult for you to sit back and watch him struggle?
> Marilyn (M): Yeah, it is, but he's lucky he's here and I'm lucky he's here.
> I: He's lucky to have you?
> M: No, I just think I'm very lucky that I still have him.
> I: That keeps the positive energy going. That keeps the whole situation worth living for?
> M: Yeah it does. Because what would I do?
> I: If he wasn't here?
> M: Yeah.

She can think of nothing else she would rather be doing right now than to be looking after her husband: "we've always done things together...it's been like that for 48 years...you can't change." They still have good times together and are able to laugh at some of the awkward situations they find themselves in at times.

She does, however, get weary of the day to day constant vigilance of looking after Alex. If she isn't watching, he might wander off outside even in the depths of winter, which he did once. He is incontinent so the bed linens and his underwear must be changed frequently. She wants him to be as independent as possible and will encourage him to do things himself. It is also a way for her to maintain his dignity as her husband and as a human being; "I like him to do as much as he can for himself. I don't want to take that away from him."

But she really looks forward to the days when her husband goes to an adult day program for frail older adults: "Wednesdays and Fridays are sacred." That is like being off duty, of being able to switch off the responsibility, she says. She knows he enjoys being there, he looks forward to going every week, and, from her perspective, he is being well cared for. She also likes to play bridge with her friends occasionally but that is all she needs, she says. She describes these "breaks" away from the caregiving, when he attends adult day care or when her daughter looks after him while she plays bridge with her friends, as "....doing my own thing and freedom."

With these few interludes from her caregiving responsibilities she says she is quite content and happy with her life. Of course she would like to have traveled more but when she or Alex feels down about their present circumstances she gets out the photo albums and together they reflect back on the good holidays they have had together: "...I just get out the albums and the two of us look at the albums and I'll say 'gee, do you remember when we were here'....and he'd say 'oh yeah', and it's funny he does remember a lot of it." This is enough for her to carry on.

Reflecting on the adult day program, Marilyn says she thinks Alex likes to go because he feels some benefit for himself at the program; there is social interaction and he is with other people. He, however, doesn't like her to go out to play bridge or to other social events even though their daughter or a friend comes to stay with him. But she does go occasionally although she feels guilty about it: "but you know I felt guilty for not taking him....because he used to love things like that." Because of his unhappiness about her going out and leaving him at home, she is cutting back on the bridge next year, although not eliminating it completely. She further states that if he did not like the adult day program she would not be able to use it. As well, she does not consider using an institutional respite bed at all because "I'd be worrying that he wouldn't be happy...I'd still have him on my mind." From her perspective, if she "still had him on her mind" that would not be respite for her.

Betty's Story

Betty is 68 years old and has recently retired from an active college teaching career. She lives with her husband, Bill, and her young adult son. She is the primary caregiver to Bill who is in the early stages of Alzheimer Disease: "...he retired and got the label in 19**." Betty reflects extensively on her caregiving situation and, in the process of coming to terms with her situation, has developed profound philosophical beliefs and practices which sustain her in her day to day activities. She is genuinely in touch with her emotions and is articulate in expressing them.

Betty questions the diagnosis of Alzheimer Disease for her husband at this early stage because "they can't accurately diagnose that until the post mortem...it's more accurate to say dementia." She talks of the man she has lived with for so long as being gone, like a death. Now she lives with this other strange person who has all these difficult behaviours, some of which she recognizes from the past before he became ill: "...like the death has already occurred...then there is this person," she says. Particularly trying are the present behavioural difficulties which are similar to but exaggerated forms of his past behaviours which were annoying: "...I find that his abnormal behaviour that I relate to his dementia I can handle fairly good, it's the old personality problems that we've always had...I have much more difficulty dealing with them." Perhaps these behaviours form a link to the past so that she cannot cognitively and emotionally make a complete break with the past personality of her husband, she muses. She wonders how he experiences his world and his body and gives examples of how he will say he is hungry and, if given the opportunity, will heartily eat again even after he has just eaten.

Betty does not use formal respite services now but does not rule these out for the future when Bill's condition warrants it, "...but it isn't to that point yet." She talks of her son coming to her rescue when she is not coping very well. He will enter the interaction and change the topic which gives her the cue that she is not coping very well. "Then I can reorganize my thinking and my behaviour, but it would be doubly hard if he wasn't there." She will also negotiate with her son to keep an eye on his father while she is out. However, if both want to go out at the same time, she will leave Bill alone in the house for a period of time, even though she recognizes the potential risks.

She talks of having a life of her own; that she can't let her whole world be dominated by her caregiving responsibilities. She explains: "...I don't devote my life to this situation...this is part of my life but I have my own life...so again, I made the decision, there's a line." She is able to separate her own world from that of her caregiving world. It seems that the assistance she receives from her son is important when she loses this ability to keep the two worlds separate. She talks of consciously telling herself when she will start worrying about her husband and she will stick to this "rational cognitive" way of viewing her situation. When her husband is out of the house and she does not know where he is or what he is doing, she does not worry until a designated time she has set: "...when he leaves the house I decide not to worry...I decide when I'm going to start to be concerned." She is concerned, however, about how his unsafe behaviour, over which she has no control and which might harm others: "...one of my biggest fears [is] with his driving in case he hurts somebody."

She frequently identifies humour as a coping strategy when talking about her situation. She says, "so if he does something really crazy...you might as well laugh, why not...and some of them he laughs at too, when he realizes." Another time she says, "you either laugh or you cry don't you, and it's better to laugh." She also compares her situation to the others who are less fortunate. She says, "this is unpleasant but then there are other people who have a lot of problems...and looking at all the problems people could have, this isn't the worst one, at this point at least." She is able to see a gradual decline in Bill's general functioning and has given thought to her future coping strategies: "I do have in reserve, friends who will help me out in case it ever gets bad that I can't handle things...then I do have the two boys, you know. If we have to stay each other off, there are three of us."

For Betty, respite means an attitude or a way of thinking: "...my philosophy of thinking things through in a sane rational way." The time when Bill is out of the house, even though she does not know where he is or what he is doing, is the time she has to herself, when she is in her own world where she does the things she wants to do. She is able to achieve this mental state of respite because of her attitude which allows her to decide "...that I'm not going to be concerned." She also says that she can achieve this mental state of respite when she is together with Bill. Her attitude is reflected in the following quote:

> Betty: Well a break away from home is one form of relief, but even in the home....I just detach myself from him and just let him be....I'm my own person at that time....it isn't that I totally don't pay any attention....but I don't get involved and often when there is something lost I kind of say in my mind I'll let him hunt this long for whatever it is and then I'll go about my business and if he is still hunting then I'll give him a hand.

She is able to achieve this mental state of respite without the aid of formal or informal respite service. If she did not have this time to herself she would be able to cope, she says, but she would more unhappy. She maintains a strong sense of self-identity and vigorously pursues activities associated with her own world such as visiting with her friends, sewing, reading, hiking and maintaining professional linkages. If she didn't do this, she says, "...I'd be mentally ill in no time."

Rhea's Story

Rhea is the 65-year-old wife to Carl. She has been the primary caregiver to Carl ever since he suffered a stroke seven years ago. As a result of the stroke Carl experienced paralysis, aphasia, brain damage and impaired cognitive abilities which have resulted in his present dementia-type behaviour. Carl retired from the engineering profession just prior to the time of his stroke. Rhea retired from teaching and curriculum consulting to take care of him after the stroke and has regretted this decision ever since. It not only reduced their income, she says, but it also put a sudden stop to all her valued professional contacts and activities. She reminisces fondly of how, before the stroke, they together were busy with their family and both in their own professions. She is articulate and thoughtful about her caregiving situation and about how she experiences respite.

Talking about her present situation, she speaks of living in the stroke or caregiver world most of the time but that there is another world out there, a world she calls the real world. For her, respite means getting into that real world. In this real world she is her own person, is able to do the things which interest her and she has her own identity. She talks of work as being a type of respite for her in that it is a way of maintaining her own identity different from being her husband's caregiver. This is the main reason why she regrets having retired when she did. She is not involved with her profession to the extent that it gives her this individual and separate identity which would provide her with the emotional stability she needs. She says,

> I think it would have been better if I'd stayed teaching even part time and got somebody to stay with him at home. I wouldn't worry....he'd be happy to see me at home....I'd be happy to see him....it would work out better.

She goes on that for her, work

> ...is like respite....you still do what you enjoy and then you come home and you feel you're still there with your husband. You have the best of both and you don't feel that you're saddled, like you can't do anything about it anyway. Even if I had to work and give all my salary away....it would be worthwhile just, I guess, in the emotional stability that results.

She also talks of some of the things she would like to do in the future in that real world away from the caregiver world.

In the caregiver world she feels she is missing out on things that are important to her. She talks extensively about the details of her life in this world, the worry about him falling, dealing with the difficulties of his behavioural changes, feeling so responsible for monitoring the medical aspects of his care, and feeling helpless as a wife in influencing his behaviour. She says,

> ...what he needs is a good scare. If you tell him, okay then you have to go to a nursing home, then he....would cry and that scares him, but it has to be somebody else with authority, not me. The wife is there to make things nice for them and comfortable and cook for them and bathe them and take them for a drive. But anything to do medically, hands off. And it is easy to say to the wife,[she is talking of professionals here] do this or do that and you're willing, but they don't realize that you can't make an adult do what they're supposed to and in addition to not doing it, he will really storm you.

She also talks of how the present situation is like living with a "stranger, and not a very nice one, you know, that is the sad part, a stranger who is not very nice at times." Like Betty in the previous story, she says that you have to:

> ...almost put that person totally aside and just deal with the present... only there are certain threads of behaviour that come through in the present that were behaviours that irritated you in the past as well and all of sudden....there it is again and it's profoundly irritating now....you can compartmentalize; you can say okay that wonderful person is no longer...then all of a sudden there are parts...it brings back that old person.

Now she actively makes time in her life to get to this "space" she calls the real world. She sets aside one evening a week and goes out with a girlfriend to do the things she really likes to do, like going to art galleries or shopping for special fabrics and patterns for her sewing hobby. At first though, she did not do this and relates how isolated and alone she felt. She says, "it took me a long time; you know how they always say take time for yourself. That's easier said than done, but I finally learned after about the third year after [Carl's] stroke that...Friday nights are my nights off." Even though she does not like to leave her husband alone and he does not like her to do this, she will still go out this one evening a week. She laughingly says, "he says he doesn't mind...and if [he does] mind I go anyway." If she can arrange the situation so that he is doing something productive that night, it is a bonus, she says. She worries about him if he is alone but she will still go out that evening. Later on she says that she does not consider the Friday nights as respite because she is still worrying; she goes out to maintain her own identity and interests. She talks of how difficult it was for her to make these kinds of decisions; "at the beginning, you can't do that at the beginning....because you feel sorry for him....you have to go through it the hard way."

Like Alex in the first story, Carl also goes to an adult day program one day a week but, unlike Alex, he is reluctant to go. When he does go, it is a day Rhea does not worry about him at all and she has the day to herself to be in her own real world. To be in this real world and to be free of the worry is the true feeling of getting respite, she says. For her, respite is "the not worrying part and also you're able to function in the normal world so to speak." Because he is reluctant to attend the program, getting him to go is a difficult procedure for her. She talks of how she starts the night before to try and prepare him and how she is "upbeat and positive" the morning he is to go.

In talking about respite services, she says that if these would have more therapeutic value for her husband, he might not be so reluctant to attend. It would not be seen by him as just a babysitting arrangement. She also says that physicians should prescribe respite just like they do other treatments. She thinks that in her situation, Carl would accept respite more readily as a treatment rather than a service which benefits only herself. Also respite services should be more widely advertised so that it is more common knowledge and you don't have to learn about them through happenstance. She also talks about the cost of using respite services, they can't be too costly because of fixed and reduced incomes when there is a chronic condition in the family.

Rhea says she used an institutional respite bed admission once for her husband. She talks about how both of them functioned after Carl used this respite service in a long term care facility while she went on a holiday:

> I'll tell you one thing...when he came back he was in a much better frame of mind. I think he appreciated the things he had at home...and I know I don't think I lost my temper for about a month after that...I was more easy going, I think I had a better sense of humour...just all the crazy things, even when he got angry at me, it didn't bother me the same way...I felt that I had [been] rejuvenated.

Eventually, though, it got back to the same level of frustration and worry. Another time she tells the story of how she left him with relatives for the weekend while she went to a 40-year class reunion of her former students. She says,

> I left him with my sister, I knew he was well taken care of....I didn't worry about him. I took the weekend off....I didn't think about him at all....it was as though those years slipped away....it was so nice to see what they had done with their lives....you could sit and have a bottle of beer with them and it was just like it used to be when you could tell jokes and all that and you didn't think about anything else.
> Interviewer: You were in your own world, your personal world?
> Rhea: Yes. It was so nice....just like a different world.

She also talks of the deep commitment between her and Carl from the many good years in their marriage, and says that is the reason why she carries on with her caregiving although she is often frustrated with her life now. Throughout her story there is an undercurrent of respect for her husband as a person with dignity which must be maintained in spite of his present debilitated condition. When asked whether she could achieve a mental attitude of respite like Betty in the previous story, she says she could not do this and does not know of anyone who can. It seems that for her, the mental state of respite can only be achieved with the help of a respite service.

She also talks positively about the support group she attends regularly. She says that caregivers can talk about their frustrations and share their feelings with others in similar circumstances. The benefit derived from this support, however, is different from respite but just as valuable. The support group is still part of the caregiver world while, with respite, you are out of that world and in the real world, she says. When asked about the future, she says,

> You're sort of in limbo, you go from day to day and don't think about the future. You have an idea if this happens what I'll do, if that happens, this is what I'll do. Right now you just go from day to day. I don't know what else I can do.

Gladys' Story

Gladys is 66 years old, the wife and primary caregiver to Fred who suffered a stroke seven years ago. Like Carl in the previous story, his dementia-type behaviour is the result of the brain damage caused by this stroke. Gladys is unlike the other three caregivers in that she uses different types of respite services regularly. Fred goes to an adult day care program two days a week and she arranges for his intermittent, but regular, admissions to an institutional respite bed for short periods of time. She is a talkative and energetic lady with many interests. She is thoughtful and insightful in her reflections on her caregiving situation and on the meaning of respite to her.

Gladys describes the quality of the relationship between herself and her husband as being very good, "...our marriage was very strong," this being the second marriage for both of them. They both brought independent identities with them into the relationship: "...[Fred] and I have a dependency too, but we're both very independent." Gladys' independent sense of herself is still very evident; she says, "...I learned a long time ago you don't look to somebody else to do it for you...I have an independence that I see other women not having." She also talks about the person she has lived with for the last number of years as being different following the stroke:

> ...you've lived one way and you've known the person for 20 years and you've learned to work out a relationship on that basis. Then that basis changes completely, but you keep sticking to what you know - it's far harder to unlearn an old pattern than it is to learn a new one, and to learn something new in a relationship you have to unlearn the old.

She laughingly describes how this relationship changed almost completely following the stroke: "...that relationship changes...100 percent is an exaggeration...so maybe 95 percent." At another time she talks about what this change in the relationship means to her, "you're not married and you're not widowed, you're not married and you're not single...," and then goes on to describe how the sensations of a "lack of freedom" and "monotony" permeate all aspects of her situation. Then she fondly relates an incident where she and Fred spent one entire afternoon with total absorption, watching a squirrel retrieve nuts from its winter food cache after a major snow storm, one nut at a time: "...that hasn't changed...we've still got that."

She goes on to describe how she has learned to cope with her caregiving situation over the years. At first "I would feel sorry for him, then I would feel sorry for me and then I would say just a minute everything on your terms, 24 hours a day? - this is human bondage." Then she would go through an "emotional grinder...I mean I love my soap opera, poor me, poor me...when am I going to be out of this, when am I going to have some freedom." Now she says she bites her tongue and puts things more into perspective. The only thing she can change in her situation is herself, "...you have to start changing you're mind set...the only person I can change is me, and the minute I change me everything outside of me changes because of the reaction of other people. It's quite an education." And, she says, it is this changed mind set which gives her the sense of freedom she so much desires.

Gladys defines respite, without hesitation, as the feeling of freedom for herself. What she wants from a respite service is "...a block of freedom," freedom to do the things she wants to do. It might be staying in bed, "I just needed a day in bed to do as I pleased" or it might be working outdoors in the garden. She clearly articulates the idea of achieving a mental state of respite without help from anyone, even when her husband is left unattended:

> When I'm outside I have some freedom, I know that I'm going out for an hour and I know he's going to be alright for an hour and I'm not going to think about his needs for an hour. It's a mind set...my mind is completely on something that I am doing and not subliminally on...somebody's needs. He's in the bedroom, there's the rapping on the wall and you're always tuned into

> that when you're in the house, but when you're outside...you completely forget about time, he has to wait, doesn't he.

Then she makes two interesting observations which reflect the nature of their relationship and how it is influencing her ability to cope with the present situation. She says, "and he has never ever made me feel I have short changed him" and "I don't let it lay a guilt trip on me."

She further elaborates on this mental state of respite by describing one incident where her husband was in respite at a long term care facility and she was at home depressed, exhausted and did not experience respite at all. She says that respite is a mental state, a feeling of freedom to do as she pleases. In this particular instance, he was physically in a respite service and she was at home feeling utterly exhausted and depressed. She says she was not feeling any sense of relief. She was not experiencing that sensation of freedom. Therefore, it was not a respite experience for her.

Gladys also talks about being able to tell herself, even when her husband is doing unsafe things, that she will only start to worry about it after a designated time. Before then she will not be concerned: "...I was turned off." She describes how he would take the dog for long walks in the bush after he had his stroke. She describes how she managed her concern for his safety during these times:

> I'd watch him go and think what if he stumbles and fell and couldn't get up...I'd start and say: okay, if at such a certain time he is not back or I can't see him across the field, I will go with the dog whistle and see what direction he [the dog] is coming from and I will not worry about it until then.

She also saw the positive aspects of this activity in that it helped him gain a measure of control and dignity in his situation and it had therapeutic value for him. She says,

> [I]...taught myself to see him go and be happy for him because I knew he was enjoying himself and...instead of dragging [his feet] along, as the snow gets deeper, there is only one choice and that is you have to pick them up and it was tremendous....

At another time she says,

> ...if I have made the decision to go [out], and have made whatever arrangements are possible to make things comfortable that he's going to be taken care of, then I can turn that [caregiving] off, I can put up a wall,

> bang...one thing I have learned is the absolute futility and how energy draining worrying is if there is nothing you can do about it...so my stroke husband was completely and solely turned off.

She says it is because she has managed to maintain her own self-identity that she has been able to develop this attitude of achieving respite for herself.

She also talks about how her attitude has changed over the years in how she uses the free hours she has when he goes to the day program. She used to be very chore oriented, get things done around the house. Now she may still do these things but she may also just sit and read or watch the birds or do other things she enjoys. She also does things that she knows will be enjoyed by her husband when he comes home:

> ...so come 3 o'clock, anytime after that he's going to be home...oh I've made some rice pudding, he loves rice pudding. I enjoy his coming home because I...get myself in the frame of mind I am ready to let him tell me about all the things he did at [the adult day program].

She says that having a respite experience enhances the quality of their relationship. She also associates respite with not doing the regular caregiving related activities, "if I'm going to do something on Wednesday, it sure isn't going to have anything to do with stroke." Respite helps her maintain her own identity, she says. Respite has also helped her to stop feeling sorry for herself. She now thinks that everyone is going to die, so the enjoyment of each day is what counts. Enjoying the freedom when you get it, developing an attitude that gives this same sense of freedom, are all part of the respite experience.

Talking to Gladys two months later, Fred has had another major stroke. This time she knew she could not take him home again. He is now in a long term care facility in their community. She says she is at peace with the decision, knowing that she did all she could to keep him at home as long as she did. Sitting quietly reflecting back on her caregiving experiences, she says that the personal world, that real world, away from the caregiving world,

> ...it didn't seem to exist...there were times that I'd get into that little world and I'd say oh this is what it's all about, then it really made coming back to the caregiving world tougher - for a couple of hours yes.

She then relates an experience to further illustrate this point. Gladys attended the International Toastmasters conference in Edmonton and describes in detail what a wonderful time she had there. Then she had to go home. She says,

> ...I was still pumped up and then I got home...[Fred] was excited and he was interested in hearing about it and then when that was over, it was like, 'oh my god, I'm back in prison'. It was just like the walls closed in. I couldn't have felt worse. It didn't last long, but it hit hard because I had so enjoyed myself for a day and a half. This other world, this exciting world...I could feel exactly like myself. I didn't know I could any more.

She goes on to say that, although she felt down, after this peak experience, she would do it again because the positive feelings she had from that episode helped her to feel better about her situation. She then gives some advice to other caregivers about getting extended respite services by saying:

> ...if I was to set down a schedule of what people should do, it would be every six months. You need those batteries recharged often. Because you know what happens to the battery...you let it run too low and you have to buy a new one.

She also says that with the other respite experiences, she did not have this same "slump" experience; in fact, she would look forward to seeing Fred again: "I had something new to tell him" and he could tell about his experiences in respite. She felt she could then carry on again.

Anna's Story

Anna is the 77-year-old wife and primary caregiver to John. Anna's distinctive speech reflects her Ukrainian background. She is a tiny woman with a bright smile. Although both are modest, the house and the yard reflect the pride of ownership; everything is immaculate and tidy. About two years ago Anna really began to notice a difference in John's behaviour and an increasing forgetfulness. She relates one particularly frightening incident that occurred during this time:

> I noticed probably for a couple of years, and he was driving, I was so scared I watched him like..., and then he'd make mistakes and then the car was going over and I'd get scared. I remember one time coming back from my cousin's funeral and we had to make a left turn but, you know, when there's a four

> lane, you know, the cars that are coming go first. The light changed to green but you don't go yet and here he was going, and all those cars coming at us, they were blowing their horns. I got so scared I cried going home all the way.

He has now been diagnosed with dementia, origin uncertain, but he appears to be in the early stages of Alzheimer's disease.

Throughout the first interview, Anna focuses almost exclusively on the negative quality of her relationship with her husband throughout their many years of marriage. She talks of how she had been mistreated and how, very early in their marriage, she had to take charge of every aspect of the family affairs. She earned the money and raised the five children while he drank and did his own thing. Now that she finds herself in the situation where she has to take care of him, she feels very resentful and she affirms that the marriage vow is the only reason for continuing her caregiving. She relates a story when she was sick two years ago:

> Anna (A): You know he wouldn't even warm up a casserole or anything. I had to get it and I practically crawled to do it and now I have to pick up everything for him.
> Interviewer (I): It makes you very angry?
> A: I look at him sometimes... (pause)
> I: You don't want to continue.
> A: Then I think back for better or for worse, I promised.

He never did anything for her and now in her old age she still has to continue to look after him. The past poor quality of the relationship is influencing how the present caregiving is being experienced.

She is able to see, though, that the present is better than the past in that she now has control, which she did not have in the past:

> Anna: ...comparing to what it was to what is now, it's good for me now because I can, you know, even if I have to work still and all that, but nobody is controlling me, like he used to be all the time.

He does go to a day program two days per week. She says she has these two days to herself but that they do not help her feel better or be less resentful of her caregiving situation. She hesitantly discloses that she wishes that he would be placed in a nursing home soon, so that she could have a few years of freedom for herself.

Despite her feelings of disaffection, she has great difficulty in using respite services which might be of benefit to her. She had guilty feelings when family members and the home care nurse encouraged her to use a respite institutional placement so that she could go to a wedding in another province. The following lengthy quote demonstrates her emotional struggle and feelings of guilt:

> Anna (A): See we have a wedding invitation to Vancouver on July 9th, my niece's son is getting married, so I would have liked to go and then I thought what the heck, you don't have got to go, but then from Home Care, the girl phoned and she said I should go. So she started looking or whatever you call it for a bed for John and she told me about the respite beds and all that and she says I think you should go, it would do you good, it's a break for you. So I didn't really say yes or no, I said okay you look for a bed and I'll think about it...she phoned me and said yeah no problem, 'I found a bed'...I wouldn't go for long, just six days. Then I thinking and I'm thinking at nights, not sleeping, it's bothering me.....
> Interviewer (I): Why would it be bothering you?
> A: So I went and phoned Joanne [home care nurse], I says, 'Joanne cancel that bed, I'm not going'. She said 'well' because at first I said yes and then I said no, you know. And she says 'no, no, Anna, don't do that', I said 'yes Joanne please do it for me, I'll be alright'. Then we went to the doctor, he says 'maybe I'm not supposed to do this but I have something to tell you, Joanne phoned me and she never did cancel the bed for then (laughter)...Because she says they really think that you should go, you should get away'. I went to the doctor you know, he comes in and he asks me 'when was the last time you had a holiday' (laughter)...I says 'not for a long time, quite a while'...and he says 'I think you should go'. I says 'I cancelled the bed already' and he was laughing and he's writing me a note - 'for Anna to get away, maybe you won't give it to him, but I'm writing it'.
> I: He wrote a note to John saying Anna needs to get away?
> A: I gave it to John.
> I: What did John say?
> A: He didn't say go, he didn't say why did you cancel it - I told him I'd cancelled the bed - not a word and then when I told him I'm going, even the doctor thinks I should be going, he didn't say go, don't go - nothing.
> I: Just silence. Can you tell me why you changed your mind, first of all to cancel?
> A: Guilt. I didn't sleep that night hardly any at all and I in the morning I got up and about 10:00 I said 'I'm going to phone Joanne and cancel....'
> I: But now you've changed your mind back again, and how are you feeling about it now?
> A: But I still feel kind of guilty, really I shouldn't....

At the end of this lengthy internal struggle, Anna still is not sure that she will, in fact, use the help being extended to her. She thinks she might use it but is still ambivalent about it.

There is no past high quality relationship to sustain her in her present caregiving situation. Getting relief for herself seems important but she is not able to articulate why. All she says is that she needs it because she is not getting any younger and she needs to get some rest. She seems to long for the freedom of not being the caregiver. However, the past negative experiences and relationships prevent her from being able to achieve the attitude of respite that Betty or Gladys talk about.

When interviewing her two months later, Anna seems more contented and less bitter. About her decision to use a respite bed for her husband, she says:

> Anna (A): Yeah we got John into a respite bed...and I went. The wedding was beautiful, I had a nice visit with my sister...I came back, John wasn't very happy because there was too much noise there, there was ladies fighting (laughter).
> Interviewer (I): How did you feel about that?
> A: Well, I feel, better, I think about it, you know.
> I: Did it bother you that he was upset when you came home?
> A: Not really. Well, I didn't see anything wrong, like you know.
> ...
> I: Did you feel...you were feeling down to come back or were you looking forward to coming back?
> A: I wanted to be home.

Anna had used the respite bed for her husband, she had a good time, and she wanted to come back home. She had indeed overcome the emotional barrier which seemed to prevent her from getting away from her caregiving situation for a while, although she continued to be plagued by feelings of guilt the whole time she was away. She says, "it bothered me right along even when I was there." However, she said, after she returned home:

> ...when I came home and it was the next day, it was after supper I went to lie down...I had two hour sleep and I got up and I was a different person...I just felt like myself, I didn't have that guilty feeling.

As I talk to her during this second interview, Anna seems more content with her situation. The feelings of resentment did not dominant the conversation, as in the first one, and she indicates a sense of contented resignation that she will continue with her caregiving lot in life. She talks about John going to the day program and how she encourages him to see its positive features:

> ...he wasn't going to go, and I says, you go because you're going to sit at home, what him and I, we have nothing to talk about really that much...then it's hard for me because he can't hear to communicate with him, you have to repeat and I says you go at least you see different faces, you talk to some people there and if you play pool or whatever if you paint something, he comes home with paint on him. I says that's good for you, something different.

She recognizes the importance of those few peaceful hours for herself and seems to now have the self confidence to encourage him, even when he doesn't want to go. She also indicates that she thinks she won't have the same difficulty using the institutional respite bed again in the future.

Peter's Story

Peter is the 47-year-son of Jim who is in the advanced stages of Alzheimer's disease. Jim has been living with Peter and his family for four months. Peter and Linda, his wife, have two active young school age children. Peter is a busy professional while Linda is a "stay at home mom" but both are involved in caring for the disabled father and their two children. The first interview was conducted with Peter because Linda was on a vacation, while the second interview was conducted with both present. Jim's situation while living alone in his own house, had become very unsafe. The family tried to place him in a long-term care facility but could not get themselves to do it: "It was our intention to put him in an auxiliary hospital...took all his possessions there, showed up...saw the very unfortunate physical state of most of the people, totally broke down, turned around and said he's coming home to live with us." Peter describes what it has been like since his father moved into their household:

> Peter: I remember...watching Ed Sullivan where you have a man with all these spinning plates and in the end they had about 10 plates going, some balanced on his ears and tongue and every eye lash. Well that was a comparison I used today. That how your life feels.

He also speaks of how easy it can be to:

> ...to wear caring for your demented father [as] a badge of honour...oh what a wonderful thing. You've got to look into the mirror and [say] stay humble, pal...we're doing it because it's right for us...I happen to subscribe to the Christian religion and that's the Christian thing to do, darn it.

He also talks of a desire to reciprocate, to pay back, what his father gave him in his childhood, as another reason for taking on this difficult task. For Peter, one of the most rewarding things about looking after his father is the intergenerational sense of the family: "we were playing road hockey and it's wonderful to be out there with my son and my dad and I...." He adds,

> I think in the long run, this...period that he's staying with us as the highlight of my life...money isn't everything....I've worked my tail off and we've benefitted from it...what's most important is...my father...and my family.

He worries though about how all these responsibilities are affecting their marriage relationship and their immediate family situation but reassures himself with talking about what a wonderful sense of family they have every evening at dinner time when they are all together - grandfather, mother, father, and the two children.

When asked what respite means to him, he replies "we give ourselves our own respite," but does not elaborate on this thought. Rather, he goes on to outline numerous coping strategies which he labels as respite; for example, "we find that scheduling is another aspect of respite which is absolutely a must." Other such "respite" coping strategies he identifies include having a sense of humour, supportive neighbourhood, family and friends. He also talks about how he and his wife take turns "being on duty": "I do it all from, he's a very early riser, from 7 am until about 9 am" when Jim goes off to the day program. Linda picks up at the time Jim comes home from the day program around 5 pm. When Linda is not at home, like at the time of the first interview, Peter is "back on duty at 5 pm." They all have supper together and both share the responsibilities of children and father throughout the evening.

Peter provides a detailed description of a day program his father attends five days a week, how it helps them manage their situation, and how much his father enjoys the bus ride and the program itself. He confesses that they have little time for themselves, either personally or as a married couple, because programs similar to the father's day program are not available for their children. Even when father is being looked after the children are still there. For Peter and Linda it seems that the respite services they use for their father provides them with the time to be parents to their children.

In the second interview, however, their situation has changed dramatically. They tell the following story of what happened in the two month interval since the first interview. Both Peter and Linda had realized that, with summer approaching, they needed a break from the continuing demands of their caregiving responsibilities. They assessed their situation and felt they needed one week and perhaps another four day weekend to themselves as a family without Jim. However, as they explored their options for respite, seemingly, the only arrangement available for their father was a one month placement in an institutional respite service. After much debate, they reluctantly accepted this arrangement as it seemed to be the only respite service available to them. They went camping with the children and had a wonderful time.

When they came back from their camping trip, however, they found their father had deteriorated to the point that they could not take him home again. Linda says:

> He has failed miserably through this and so respite, what respite? We went away and we had some wonderful times camping, but what it's done to us emotionally has been horrible...we're left with these horrible feelings of having ended his life. I mean, what we were trying to preserve for him has been lost in six weeks...what they've done is they've focused on all his disabilities and never nursed his abilities at all.

Peter summarizes their negative experience with using respite services by saying, "respite care is only respite if the same quality of care is offered to the patient, in a respite facility that is offered at home." During the interview both conveyed feelings of guilt, anger and confusion at what had happened to them and their father. They were emotionally devastated. They had recognized their need for a break, they had reluctantly taken what was offered them, although this was not what they had requested, and now their worst fears were confirmed. In Jim's present state of deterioration, which resulted from his time in a respite service, they could not continue to have him live with them. Peter makes the following brief but telling statements: "How did we enjoy our summer without Dad? It was a wonderful, beautiful time. How do we feel now? Awful!" and "we went away and we had a wonderful time camping, but what it's done to us emotionally has been horrible."

Wally's Story

Wally is the 70-year-husband who looked after his Alzheimer wife, Helen, for 10 years. She died just one month prior to my first interview with him. The story he tells is one of a deep and long term commitment to his wife, of wanting to keep her out of the nursing home as long as he could, and how he finally institutionalized her about nine months before her death. The love and commitment to his wife and the quality of their relationship over the years were evident throughout the interview. It is this quality in their relationship which accounts for his lengthy experience as her primary caregiver, he says. He talks lovingly of her happy personality and how this helped him in caring for her: "she was a happy little person and that made for a lot of good living." Her smile would make it all worthwhile, he said.

What finally triggered her move to a long-term care facility was his concern about her safety. He did not feel physically secure enough to manage her daily care safely:

> Wally: She couldn't even stand herself, she'd fall forward or backward so this became quite a worry for me...I said it wasn't going to get any better, it is only going to get worse so I started the move towards the hospital.

He talks of the detail of the daily routines, how he would try to solve each new problem as her functioning deteriorated. This problem solving approach is demonstrated in the following quote:

> Wally: ...I got queen sheets and put them straight across, and then every time she started to get out of bed, I'm a light sleeper, I always woke up because she was taking the covers with her and so I was kind of able to watch her from that aspect...she started to become incontinent and, God I became real proficient. I was out of bed and change it all, into the laundry, put fresh bedding on and what not and get back to bed myself until [the next time].

At another time, Wally talks proudly about how good it felt to find a solution to his concern about his wife falling down the stairs:

> Wally: ...the one that really made me feel good was blocking off the stairs here. It was a very simple deal. I got one those orange garbage bags and I put velcro tape on both ends and I had it taped here and here and I could undo this, I'd bring it across and I'd tape it on here and it ran right across like so, just that height, up high enough that the cats could come through but Helen saw this as a solid wall that she couldn't go through so she'd come by the odd time and maybe give it a shake or something but I didn't have to worry about her falling down the stairs and that was a real saver for me mentally.

He was always concerned about how she experienced events and about her happiness and contentment. He interprets respite as a feeling of being free from worry, particularly in relation to her safety. In his first story about what respite means to him, he describes the feeling of not worrying during the night after he managed to get bed-rails for her bed so that she would not fall out of it. With these bed rails in place he could get a good sleep at night. Before, he was always semi-alert, listening for movement and a possible fall out of bed before he could get to her.

Wally talks of using different types of respite programs over the years. In his experiences with all of them, he always reassured himself that his wife was happy and safe before he would "do his own thing." This is demonstrated in the following:

> Wally (W): The first time she went into respite was into MP. It's an older establishment...I put Helen in over there, I think it was for about three weeks, I used to go over every morning and feed her breakfast and I would just make sure she was settled in comfortably...they were great to her. Then I took off and went to Vancouver, I thought, 'gee I just got to get away on a rest'...I put in a couple of good weeks...I didn't have to worry...because I'd seen Helen on the entry enough in the morning and a couple of evenings to see how it was going.
> Interviewer: You would put her in and then you would stay home for the first little while?

> W: Yeah, that's right. About four or five days before I took off, then I'd go on my holiday and come back...so I didn't have a worry. I just went and came back and felt really good for it all.

He talks of needing time for himself, of needing to be away from the caregiving situation for a while, but this was always contingent on him being sure that she was happy and content where she was and with the service she was receiving. He was always watchful about how the formal helpers treated her. His experience of respite was dependent on his perception that she was happy while he was away. He concludes that the regular use of different types of respite services helped him achieve his goal of keeping her at home as long as he did:

> Wally: ...it was very important to me because it allowed me to keep her at home. You know, if I hadn't had that I'm sure I...unfortunately would have had her in [an institution] much sooner...I always had the objective in my mind that I was going to look after her as long as I could...I was going to keep her at home and look after her and I did that.

Milly's Story

Milly is the 77-year-old wife and primary caregiver to Randy who suffered a stroke four years ago. Randy's dementia is the direct result of this stroke. She talks of how dramatically he changed following this illness. Before the stroke he was an outgoing, socially active, and friendly person. Now he is a person who does not speak well and when he does, he swears and calls Milly names. He is easily frustrated with his environment, gets angry quickly, and is very stubborn. Milly says she should be thankful for the good marriage and the wonderful life they have had together but finds this personality change so difficult that she can hardly manage to continue with her caregiving responsibilities.

To illustrate, she tells a story of how he, for example, suddenly told her he wanted to go to a football game when, in fact, there was no such game scheduled anywhere. When she told him this, he paid no attention to her. He got dressed for the game and sat in the living room. What helped her cope with this was ignoring him, she says. He continued sitting in the living room, wearing all his outdoor clothes until bedtime. She would go to bed and eventually he would go to bed too. This happened repeatedly.

At other times, he put on double pairs of trousers or two heavy woolen sweaters even when the weather was quite warm. In one incident, she relates, she took him along to the bowling alley and he started to undo his belt and zipper. She thought he was undressing himself and became very embarrassed in front of her friends. Then, gradually she began to realize that he had another pair of trousers on underneath the pair he was taking off and that he was in fact looking for his wallet which was in the "underneath" pair of pants.

Besides her distress in dealing with his changed personality and his problematic behaviours, she finds the lack of social contact particularly difficult. Before Randy's stroke, they had many friends who now rarely come to visit. When they do come, they just talk to her and ignore Randy as if he is not there, which she finds very painful. She talks of living with a stranger, a person who is not her husband. She misses their conversations and having someone to talk to; "I have to make all the decisions by myself and I really don't have a husband anymore." She worries whether she will suffer physical illness and die before he does.

Randy goes to a day program and a home support worker comes in to help with his physical care. He loves to go to the day program and he would go every day if it was available. She says that this program is "God sent" for her and that these days are "like a burden rolling off my shoulders." She is concerned, though, about the way helping professionals treat her husband but is reassured that, at the day program, he is treated with respect and dignity. While Randy is at the program she can maintain her social contacts which are so very important to her. She loves to go bowling or golfing with her friends. To accomplish this she finds it quite a juggling act on those days when he goes to the program. Because the program starts at 10:30 a.m., she gets another lady to come in at 9 a.m. to stay with him until the DATS bus comes around 10 a.m. He doesn't come back home until about 4:30 p.m. She is "off-duty" from 9 a.m. to 4:30 p.m., although she has to make sure she is home before the bus delivers him to the front door. She also talks of having the day to herself to do whatever she pleases. However, she also uses that time for chores. Recently she used the free time to get some major dental work done.

Milly says she would not be able to manage her situation if she did not have this day program. She also said that if he did not like the program she would not be able to use it. She tells of another day program which she attempted to use shortly after his stroke. For reasons she could not determine, he did not like it and they had to withdraw from it. As well, she says, she is not able to achieve the feeling of being "off duty or free" when she is with Randy or when she has left him alone at home. The odd time when she has done this, she worries constantly and does not find that time away helpful at all. Now she never leaves him alone: "I always take him with me, even when he doesn't want to go."

Milly also sees the day program as a means of getting Randy accustomed to the idea of going to a long term institution. In fact, at the time of the second interview two months later, she has made arrangements for Randy to move into an institution that coming fall. She could not continue, she felt, because of his deteriorating condition and her feelings of vulnerability in relation to her own health.

Dorothy's Story

Dorothy is the 73-year-wife and primary caregiver to Andy. Dorothy and Andy live on a farm and have been farming all their lives. Their son, his wife and family live on the same yard, but in a different house. She became aware of the signs of Andy's Alzheimer's disease in the past year. She says she had noticed certain changes in his behaviour for about 2½ years, but had not been concerned about them. It was during this past year, when he became physically sick to the point of needing hospitalization, that his mental deterioration became evident to her.

In describing her life now, she talks of the constant vigilance and the disrupted sleep she experiences every night. To illustrate she relates the following incident:

> Dorothy (D): he got up and as soon as he moves, I'm up, too, to watch that he doesn't fall and he went into the bathroom and I listened and he didn't come out and all of a sudden he upset the stove.
> Interviewer (I): Upset the stove, and the whole thing tipped over?

> D: Yes. If that didn't scare me, then he was lying here and I had a hard time picking him up.
> I: That was in the middle of the night?
> D: Yeah 3:00 in the morning.

When asked why she continues, with all the changes to Andy that cause so much disruption, she says "well I can't just leave him...I have to look after him. After all, we've been married for 53 years...that's a long time, you can't just forget that...we've had a good life, we've done a lot of travelling. It's just since he got sick."

Dorothy tries hard to preserve her husband's dignity and tries to protect those things in his environment which preserve his identity. For example she talks about the ambivalence she feels when Andy's drivers license needs to be renewed:

> Dorothy: ...if he wouldn't get his drivers license. It will really upset him. You know you've driven all your life. But then, you see, it was the same in the spring when field work started. We're still farmers and he's still always done the farming and he always kept saying he was going to go out on the tractor and I knew he couldn't do that...so I phoned Dr. W... and I told him would you please tell him that he cannot drive and he did and he never asked whether he could go out in the field...but the car, I don't know.

At another time she talks of the frustration of trying to maintain this facade of preserving his dignity. She relates how the neighbours keep telling her that Andy looks so good he should be out on the tractor doing farm work. She says,

> ...that upsets me because I know he isn't...sure he looks good just to look at him, but then as they were leaving he came to the door with me and they weren't even out of the yard and he had fallen.

As well, Dorothy reflects on how the quality of their past relationship influences her present situation. She says that she never nagged Andy, and that if he didn't want to do something she wanted to do, she always acquiesced: for example, "because I can't push him too hard [now], like trying to make him do things, because I've never pushed, ever."

Andy goes to a day program twice a week. If he didn't go there he would not get out of the house at all, she says, and that would not be good for him. At first, Andy did not want to go but she is concerned about maintaining contact with helping professionals, almost like an insurance just in case they need something more:

> Dorothy: I keep on telling him he's got to go because I say if he doesn't go we're going to lose all contact with the nurses and doctors and then what have we got. You have to have some place where you can turn to....On those two days I'm relaxed. I mean we go out...my son and daughter-in-law...if she's working he takes me and if she's off then we go for lunch and we go shopping, we do different things...for six hours I'm free.

She also says she uses this time to do things like banking and other chores and that the time is short; "you can't do that much" during these six hours. At another time, she is talking about the hassle of getting him to go to the day program:

> Dorothy (D): ...he has a hard time walking - like this morning his legs are so bad, the arthritis.
> Interviewer (I): Then you have to keep pushing, pushing, pushing.
> D: Very slowly with lots of patience.
> I: Patience and positive outlook.
> D: Exactly.
> ...
> D: Once he's on the taxi then I'm free (laughter), as I say. It's not a nice thing to say but that's the way you feel.

Because of her perseverance Andy now likes to go to the program but, she says, if he really did not want to go she would not be able to use the day program. She also finds the support from the immediate family living nearby very important in helping her cope from day to day.

For her respite also means getting adequate rest, getting enough sleep, so that she can continue in her daily caregiving activities. She has a night-sitter in and as a result has an uninterrupted sleep for one night a week. When this night-sitter arrives, she says she switches off and she is able to get to sleep without worrying.

She also talks of the day program as being a bridge for him to accept at least partial nursing home placement:

> Dorothy: He goes there Mondays and Wednesdays anyways. It would just be an extra day, but he would be staying overnight. So those would be three nights that I could have, be really rested up by the time he comes home.

In this way she can still maintain his desire to be at home and she can have the time where she can get rested and do her "own thing" without worrying; she could be off-duty for three days. The following interaction demonstrates how she views her present life with Andy:

> Interviewer (I): Would you say there are any parts that are not stressful, or that might even be considered good times that you have with Andy?
> Caregiver (C): I don't know how to answer that.
> I: Some people say 'no they can't identify any good times', others can still, even with all the difficulties, can sometimes say oh yes we can still laugh together or..
> C: Oh yes. We can still do that when he's okay, when his mind is okay. That's a hard question to answer.

Despite all the good times they have had over the years she cannot identify anything positive about her life at present.

Jeanette's Story

Jeanette is the 82-year-old wife and primary caregiver to Steve who has had Alzheimer's disease for a long period of time. Jeanette is not able to say for how long because the onset was so gradual. Both interviews with her were conducted in the basement of the house because she has claimed this space as her own. Steve cannot navigate the stairs anymore so Jeanette can comfortably be there without constant reminders of her caregiving responsibilities, she says. She can do this because she uses a day-sitter service for eight hours a day, five days a week. During those eight hours she does not have to worry about Steve's safety or care. It seems that Jeanette is physically demonstrating the separation of her personal world from the caregiving world that the other caregivers talk about. This sitter service was arranged for and funded through the government home care program.

From her descriptions Steve seems to be in the advanced stages of the illness. She says that, although his condition is more deteriorated than a few years ago, it is now easier to manage the situation. Before he would do repetitive things which were very irritating: "it used to be arranging the fringe on the rug in front of the vanity and this would go on 500 times a day." Now, "he's lost all these phobias that he had." Both have been married before, each with children from these previous marriages. Although she did not emphasize the quality of their past relationship she did hint at some problems with Steve's alcohol abuse in the past and seems to link his dementia to his past heavy alcohol consumption. She did, however, talk about her independent nature which she had developed during her time as a widow with four small children; "I think I've been a strong person. I think because everyone says 'I don't know how you cope with it'...but I've been a strong person and I guess that's the only way, thank God."

At the time of the first interview, when the daily sitter service had just been arranged, Jeanette is very dispirited with her caregiving life and wishes that things were different for her. She had not anticipated this kind of old age for herself, she says. She feels she is missing out on the good things associated with being older, like socializing freely with your friends. She feels so tied down, she says. She then tells the following story as she describes the daily frustrations of her caregiving life. Steve is a long-time diabetic who has always had a carefully controlled diet. As his dementia worsened, she had to watch him constantly because he would indiscriminately go to the refrigerator and eat large quantities of inappropriate food. Finally, in total frustration, she decided to padlock the refrigerator:

> Jeanette: ...it's not easy living with a padlocked fridge...at least I feel I am doing what needs to be done for him...I think it has helped.... Mind you he's also on insulin twice a day now and whether that has anything to do with it or what I did, but it's awful feeling to have to padlock the fridge in your own house, for your husband...the guilt feeling is there and it's also frustrating....

Jeanette has used institutional respite placement in the past and now has a day-sitter with Steve eight hours a day for five days a week. She reflects on how she got Steve to go into this respite placement:

> Jeanette: ...he was very receptive and I thought oh I can't believe this...then the next morning he got up...and he just went wild. I am not going anywhere, I am staying here to look after the cat and dog - which he used to do. And so I didn't say anything, I thought - well he'll get it off his chest but I knew he'd made up his mind and that was going to be it...a couple of hours later, I said to Steve 'you know I need two weeks, I have to have these two weeks'. He says 'you can go where you want to go but I am staying home'...well it's impossible...so I phoned the coordinator and told what happened...she said get one [of his children] to come over and talk to him and see if he'll go on a tour, which he did. He was very, very receptive.

He went into the institution for two weeks, really enjoyed it and she had a wonderful time traveling and visiting relatives.

At the second interview, two months later, the sitter service is still in place. Jeanette seems calmer and more accepting of her situation. She says she uses the daily time she has to herself to do "my yard work, the lawn...it's exercise for me and I like to do it...I like to spend time just puttering out there...I'm also a quilter and crafts, all the rest of it and I like to socialize at the drop in centre...I can go next door for coffee." She feels free to do the things she likes to do with the sitter in the house; she is not constantly watching Steve. She feels she is better able to manage. She doesn't know how much longer her situation will continue but with the on-going assistance from the sitter service she thinks she can manage for now. She knows that institutional placement for Steve is inevitable but she will carry on until that time comes.

Summary of the Narratives

The uniqueness of each of the ten caregiver stories is readily evident. Each brings a different perspective to the way they interpreted their particular situations. Each, individually, contributes to my "close up" and increasingly intimate understanding of their caregiving circumstances and how the experience of respite was set in its context. In the following section, I outline the specific understandings each of the caregivers provided me in my search for understanding and meaning of the respite experience. In this summary, I group the caregiver stories in relation to the new perspectives and expanding insights they provided to me. Therefore, the stories of Marilyn, Betty, Rhea, and Gladys are featured most prominently because each provided extensive and broad insights into their caregiver and respite experiences. The stories of Anna, Peter, and Wally have a secondary emphasis in that each provided more definitive insights into particular aspects of their caregiver and/or respite experiences. The stories of Milly, Dorothy and Jeanette provided a unique background and contextual density to the insights gained in the other stories.

Marilyn's story highlights how the quality of the past relationship between her and Alex influenced her present caregiving situation. Her fundamental contentment with her situation, and her continual efforts to maintain Alex's dignity as a human being demonstrates this clearly. Her use of respite services, although minimal, indicates how the time she had to herself helped her cope with her caregiving situation.

Betty's penetrating story provides insight into how she experienced the cognitive decline in her husband. Her story provides the beginning notion that respite is a mental process, not necessarily contingent on external respite services. She also talks about the separation of the caregiver world and her personal world where she had her own identity and freedom. She provides greater insight into the influence of past relationships on her present situation, although from a different perspective than Marilyn.

Rhea's story is rich with reflective thought on caregiving, respite, and components which influences each. Of all the caregivers, her image of the two separate spheres of the caregiver world and the personal "free" world and of the movement between them was the strongest. She articulates clearly the necessity of respite for herself and how it facilitated her coping and she provides details on conditions which influence the use of respite services. Unlike Betty, she cannot imagine respite as a cognitive process which could be achieved without the aid of external support. However, she provides insight into how she used the respite time, gave some initial indications of how she re-entered the caregiver world, and how the respite experience influenced her continued functioning as a caregiver. She further illuminates the extent of the demands and responsibilities within the world of caregiving.

Gladys' story is another rich reflective narrative providing further insight into the complexities of caregiving and the respite experience in its context. She strengthens the notion of the two worlds, the caregiver world and the personal world, highlighted in Rhea's story. Her reflections about time in relation to the respite experience and her reentries into her caregiving world following her frequent and regular use of respite services were particularly keen. Like Betty, Gladys was able to achieve a mental state of respite without the aid of external services, therefore, strengthening the notion for me that respite was a mental process. Both Gladys and Betty provide details of "peak" respite experiences and how these influenced their ability to come back to the world of caregiving and to continue in it.

Anna's story provides rich detail about how past relationship difficulties influence and add to the burden of caregivers'. This story is particularly poignant in outlining why Anna continued in her situation and how difficult it was for her to "give herself permission" to leave the caregiver world temporarily.

In contrast, Peter's story is particularly unique in that he is a male caregiver, a son with a young family. His story is full of details about the coping strategies he and his wife used and provided reasons why he was engaged in caregiving. Peter's story provides particular insight into the factors which influence the re-entry into the caregiver world following a period of respite. His deep disappointment and emotional devastation upon his realization of the extent of his father's deterioration as a result of the respite service, is particularly powerful.

Wally's story provides yet a different perspective to the caregiver world, the personal world, and the experiences within each. Because of his extensive and lengthy experience with caregiving and because of its recent termination after his wife's death, Wally's story provides a panoramic view of his caregiving life and what helped him survive in it. Like Peter's story, Wally's is full of details about the coping strategies he used to manage his situation. He also provides a clear perspective of the specifics of respite services which enhanced the quality of his respite experience.

The stories of Milly, Dorothy and Jeanette add to my understanding of the complexity and emotionally exhausting nature of the caregiver world. They provide additional information about how their use of respite services helped them cope with their particular situations. They extend my understanding about how each used their respite time and what this respite interval meant to each of them. Jeanette's physical demonstration of the separation of the caregiving world and her personal world particularly affirms this concept for me.

However, within the distinctiveness of these stories, the respite experiences in the caregiver narratives form a pattern which is set firmly in the context of the dominating, time-consuming, and emotionally draining world of caregiving. The stories are full of different coping strategies the caregivers used to manage their particular situations. As well, the experience of respite is talked about as a coping strategy. Respite seems to represent the ability to "get out" of the caregiver world for a while and to "be in their own world" where they feel free to be themselves, to have their own identity, and to NOT be the caregiver. They also talk about the experience of getting back into the caregiver world after they had a time interval of respite.

Therefore, I have used this emerging pattern of a respite model as the foundation in organizing the following analysis of the collective data from all ten caregivers. This preliminary model is presented in Figure 1 following. In this analysis, the stories of Marilyn, Betty, Rhea, and Gladys are used most extensively because they illustrate different components in the model. The stories of Anna, Peter, and Wally are used to exemplify specific segments within it and the stories of Milly, Dorothy, and Jeanette are used to add depth and richness to the illustrations in the discussion.

The analysis uses the headings within this preliminary model as the organizing structure. First, a description of the caregiver world, including the caregiver's commitment to it and how they cope within it, is provided to establish the context of respite experience. Within this description, respite is identified as a caregiver coping strategy. Secondly, the "process of temporarily getting out of the caregiver world" is discussed, including the factors which influence the caregivers' abilities to "get out." The discussion continues with "moving to your own world," presented as a cognitive mental process occurring at a deeply personal level within the caregivers, followed by the component "being in your own world," the quintessential experience of respite. The analysis continues with a discussion of the process of re-entry into the caregiver world following the experience of respite, and concludes with a more detailed presentation of the model of respite.

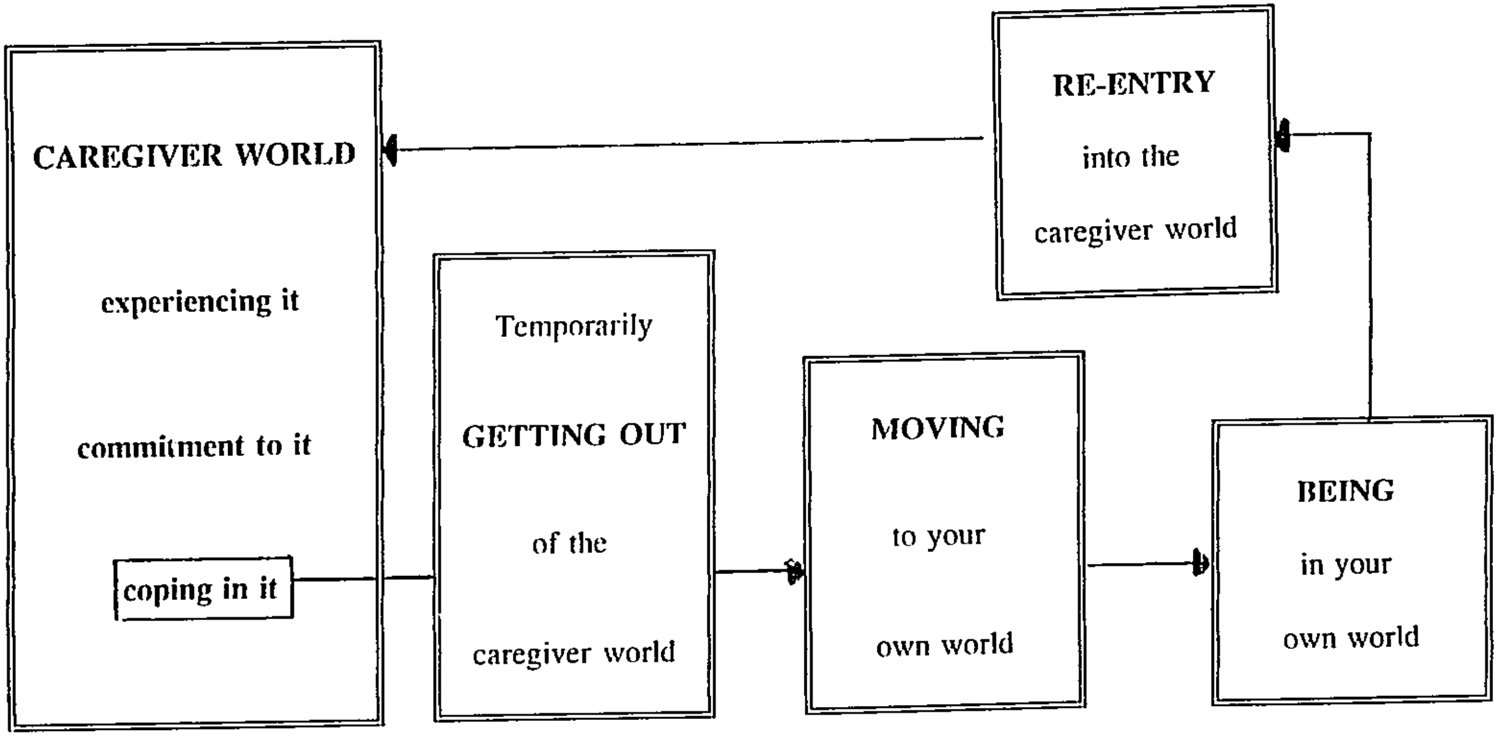

Figure 1 The preliminary model of the caregiver respite experience

The Caregiving Experience - The Context

The caregivers in this study provided detailed narratives about the nature of their daily caregiving lives, both past and present. Their individual stories were filled with abundant practical insights and rich descriptions of their individual caregiving experiences, what the rewards were (if any), and why they continued to do it. In addition, the narratives contained dense descriptions of the coping strategies they had learned to use in dealing with their various and difficult situations. Therefore, in this section I describe what caregiving was like for the caregivers in this study, the commitment they had to it, and how they managed to cope with it.

The Experience of Caregiving

The caregivers talked of the physical and the emotional aspects of their present caregiving situations. The physical aspects included the personal care, the constant vigilance of monitoring the dementia person's activities, the daily hassles of adapting and adjusting to the routines of their dementia person, and the coordinating or juggling of the many activities and responsibilities associated with caregiving. For example, Milly talked about how she managed her various activities without leaving her husband alone - she took him along with her wherever she went, whether it was to the bowling alley, the grocery store, or the bank. Marilyn talked about some of the more difficult physical caretaking details of her life:

> Marilyn (M): ...I had to change him and everything and change the bed.
> Interviewer (I): So he's incontinent then?
> M: Yeah. Well he does wear the pads, but I don't know, he just seems to soak everything.
> I: So that's another difficult part?
> M: ...Yeah.
> ....
> M: ...he takes a long time to bath. He doesn't shave himself properly, so by the time he gets out here for breakfast, I usually go in and finish the shaving and everything.

Peter provided a graphic image of the juggling act of his daily life:

> I remember...watching Ed Sullivan where you have a man with all these spinning plates and in the end they had about 10 plates going, some balanced on his ears and tongue and every eye lash. Well that was a comparison I used today. That how your life feels.

Other caregivers talked about the constant vigilance in their lives. For example,

> Marilyn (M): ...the reason I have to sit with him all the time is if I don't, he gets his walker and he'll get up and he'll, well one night I found him going outside and I thought, oh, he'll just walk down the hall, I'll just leave him and he didn't come back and didn't come back, and I thought well I better go and check and see what he's doing. He had the door open, he was in the winter.
> Interviewer (I): He didn't have a jacket on?
> M: No, and you know that ramp - and he was on his way out. So you've got to watch him every minute.

Wally said,

> ...I got queen sheets and put them straight across, and then every time she started to get out of bed - I'm a light sleeper - I always woke up because she was taking the covers with her and so I was kind of able to watch her from that aspect...she started to become incontinent and God I became real proficient. I was out of bed and change it all, into the laundry, put fresh bedding on and what not and get back to bed myself until [the next time].

In describing the emotional aspects of caregiving, the informants included poignant details about their feelings of guilt, worry, fear, grief, embarrassment, conflict, anger, frustration, helplessness, sadness and loneliness of their situations. Rhea related the following incident as she talked of her constant worry and how she attempted to monitor her husband's safety. It provided a good summary of the feelings of frustration, helplessness and guilt which were evident in so many of the stories:

> Then he has these falls and I worry about that...he doesn't think I should, it's like when he walks up the stairs and I'm always a few steps behind him in case he should fall...I've seen him and he's fallen so many times and down the stairs...four days ago when [he] fell and took one of the paintings with [him]...one time both of us fell down, he fell on top of me...and then I couldn't get him up...you know he lifted one leg and I was taking the shoe off and he fell on top of me and I crawled out and then I couldn't get him up and he was wedged in the hallway and I couldn't get him up....

> ...I tell him don't go down the stairs when I'm out...but of course he will. But then in the back of your mind you're thinking - what if he did, what if he fell and I'm not there and I know it wouldn't be my fault, but yet you'd feel, yeah it would be. That never leaves you...

Marilyn specifically mentioned the guilt she felt when she couldn't include her husband in the social activities which he loved so much before his illness;

> ...I said would you like to go - well I'll think about it...So I don't think he was that fussy [to go] and my brother came over and stayed with him that night and they watched the hockey game so he was happy. But you know I felt guilty for not taking him...I really did feel guilty about it, because he used to love things like that you know. We used to take in everything.

At another time Marilyn was trying to understand why this illness happened to her husband and confessed that "I just think I must have been a terrible person. I know I wasn't the good one so maybe this is my punishment."

Despite all the difficulties articulated throughout the caregiver narratives, there was a continuing desire to maintain the integrity, dignity and humanness of the dementia person in their care. There was a reluctance to use devices or general help which would demean their family member. Dorothy talked about how upset she gets when friends or family come to visit and they just talk to her and ignore her husband. Marilyn talked of how concerned she was that her husband might fall down the basement stairs but was hesitant to use devices which conveyed a message that he was no longer a fully competent adult:

> Marilyn (M): I'm frightened that he'll fall down stairs or something you know...
> Interviewer (I): Always worrying about what might happen.
> M: Yeah.
> I: Have you thought about putting something in front of that stairway?
> M: Yes. I have, like a children's gate.
> I: That might prevent some of that.
> M: He's pretty good the way he walks with the walker though, but I should get something.
> I: But there's also that feeling of children, giving him a message...
> M: That's what I'm frightened of. Because I don't want him to feel any worse than he does.

Betty talked about the possibility of having to put on locks to prevent her husband from wandering away from home. She said,

> ...I know there are locks that you have to lock and unlock from the inside to get out and at this point it's not necessary...so if that actually becomes a problem I can do that, but now he can still really be by himself...I don't want to take that away too soon...

Jeanette talked about the frustration of finally deciding to padlock the refrigerator because her husband was continually going to the refrigerator and eating foods inappropriate for his diabetes:

> ...it's not easy living with a padlocked fridge...at least I feel I am doing what needs to be done for him...I think it has helped...mind you he's also on insulin twice a day now and whether that has anything to do with it or what I did, but it's an awful feeling to have to padlock the fridge in your own house, for your husband...the guilt feeling is there and it's also frustrating....

In considering the use of devices and approaches they considered demeaning many of the caregivers talked of trying to understand their dementia person's behaviour so that they could handle the situation better while preserving their dignity. Dorothy talked about the ambivalence she felt about her husband's drivers license being renewed:

> ...if he wouldn't get his drivers license. It will really upset him. You know you've driven all your life. But then you see it was the same in the spring when field work started. We're still farmers and he's still always done the farming and he always kept saying he was going to go out on the tractor and I knew he couldn't do that...so I phoned Dr. W... and I told him would you please tell him that he cannot drive and he did and he never asked whether he could go out in the field...but the car, I don't know.

They persisted in trying to get their dementia family members to do things the dementia persons resisted doing for themselves; such as toileting and personal hygiene activities, feeding themselves, and activities seen as having some therapeutic value. They did these things in their efforts to preserve the dignity of their dependent family member. For example, Dorothy said:

> ...when I can't get him mobile, you know, it takes so long. Just doesn't want to get up or just lies there and pretends I'm not even there you know. You stand and hold his pills and you wait and you wait...you just keep on. You know telling him, "Come on you've got to take your pills. You've got to take

> your insulin. You've got to have breakfast as soon as you take your insulin. You're suppose to eat."

It also led to the caregivers taking risks when they knew the situation might not be safe. For example, Betty left her husband alone when she went out but did not stop him from driving his car because he still had his driver's license. In another situation, Dorothy talked of how the neighbours kept telling her that her husband looked so good he should be out on the tractor doing farm work. She said,

> ...that upsets me because I know he isn't...sure he looks good just to look at him, but then as they were leaving he came to the door with me and they weren't even out of the yard and he had fallen.

For the caregivers, this then led to dealing with the criticisms from others who did not understand the extent of their family members' deterioration and the conflicting dilemmas that deterioration forced them to confront in their unique situations. Betty stated:

> You're just prepared that I can only do the best I can...not to blame myself regardless. Even when you've got your own blame [under control], you've got the environment, people pointing fingers. This is what I find...people are very ready with advice and criticism.

Within this stressful context of the caregiving experience I wondered why they continued in it. From my external perspective their lives seemed so difficult. As I enquired, the caregivers provided me with detailed and emotional reasons for their perseverance.

The Commitment to Caregiving

When I asked them why they continued in their situations, many of the caregivers talked of a deep-seated commitment to their dementia family member and of the high quality of their past relationship as reasons for continuing in their present situations. For example, Marilyn said, "Oh we had a wonderful life. I have no regrets...we've had a wonderful 47 years. I couldn't ask for anything better." They highlighted the aspects of their relationship which were still intact and rewarding to them. Marilyn, again, related the following incident which exemplified this:

> ...I take him out, when the weather is nice...so we walk over there and coming back it's quite a hill and I'm pushing and I'm puffing and he'll say 'what are you puffing for' and laugh, and I'll say 'okay you get out and push me'. So you know we still have our fun.

Rhea said:

> ...like with Carl, he got his sense of humour back...[he] can still laugh and he can joke and we kid around and he can take a joke, you know.

They also commented on how the personality of the dementia person had influenced their continuing caregiving efforts. For example, Wally said: "That was a big plus. she was a happy little person. If she'd been a dour individual I don't know that I could have done it as long as I did...even up to the end she would, I was getting smiles out of her...."

Where the past relationship had been difficult and conflictual they talked of fulfilling social norms and roles expectations that they felt were expected of them as a wife or husband. For these caregivers the rewards of caregiving were minimal or non-existent. A number of these caregivers, when asked what was still rewarding in their situation or relationship, either had difficulty in answering it or said they could not see any rewards whatsoever. For example, in the interview with Dorothy, the following interaction revealed the difficulty she had in identifying the rewards of her situation:

> Interviewer (I): Would you say there are any parts that are not stressful, or that might even be considered good times that you have with Andy?
> Dorothy (D): I don't know how to answer that.
> I: Some people say no they can't identify any good times. Others can still, even with all the difficulties, can sometimes say oh yes we can still laugh together or..
> D: Oh, yes. We can still do that when he's okay, when his mind is okay. That's a hard question to answer.

In another example, in Anna's situation, where the relationship had been particularly problematic over the years, the marriage vow was her only reason for continuing in her caregiving situation. She related a story when she had been sick two years ago:

> Anna (A): You know, he wouldn't even warm up a casserole or anything. I had to get and I practically crawled to do it and now I have to pick up everything for him.

> Interviewer (I): It makes you very angry?
> A: I look at him sometimes... (pause)
> I: You don't want to continue.
> A: Then I think back for better or for worse, I promised.

Further on, in the same interview, Anna tried to make the best of her present situation:

> ...comparing to what it was to what is now, it's good for me now because I can, you know, even if I have to work still and all that. But nobody is controlling me, like he used to be all the time.

Further, some of the informants felt obliged by their personal values to continue. There was satisfaction with the living out of one's values. Peter said,

> I think in the long run, this...period that he's staying with us as the highlight of my life...money isn't everything....I've worked my tail off and we've benefitted from it...what's most important is...what [is] doing with my father...and my family.

For Peter, one of the most rewarding things about looking after his father was summarized in the following quote: "We were playing road hockey and it's wonderful to be out there with my son and my dad and I...."

Others talked of going through a process of reorienting their personal values as a result of their caregiving. They were, in fact, learning from their experiences - things which seemed so important in the past were now not as significant. According to the caregivers, new values more linked to real life issues were now emerging. Despite the hardships there seemed to be a deeper sense of contentment with this values reorientation process. For example, Gladys said,

> ...my values have changed based on what counts and what doesn't count. With Fred having had a stroke and since that time I'm not looking out there saying look what I'm missing, because there is an awful lot [I am missing]...if I went out to do it again I would not miss it, it would seem too trivial...the thing I appreciate the most is people I can laugh with.

Additionally, despite the nature of relationships in the past, there was a commitment to maintaining the quality of life for their dementia family member: Rhea took her husband out for drives three time a day when the weather was nice; Marilyn pushed her husband in a wheelchair to the shopping mall everyday; Peter played road hockey or cycled with his athletic but demented father. Others, like Dorothy and Betty, were hesitant to have their husbands' driving licenses taken away because of the meaning that license had for these men. Rhea's summarized the general feeling of ambivalence about maintaining the dignity of their family member and the commitment to taking care of them, expressed by all the informants:

> Well I don't want anything to happen to him. You know, he's had enough. But he's also very stubborn. He wants to do everything by himself and I can understand that but there comes a point that you have to think that it's dangerous for him to do it.

As the caregivers talked about their deep sense of commitment to their caregiving, their stories consistently showed how they managed in their situations. These included the strategies they had used, what helped them and what didn't help them and they had a strong problem-solving orientation to them. However, they also included extensive strategies about managing the emotional components in their situations.

Coping with Caregiving

The caregivers identified many different strategies which helped them get through each day. Among all the strategies identified, having a sense of humour or being able to laugh at some of the ridiculous situations they found themselves in, was considered a major one. For example, Peter stated, "You have to maintain a sense of the ridiculous...it is a black humour, but it helps us immensely...." And Betty said, "some time for relief, if I have a choice whatever goes on, between crying and laughing, I choose to laugh about it...."

The caregivers identified numerous other coping strategies. These included practical things like having a specific and regular schedule. For example, Peter said, "we find scheduling...is absolutely a must, we must have a schedule" and having a similar kind of patience as that required to raise young children, "...the patience that you have to have with children is just a natural spill over to the care of a demented person." Engaging in physical activity was also seen as useful: Gladys said "I found that physical work, getting out around here is very healthy for me." Dorothy found bowling and golfing regularly very helpful.

Having supportive friends and family was also identified as being very helpful to the caregivers. A number of them spoke warmly about the support and assistance they received from their daughters while others spoke about their friends in the same manner: for example, Marilyn said, "we have wonderful friends...they're all so good." The support provided by spiritual beliefs and the church were also seen as useful coping strategies. For example, Gladys said,

> ...one of the things that helped, I was raised Catholic and so you ask and thou shalt receive and all those kinds of things...either you trust in what you've asked for...and I would see him go and I would say he's being taken care of...I was raised with a guardian angel....

Being able to solve specific problems which helped to reduce their worry or constant vigilance was also seen as helpful in coping with the day to day activities. Wally talked proudly about how good it felt to find a solution to his concern about his wife falling down the stairs:

> ...the one that really made me feel good was blocking off the stairs here. It was a very simple deal. I got one those orange garbage bags and I put velcro tape on both ends and I had it taped here and here and I could undo this. I'd bring it across and I'd tape it on here and it ran right across like so, just that height, up high enough that the cats could come through but Helen saw this as a solid wall that she couldn't go through so she'd come by the odd time and maybe give it a shake or something but I didn't have to worry about her falling down the stairs and that was a real saver for me mentally.

In the process of solving these problems various resources would be sought and used. Services such as Aids to Daily Living and becoming active members of the Alzheimer's Association or the Stroke Club were seen as particularly helpful, although Milly found attendance at the Stroke Club difficult because she tended to break down and loose control at the meetings. Some also identified that having adequate financial resources was another aspect which helped them cope with their situation, as Peter said, "he's fortunate he has funds because with those funds we are able to better care for him."

The attitude of the caregivers themselves and the way they viewed their individual situations were strong forces in helping them cope with their circumstances. The following quote outlined how valuable being self reliant was to Gladys:

> Gladys (G): I learned a long time ago you don't look to somebody else to do it for you...
> Interviewer: So that's given you these coping skills, because after Fred got sick you had to take over the decision making?
> G: You were used to running your own show...yes, you just said it.

Another useful attitude was comparing themselves with other people whom they viewed as being less fortunate than they. For example, Peter indicated that compared to the problems Bosnians faced everyday, his caregiving difficulties faded into insignificance while Betty said, "Well see, he isn't nearly as bad as lots of other people." Still another outlook was having a realistic view of the situation and the prospect of ongoing decline in their dementia family member. For example, Wally, in talking about moving his wife to an institution, said,

> She couldn't even stand herself. She'd fall forward or backward so this became quite a worry for me...I said it wasn't going to get any better. It is only going to get worse so I started the move towards the hospital.

Yet another attitude was one expressed by two different caregivers. Gladys talked about how her outlook had changed in the years she has cared for her husband. She says, "The only person I can change is me and the minute I change me everything outside of me changes because of the reaction of other people. It's quite the education." She articulated how this outlook of controlling her own attitude had helped her cope with her difficult situation. In another example, Betty talked about a type of mental self talk where she told herself she would not worry about or act on a particular situation until a certain time. She talked about a useful philosophy she had developed:

> You're imperfect, you're a human being, you can't know all things, you can't prevent all things and other human beings are responsible to a certain extent for themselves...I'm responsible for my decision to not do anything more about it...but I am not a bad person...often things occur that we can't anticipate and even if we may anticipate it, we may not be wise enough to do the right thing and that's just the way life is. So I do the same thing, I think I do handle him quite well...but once in a while I lose my cool. As soon as I

> do, I calm myself down and say, well, you're imperfect so you goofed again and let's get on with it instead of feeling guilty about the fact that I really did something rash.

Yet another type of coping strategy for the caregivers was their ability to seek out ways to get respite or relief for themselves from the demands and drudgery of their daily lives. Since the experience of respite is the focus of this thesis, this coping strategy is discussed in detail in the following section.

Respite as a Coping Strategy

All the caregivers except Betty used some type of respite service. Betty relied on her son to some extent to get the relief she needed. The caregivers talked of needing a break from their caregiving activities and of feeling free from the constant demands placed on them when they got this break. They talked of: getting out of the caregiver world so they could do what they wanted to; being their own person; feeling free of worry; feeling free to do things they liked to do; being with their own friends; or just being peaceful and quiet enjoying their flowers or animals. A number of the caregivers did not seem to have difficulties in achieving this mental state of respite while others faced many challenges in attaining this state of freedom. It seemed that the coping strategy of finding temporary relief from their caregiving duties, whether it was a relatively difficult or easy process, required a cognitive process of admitting to themselves that they needed some help. For example, Rhea said,

> ...I used to say, I'm managing just fine, I don't need it, I'm managing just fine. But then there comes the point where I start losing my temper and I yell...and I swear and then you realize - hey, I'm not managing as well as I should. You know that's when you admit to yourself that [you need relief].

For some caregivers this process of admitting their need for relief or giving themselves permission to get relief for themselves was a very difficult one. The following excerpt from the interview with Anna clearly exemplified the difficulty of this process:

> Anna (A): See we have a wedding invitation to Vancouver on July 9th, my niece's son is getting married, so I would have liked to go and then I thought

> what the heck, you don't have got go, but then from Home Care, the girl phoned and she said I should go. So she started looking or whatever you call it for a bed for John and she told me about the respite beds and all that and she says 'I think you should go, it would do you good, it's a break for you'. So I didn't really say yes or no, I said 'okay you look for a bed and I'll think about it'...she phoned me and said 'yeah no problem, I found a bed'...I wouldn't go for long, just six days. Then I'm thinking and I'm thinking at nights, not sleeping, it's bothering me.....
> Interviewer (I): Why would it be bothering you?
> A: So I went and phoned Joanne [home care nurse], I says 'Joanne cancel that bed, I'm not going'. She said well because at first I said yes and then I said no, you know. And she says 'no, no, Anna, don't do that', I said 'yes Joanne please do it for me, I'll be alright'. Then we went to the doctor, he says 'maybe I'm not supposed to do this but I have something to tell you, Joanne phoned me and she never did cancel the bed for then (laughter)...Because she says they really think that you should go, you should get away'. I went to the doctor you know, he comes in and he asks me 'when was the last time you had a holiday' (laughter)...I says 'not for a long time, quite a while'...and he says 'I think you should go'. I says 'I cancelled the bed already' and he was laughing and he's writing me a note - 'for Anna to get away, maybe you won't give it to him, but I'm writing it'.
> I: He wrote a note to John saying Anna needs to get away?
> A: I gave it to John.
> I: What did John say?
> A: He didn't say go, he didn't say why did you cancel it - I told him I'd cancelled the bed - not a word and then when I told him I'm going, even the doctor thinks I should be going, he didn't say go, don't go - nothing.
> I: Just silence. Can you tell me why you changed your mind, first of all to cancel?
> A: Guilt. I didn't sleep that night hardly any at all and in the morning I got up and about 10:00 I said I'm going to phone Joanne and cancel....
> I: But now you've changed your mind back again, and how are you feeling about it now?
> A: But I still feel kind of guilty, really I shouldn't....

At the end of this lengthy internal struggle Anna still was not sure that she would, in fact, use the help being extended to her. Despite all the external pressures on her from the home care nurse, her daughter, and her physician to get away from her situation it seemed that, within herself, she still had to come to terms with the idea that it was "okay" for her to leave. Cognitively and emotionally, she had to give herself the permission to get away from that situation. Interestingly, at the time of the second interview, two months later, she stated that she had indeed come to terms with the decision; she had given herself this permission to get away. She had gone to Vancouver, had not worried about the situation at home, and had had a wonderful time.

It seemed that this emotional cognitive process of giving the self permission to get out of the caregiver situation was fundamental to the caregivers getting relief or respite. For Anna the process was very difficult. For other caregivers this process was also difficult but not as complicated or guilt-ridden. For example, Rhea said it took her three years after her husband's stroke to finally realize that she had to get away from her caregiving situation for a while so that she could continue in it:

> ...it took me a long time. You know they always say take time for yourself, that's easier said than done, but I finally learned after about I think the third year after Carl's stroke that I have Friday nights are my nights....

Still others had little or no difficulty in acknowledging their need to escape. For example, Gladys talked of having no difficulty in making the decision to use a combination of regular weekly day program attendance and annual or semi-annual institutional respite bed placement for her husband. She saw it as absolutely necessary so that she could continue in her caregiving. In fact, she advised the following about regular respite service use:

> ...if I was to set down a schedule of what people should do, it would be every six months, you need to recharge those batteries often. Because you know what happens to the battery. If you let it run too low, you have to buy a new one.

When the caregivers were able to temporarily get out of their world of caregiving it seemed to help them cope with their situation.

Temporarily Getting Out of the Caregiving World - The Process

In this section, I present data so as to illuminate the processes used by caregivers in giving themselves permission to get out of the caregiving world, of temporarily escaping from the caregiving world, and of getting relief or respite from the caregiving situation.

Factors Influencing the Caregivers' Ability to Get Out

It seemed that numerous factors influenced the process of getting out of the caregiver world. As cited above, the first and most fundamental factor seemed to be the cognitive and emotional process within the caregivers of giving themselves permission to escape. A number of important factors seemed to contribute extensively to this process. These factors might clarify why some informants had great difficulty with the process while others were able to make the decision to temporarily leave the caregiving world without great emotional duress. The factors which seemed most evident in the data included: the nature of the pre-illness relationship between the caregiver and the dependent family member; personality-based factors; role expectation; and the attributes of the available respite services. Each of these will be discussed separately in the following discussion.

Nature of the Pre-Illness Relationship

The nature of the relationship between the caregiver and the dementia person prior to the onset of the dementia symptoms and how it influenced the caregiver's ability to get out of the caregiver world was exemplified most clearly by the stories of Anna and Gladys. Anna talked at great length about the emotional difficulties in their long marital relationship, how she had always sacrificed for the benefit her husband and the other family members. Throughout the marriage she had never considered herself first in anything that was done within the family. Now that she was into old age and wanted to consider small luxuries for herself, she was again faced with placing her husband's needs and desires ahead of her own. Yet, when she was faced with the decision to use a respite service where she would be the prime beneficiary, she had great difficulty accepting it. In fact, she was able to make the decision only after prolonged emotional struggle and extensive pressure from supportive people around her. It seemed that the prolonged conflictual relationship within this marriage and how this caregiver had survived in it, now profoundly influenced her ability to make the decision to use a service which might benefit herself exclusively.

In contrast, Gladys readily gave herself permission to regularly to get away from her caregiving world by using respite services for her husband. In this situation, the nature of the pre-dementia relationship had been very different. She described in detail how they had come to their marriage with their individual identities well established. She also described how, although they had developed a deep level of emotional interdependency, they had continued to respect these individual and separate identities throughout their marriage. Now that she was facing the ongoing rigorous demands of caregiving twenty-four hours a day, this mutual respect for the individual identity of the other had helped her give consideration to herself. Gladys was able to say,

> I would have felt sorry for him, then I would have felt sorry for me and then I would have said just a minute, everything on your terms 24 hours a day, this is human bondage and for somebody to be in human bondage they have to allow it...[no way].

Personality-Based Factors

Another factor which seemed to influence the caregivers' ability to temporarily leave the caregiving world, was the nature of their disposition. For example, Rhea related how it had always been her style to give in when she and her husband were having an argument. She said, "If there was something that we really differed on I'd say 'okay have it your way', like I couldn't care less it's not that big a deal, so I would give in just because I didn't think an argument was worth it." Now, when she wanted to take a course of action contrary to her husband's viewpoint, this past deferring pattern haunted her:

> Now I guess I give in because I don't want him upset. I don't want him yelling...so I figure, oh, it's easier just to let it go...it wasn't that I gave in because I was weak or afraid of him, but I just didn't want the argument and I figured usually it's not worth the argument. A lot of things aren't worth the argument.

So, rather than argue with him about going to a day program or using an institutional respite placement, which he did not want to do, she would defer to his wishes and keep him at home. Then she felt angry and resentful because of his stubbornness and inflexibility.

At another time, Rhea talked of how she always worried about her husband and how responsible she felt towards him: "I take responsibility for him. That's too much I think. It's too scary it seems." She was always concerned about the consequences of his behaviour:

> It worries me because...I can see where it's going and he doesn't seem to...every time he tries to walk down the stairs I try to run and make sure I'm right there. I don't know what I could do if he was falling. We'd both fall. I figure I could break his fall but of course I can't. But you try.

In contrast, Betty was coping with her husband's unsafe driving behaviour without too much worry or anxiety. When she was asked how she coped with this concern, replied:

> You look at the thing realistically...you're imperfect, you're a human being, you can't know all things, you can't prevent all things and other human beings are responsible to a certain extent for themselves. Even if you do something very stupid, you're still an okay person, but it's too bad you did it, but you're not rotten and you're not guilty of committing a crime shall we say you're responsible for your decisions. I'm responsible for my decision to not do anything more about getting him out of the car...[if something happened] it just may be inadequate or unwise...I use that all the time.

The contrast of the two temperaments was notable. In the first example, Rhea was anxious, frequently worried, and deferring to her husband's wishes and desires. She longed to escape from her caregiving world but was rarely able to do so. She seemed trapped by her inability to change the pattern of behaviour she has established for herself in dealing with conflict. In the second example, Betty appeared in charge of her situation and able to make or not make decisions as required. She appeared sure of herself and confident in the way she coped with some very difficult behaviour patterns.

Role Expectation

Caregiver role expectation was another factor influencing the ability of the caregivers to get out of their world of caregiving and was closely linked to the issue of caregiver disposition. Marilyn talked fondly of the good life she and her husband had together and that, even though her present circumstances were difficult, she seemed content even though her situation was trying and difficult at times. She could not conceive of doing anything but take care of her husband. This contentment and acceptance of her role as caregiver was exemplified when she said, "He's lucky he's here and I'm lucky he's here...I just think I'm very lucky that I still have him." She was even reluctant to admit that she might need some relief from her situation, although she thought the two mornings she had to herself, when her husband went to a day program, were "sacred." He liked going to it; therefore, it was okay for her too. He did not like her going out to play bridge with her friends even though their daughter stayed with him while she was gone. Hence, she was reducing but not eliminating her involvement with this activity.

For Anna, the only reason she continued in her difficult situation was the marriage vow. She said it was expected of her to continue, "for better or for worse." Anna had considerable difficulty allowing herself to get out of her trying caregiving circumstances even for short periods. Rhea, too, had trouble with this process. She said: "The wife is there to make things nice for them and comfortable and cook for them and bathe them and take them for a drive...Its easy to say to the wife, do this or do that and you're willing, but they don't realize that you can't make an adult do what they're supposed to do."

Attributes of Respite Services

Another important factor influencing the caregiver's ability to move out of the caregiver world, were the attributes or characteristics of the available respite services. The caregivers identified numerous respite program conditions which influenced their ability to temporarily get away from their caregiving. These conditions as interpreted by the caregivers, which were not the same for every person, included: the acceptability of the respite service to the dementia person; the willingness of the dementia person to use the respite help or service; the respectful attitude of the personnel associated with delivering the respite service to the dementia person; it's beneficial features for the dementia person; and the legitimation of the respite help by someone in authority.

The acceptability of the respite service as interpreted by the caregiver was exemplified in the following quote by Wally, who looked after his dementia wife for ten years:

> Wally (W): The first time she went into respite was in MP. It's an older establishment...I put Helen in over there. I think it was for about three weeks. I used to go over every morning and feed her breakfast and I would just make sure she was settled in comfortably...they were great to her. Then I took off and went to Vancouver, I thought, 'gee I just got to get away on a rest'...I put in a couple of good weeks...I didn't have to worry...because I'd seen Helen on the entry enough in the morning and a couple of evenings to see how it was going.
> Interviewer: You would put her in and then you would stay home for the first little while?
> W: Yeah, that's right. About four or five days before I took off, then I'd go on my holiday and come back...so I didn't have a worry. I just went and came back and felt really good for it all.

The condition that the dementia person must be willing to use the respite service was demonstrated repeatedly by many of the caregivers. When they were asked if they would use a particular respite service if their family member did not want to go there, they said no. Milly talked about trying to get her husband to go to a particular day program with a good reputation. He flatly refused to go. She had no idea why he did this because, from her perspective, the program was very good. So she discontinued his attendance much to her dismay. She, however, increasingly felt the need for some type of respite for herself and when she heard of another day program she tentatively tried it. From the very first time in this second day program, her husband loved it and the bus ride that accompanied it. She had to remind him of the days he went to the program because he would forget and think he was going every day. On the days he did go to the program he was up earlier than usual so that he would not miss the bus. She could not explain the discrepancy in his response to the two day programs. From her perspective both were high quality programs. However, it was only when her husband liked the second program that she could use it as a means of respite for herself.

Another condition was that the caregivers must see the respite service personnel treating the dementia person respectfully. For example, Peter told the poignant story of his family's need for respite and of the devastation they felt when they realized that, from their perspective, the staff in the respite facility had not treated his father with respect and dignity:

> So we had heard, when we came back from Drumheller, we had heard that he had arrived at the centre one day in a diaper and his pyjamas - so I was really concerned about whether he was, why was he in a diaper. So you know, again, there were many phone calls trying to figure out why he was in the diaper, well nobody could tell me why he was in a diaper. The best explanation I could get was perhaps, it had been casual staff that morning and they didn't know if he was continent or not, so rather than make a guess, they just put him in a diaper. And I said and what do you think that does to the man's dignity? Why would you put him in a diaper when you didn't know whether or not he needs one. You know, they just don't consider, you know, maybe they think he doesn't have feelings anymore.

Another condition which influenced the caregiver's ability to get out of the caregiver world was that they must see the respite service as beneficial to the dementia person. Rhea talked about how she felt her husband would accept respite services more readily if he would see it as a type of therapy:

> ...if they went into respite, if they had even the very basic program of a little therapy, a little physical therapy given, you know, something to make it seem that you're in there for some good is being done you, then it would be easier to swallow, for both but particularly for the [dementia person].

Another condition related to the nature of the respite service was the legitimation of that serivce as a therapy by a person seen to be in authority, like a physician or a nurse. Rhea pointed this out in the following quote:

> ...if the doctors and nurses made a definite point of explaining the importance of respite, not only to the caregiver, but for the family and the stroker [too], that it is going to be part of [the] recuperation, that it's absolutely needed twice a year minimum, you know. If that were made part of [the] discharge I think it would carry a lot of weight and it would make it so much easier.

Other Factors

Other factors influencing the caregiver's ability to move out of the caregiving world, although not as clearly evident as the preceding elements, seemed to be the length of time the person has been in that role and the extent of behavioural deterioration of the dementia person. Rhea talked of how at first she thought she could manage on her own and she resigned from her job to take care of her husband full time. It took three years, she said, for her to realize that she could not do it alone and that she needed something to help her cope with her situation, that she needed to get away from it for short periods of time so that she could continue in it. She said, "The longer it [the caregiving] goes on, the more desperately you need [respite]." Betty, at the time of the interviews, was not using any formal help. She felt she did not need help just yet, as she considered her husband to be in the earlier stage of Alzheimer Disease. When the time came, she said, when she could not manage on her own because of his deteriorating condition, she would not hesitate to ask for help so she could get away from it for a while.

The preceding discussion outlined the factors which influenced the caregivers' ability to temporarily get out of their caregiver world. As they talked about the meaning of respite for themselves, the notion of movement toward a "mental place," where they could consider themselves out of the caregiver world, seemed to fit their descriptions. Therefore, this notion of "moving to your own world" is discussed in the following section.

Moving to Your Own World

The caregivers described moving out of the caregiver world and into their own personal world as a cognitive process. Betty described how she experienced this mental process for herself:

> Betty (B): When [my son] hears that things are not going too well and then he'll come out and he may just introduce a subject of some sort, you know to get us off the track and that's a clue to me that I'm not handling it too well. Then I can reorganize my thinking and my behaviour...
> Interviewer: Does he take him out, does he take him away from you or is it just a matter of [him] being there in person and you're still there?
> B: Yeah, it's a matter of a few seconds actually, not even a minute. And then I know that I was foolish, reorganize my thinking but, no, he doesn't have to take him away.

At another time she talked of how her husband went out on his own and how he still drove the car.

> Betty (B): ...this is the problem with him driving and stuff. It's good that he's gone and then when he comes back again it's used up all his energy.
> Interviewer: So that's almost like a respite for you, even though on the one hand you're worrying about the safety, on the other hand you're not with him.
> B: Yeah. Actually, you may not understand this. I decide not to worry. When he leaves the house I decide not to worry.

She then went on to describe all the things she did which were meaningful to her while he was out driving the car. She stated that this mental process of deciding not to worry was a respite for her. She was not worrying about him and she was engaged in activities which were meaningful to her. This mental process was not contingent on him leaving the house. She said she was able to achieve it even when her husband was with her. She was able to move out of her caregiving world and into her own world by consciously deciding not to worry. She said, "I think my philosophy of thinking things through in a sane, rational way gives me relief. I don't think I'd be able to manage otherwise. I mean I'd manage it, but I'd manage it very poorly."

Gladys confirmed the idea that moving out of the caregiving world was a mental process and described in detail a number of different situations as examples. In one situation her husband was in an institutional respite program and she did not experience that mental state of respite at all. She was at home but feeling despondent and trapped. In another, she was able to experience the mental state of respite while he was in a formal respite service, while in still another situation, she experienced the mental state of freedom and respite when he was at home and she was outside enjoying the yard. She said the following about this mental process:

> Gladys (G): When I'm outside I have some freedom, I know that I'm going to go out for an hour and I know he's going to be alright for an hour and I'm not going to think about his needs for an hour. It's a mind set.
> Interviewer: you decide that you're not going to worry for a whole hour?
> G: I'm not even going to think about it. Of course, when I get outside I completely forget about it...my mind is completely on something else that I am doing and not subliminally on the other or somebody's needs. He is in the bedroom. There's rapping on the wall and you're always tuned into that when you're in the house, but when you're outside..I completely forget about the time, he has to wait doesn't he....

All the caregivers confirmed that achieving respite for themselves was a mental process. Peter summed it up when he said, "we give ourselves our own respite." However, where the caregivers differed was in how they were able to achieve this attitude. Betty and Gladys were able to achieve it on their own without assistance from external sources. Although Gladys indicated that she could achieve this mental state of respite on her own, it was obvious from her actions that she increasingly felt the need for outside sources of respite services to achieve it. Of all the caregivers in the study, she was the one who used various types of respite services most regularly and extensively.

For other caregivers, however, the mental state of respite could be achieved only with external respite assistance. Rhea stated, "But just to tell yourself 'I'm not going to worry, what happens, happens' it's very difficult. It's just very difficult...that's not what real life is like, you just can't get that kind of respite by yourself. I don't know, I can't and I haven't met anybody who can." Rhea was the caregiver who longed to be in her personal world, to be away from the caregiving for a while, and whose husband did not want to use any type of respite services.

Being in Your Own World - The Experience of Respite

In this section I have attempted to describe the caregivers' experience of respite as they talked about it to me. Being in your own world with your own identity, being in the real world, not being in or getting out of the caregiving world, were the descriptive terms used when the caregivers talked about what respite meant to them. The prevailing concept was "freedom." Rhea, when asked what she did when her husband went to the day program, said, "...I can put on my music and I can sew and sew. It's just a little thing but it's, I don't know, it's kind of an escape." At another time, as she described a conversation she had with another caregiver, she said:

> Rhea: You're in the stroke world all the time and that's okay but there's another world out there. Like one of the men said his wife had a stroke and

> he's at home with her and he's got his medical problems. His daughter came and she was going to stay for the day with the mother and he said he went to Calgary and he walked down the main street and he said you know, there's a whole new world out there I'd forgotten. And you know that's the way it is. He said he'd forgotten there's a real world out there.
> Interviewer: You don't always have to be thinking about your partner and the handicap.
> R: Yeah and it's amazing because you don't realize it because people say 'well you're in the real world'. You are but you aren't, you know. Like he said he met some buddies and they went to the restaurant and they went and shot pool, he said 'wow, this is great stuff'. We really laughed you know, but I could see the truth in it.

The idea of the experiencing respite as being out of the caregiver world and being in the personal world of the caregiver was confirmed by Gladys in the following way:

> Interviewer: ...what I'm hearing you say is that this little world over here was very small indeed for you.
> Gladys: It didn't seem to exist. There's another little catch to that one - there were times that I'd get back into that little world and I'd say 'oh, this is what it's all about'.

When asked what it meant to experience respite, all the caregivers talked about freedom in one form or another. There was the freedom from worry, the freedom to do the things you found meaningful, freedom to get some rest, freedom to have a good time, freedom to be with your own friends, and freedom to be yourself and, most of all, freedom NOT be the caregiver. Rhea put it this way:

> Complete respite [is] where you know he's being looked after. He's fine and you don't have to have it on your mind any more. You can deal with the other things you'd like to for a change.

Milly talked of respite as feeling a burden roll off her shoulders. She talked of it as enabling her to go out with "my girlfriends" and being able to belong to a bridge club because her husband went to a respite service. Gladys talked of the wonderful feeling of being yourself again when you truly experience respite: "The thing I got out of [it] later was that I could still feel exactly like myself. I didn't know I could any more."

They all associated respite with a cognitive process not as a condition of their family member going to or using some respite service. In other words, if the caregivers did not achieve this mental state of "feeling free" from their caregiving responsibilities, they did not experience respite even if their family member was in a respite service. Marilyn summarized this concept by saying:

> Marilyn (M): Mind you if I had him in respite [meaning institutional respite bed] I'd be worrying that he wouldn't be happy. So I'd still have him on my mind.
> Interviewer: So you wouldn't consider that respite then, if you were worrying?
> M: No....

Rhea made the same point in the following manner:

> Interviewer (I): If you put [him] somewhere where you were not as comfortable or you didn't feel as confident of care that he was getting...would you have had a similar experience?
> Rhea (R): No. Because always, every minute you would be thinking of him, I would be. Even when I go out shopping for two hours or something, no matter how hard I try to get my mind off him I can't...You know it's always there.
> I: So those things when you're worrying like that, you can't say those are respite for you?
> R: No, I can't relax emotionally, I really can't. You tell yourself, I'm going to relax but you don't, you really don't.

She then told the remarkable story of how she attended a weekend reunion with her former students. She left her husband with her sister whom she trusted. She did not worry about him the whole weekend and she had a wonderful time. The following quote was a small segment of that story.

> Rhea (R): you could sit and have a bottle of beer with them and it was just like it used to be when you could tell jokes and all that and you didn't think about anything else and you felt feminine. You felt like a woman.
> Interviewer: You were in your own world, you own personal world?
> R: Yes. It was so nice...it was just like a different world.

The essence of the experience of respite or of "being in your own world," as the caregivers described it, seemed to be freedom. However, from their descriptions of this interval of freedom, the dimension of time in relation to the respite experience should also be delineated.

Time and the Respite Experience

Three important time themes appeared in the caregivers' description of their respite intervals. These three components were the length or amount of the respite interval, the quality of the respite interval, and how the caregivers used the respite time. Gladys provided a particularly rich description of these three categories of time. The first category she identified was the time she had when her husband went to a day program. He would go twice a week for about six hours each time. She said,

> The day program, was - oh this is a good time to vacuum. This is a good chance to do the things that you could do in half the time because he wasn't around. Then also - oh I'll have a bath. It's amazing how important a bath became to me...oh yes, I can even have a snooze and then look at the clock after your snooze and say - oh, another hour and a half and it starts all over again.

Gladys seemed to use this relatively short time interval for chores and other activities she could not do when her husband was at home. Other caregivers who also used adult day programs regularly would use the time interval in a similar manner. Gladys did say that sometime she used this short time period for personal enjoyment activities, such as being outdoors. Other caregivers, like Milly and Rhea, also talked of using this time for personal enjoyment activities such as golf, personal shopping, bowling, and sewing. But the time was constricted and its use was oriented to the activities linked with caregiving responsibilities such as making sure of being home on time to greet the DATS bus. When I asked the caregivers about what respite meant to them, they did not generally associate the freedom feeling of respite with this short interval of respite time.

However, the brevity of the adult day program type time interval seemed different from the brief moments of respite time Betty talked about. These brief moments did seem to provide a momentary freedom experience but were more linked with a cognitive reorienting process which allowed her to "catch her breath" and carry on. It did not seem to provide that true freedom respite experience which all the caregivers longed for.

The second category of time Gladys described was linked with those rare occasions when she would engage in events which she highly valued and enjoyed. To demonstrate she related a wonderful story of how she participated in the International Toastmaster Conference and what a great time she had and how she felt when she had to come back to her caregiving world. She said,

> ...it was just absolutely wonderful...sat around and had coffee with a number of people I hadn't seen for years, yak, yak, yak, I was there all day...everyone else was going to the LRT and I was still pumped and then I got home and it was something different too. Fred was excited and he was interested in hearing about it....

Rhea described a similar peak respite experience and how wonderful it was to participate in the weekend 40th year class reunion with her former students. In both examples the interval was relatively short, the two days that a week-end provides. However, in both stories, the freedom respite experience featured prominently in this quality type of respite interval. And both talked in detail about how this quality respite experience positively affected their ability to carry on with their caregiver activities.

The third category of time Gladys identified was linked with her husband using institutional respite services. This respite interval was much longer than the other two, lasting about ten days to two weeks. This was the time she associated with recuperating and restoring her "batteries." To illustrate this, she told a story about the wonderful refreshing time she had visiting a relative:

> I didn't need entertainment, I just needed a day in bed to do as I pleased. I loved working outside...and I did quite a bit of work outside. I called it playing outside. I came in and, guess what, I didn't have to cook for anybody and she always had something ready for me.

Rhea, Jeanette, Wally, and Peter had all used this type of extended respite services at some time for themselves. They all associated this longer time period with the freedom of the true respite experience. Wally said it in the following way:

> Then I took off and went to Vancouver. I thought 'gee I just got to get away on a rest'...I put in a couple of good weeks...I didn't have a worry...I just went and came back and felt really good for it all.

The Process of Re-entry into the World of Caregiving

Having experienced the freedom of being in their own world, how ever they managed to get there, the time always came when the caregivers had to come back into their world of caregiving. In this section, I present the caregivers' experience of this re-entry as they described it to me. Certain factors similar to the processes associated with getting out of the caregiver world influenced the processes and characteristics of re-entry. Therefore, the discussion will focus on the factors influencing the caregivers' re-entry and the characteristics of that re-entry.

Factors Influencing the Caregiver's Re-entry

How the caregivers handled the re-entry into the caregiver world seemed to depend on a number of factors and included: amount and quality of the time the caregivers spent in their own world; the nature of the respite help they used for their family member; and the condition of their dementia family member when the caregiver resumed the caregiver role.

The amount and quality of time the caregivers spent "being in their own world," seemed to influence how the caregivers re-entered their caregiver worlds. The shorter time associated with the dementia person's attendance at an adult day program did not seem to influence the re-entry to any great extent. Because this time was more oriented to chores, the re-entry seemed relatively uneventful. As Gladys said,

> ...so come 3 o'clock...I get myself in the frame of mind I am ready to let him tell me about all the things he did at [the adult day program].

The interval associate with those rare peak respite experiences described by Rhea and Gladys, which were so highly valued by them, were associated with a difficult re-entry. To demonstrate, Gladys commented about her feelings when she returned home after her wonderful experience with the Toastmaster's Conference. She said,

> ...it was just absolutely wonderful...sat around and had coffee with a number of people I hadn't seen for years, yak, yak, yak, I was there all day...everyone else was going to the LRT and I was still pumped and then I got home and it was something different too. Fred was excited and he was interested in hearing about it and then when that was over, it was like, oh my God, I'm back in prison. It was just like the walls closed in. I couldn't have felt worse. It didn't last long though, but it hit and hit hard because I had so enjoyed myself for a day and a half - this other world, this exciting world.

The emotions of feeling trapped and not being in control seem to be featured in this quote. However, when I asked whether she would do it again, she said,

> Oh, yes, I would still do it...but you didn't pine and dwell on it because for the moment you didn't know when the next [such] occasion might be coming up. But it was just completely another world...that for me was the ultimate going out.

In the interval associated with the more extended time of an institutional respite placement of the dementia person, the caregiver re-entry into the caregiver world seemed positive and was anticipated with delight. About returning after a two week holiday with a friend when her husband stayed in an institutional respite bed, Gladys said:

> Gladys (G): ...I was going every six months...I was there about 10 days and it's two days on each end. I was looking forward to Fred coming home.
> Interviewer (I): When you came back after those episodes, did you have that same slumpy feeling?
> G: No.
> I: And you were sort of looking forward to seeing Fred, you'd missed him.
> G: Yes. I had something new to tell him about, talk about and so and so.

In addition to the element of time, the nature of the respite service they used for their family member and the state of their dementia family member after the respite period were pivotal factors influencing their re-entry into the caregiving world. The story of Peter and his family demonstrated most clearly how these components influenced the re-entry and the entire respite experience. Peter and his wife, Linda, realized that, as summer approached, they needed a break from the continuing demands of their caregiving responsibilities. They assessed their situation and felt they would feel refreshed if they got one week and an additional four day weekend to themselves. However, as they explored their options for respite, the only arrangement seemingly available for their father was a one month placement in an institutional respite service. They reluctantly accepted this arrangement as it seemed to be the only respite service available to them. When they came back from their camping trips they found their father had deteriorated to the point where they could not take him home again. Linda explained:

> He has failed miserably through this and so respite - what respite. We went away and we had some wonderful times camping, but what it's done to us emotionally has been horrible...we're left with these horrible feelings of having ended his life. I mean, what we were trying to preserve for him has been lost in six weeks...what they've done is they've focused on all his disabilities and never nursed his abilities at all.

For this family the respite service was too long, the conditions in the respite help inadequate, and the dementing father's condition at the time of re-entry greatly deteriorated. Peter summarized their negative experience by saying, "Respite care is only respite if the same quality of care is offered to the patient, in a respite facility that is offered at home." With Peter and his family, it seemed that the quality of the respite interval itself did not have an impact on their re-entry into the caregiver world. It was the nature of the respite service which linked directly to the deteriorated state of their father and which dramatically influenced their re-entry.

Characteristics of the Caregivers' Re-entry

Depending on the factors influencing the caregivers' re-entry into the caregiver world, a number of different characteristics of the re-entry became evident. For example, the amount and type of time the caregiver had in "their own world" seemed, after re-entry, to be related to an initial period of despondency or feelings of depression. In the previous section, Gladys' use of the stark and powerful phrases "prison" and the "walls closing in on her" after she came home from a wonderful weekend at a Toastmaster's Conference demonstrated this point emphatically. At another time she said,

> ...there were times that I'd get back into that little world and I'd say ' oh, this is what it's all about'. Then it really made coming back to the caregiving world tougher - for a couple of hours.

When the freedom for the caregiver was linked to times of separation such as institutional respite placement or adult day programs, the characteristic feelings of the caregiver at re-entry were different. That initial period of despondency did not seem to be present. The following quote from the interview with Gladys demonstrated this point:

> Gladys (G): ...I was going every six months...I was there about 10 days and it's two days on each end. I was looking forward to Fred coming home.
> Interviewer (I): When you came back after those episodes, did you have that same slumpy feeling?
> G: No.
> I: And you were sort of looking forward to seeing Fred, you'd missed him.
> G: Yes. I had something new to tell him about, talk about and so and so.

As this quote indicated, Gladys seemed to feel better about her situation, there seemed to be a renewed feeling of companionship. At another time, she talked of anticipating the re-entry after her husband had been in the day program, because she felt better for the time she had to herself. She said,

> ...and now he's coming home and instead of feeling resentful and making sure I have not laid heavies on myself...I have to do this, I should do this, and then only getting half of it done, I have not done enough for myself. So come three pm any time after that he's going to be home, I've lined up - oh I've made some rice pudding, he loves rice pudding. I enjoy his coming home...Then I've got myself in the frame of mind and I am ready to let him tell me about all the things that he did at [the day program].

Rhea made a similar point about her re-entry after institutional respite placement. She said,

> I've had him in respite once and when he came back he was in a much better frame of mind...and I don't think I lost my temper for about a month after that...he didn't annoy me the same way, I was more easy going, I think I had a better sense of humour, just all the crazy things even when he got angry at me, it didn't bother me the same way. I felt that I had. It's as though my emotions are rejuvenated and you can handle it much better and it slowly got back to the same level of frustration.

On the other hand, the caregiver re-entry back into the caregiver world could be characterized by feelings of guilt, devastation and reduced ability to cope with caregiving. The example of Peter, in the previous section, provided evidence of this. Peter made the following brief but telling statements; "How did we enjoy our summer without Dad? It was wonderful, beautiful time. How do we feel now? Awful!" and "We went away and we had a wonderful time camping, but what it's done to us emotionally has been horrible." The quality of the respite time was high but the condition of the dependent father at the time of the Peter's re-entry into the caregiver world left the entire family feeling devastated and guilty. It reduced the family's ability to carry on with their caregiving responsibilities to such an extent that they were unable to continue in that caregiver world. Their father remained in the institution permanently.

Model of the Caregiver Experience of Respite

In the process of describing the 10 caregiver stories and presenting the emerging themes of the respite experience in the context of their caregiving worlds, a cohesion within the data appeared. The first hint of this connectedness surfaced after the 10 caregiver narratives were recorded. It was presented as a preliminary model of the respite experience and was set in the context of the caregiving world as described by each of the caregivers. The main features of this preliminary model included: the caregiver world; the process of temporarily getting out of the caregiver world; being in your own world as the quintessential experience of respite; and the process of re-entry into the caregiver world.

After the more detailed analysis of the collective data, specific factors and characteristics were identified and described within each of these main features of the preliminary model. As I summarized and categorized the themes within the collective caregiver data, the relationships among and between the themes became more evident. Since the main purpose of this study was to gain a clearer conceptual understanding of respite and, in keeping with the thrust of grounded theory (Strauss & Corbin, 1990), I developed a model based on the analysis of these collective data. Developing this model, using the process of integrative diagraming (Strauss, 1987), was valuable in that it helped to clarify the various components of the respite experience and the relationships between these components. The model, as presented in this thesis, is an initial attempt at articulating the experience of respite in the context of caregiving. Figure 2 following, illustrates the model of respite as I interpreted what the study caregivers told me about their perceptions of respite within their caregiving experiences. It outlines the relationships between and among the various themes, patterns and components within the individual caregiver stories and from the collective caregiver data, as I understand them.

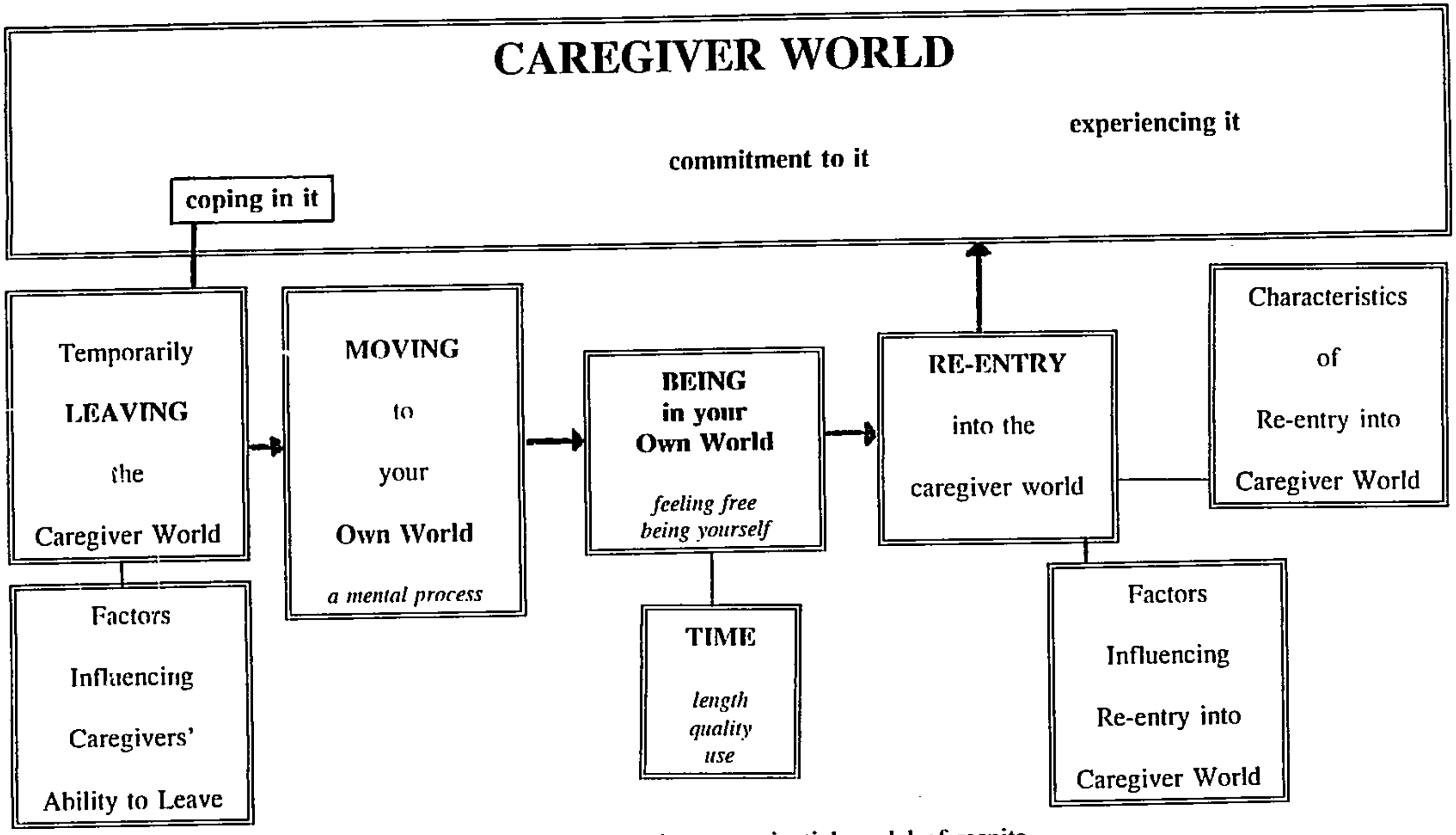

Figure 2 The caregiver experiential model of respite

Summary

Providing an overview of the model seems an efficient approach in drawing together the findings presented in this chapter. Therefore, as outlined in Figure 2, I will summarize the findings of this study by highlighting the components within the respite model.

Based on the rich contextual caregiver descriptions, the caregiver world is represented as the dominant feature of the model. This caregiver world includes the day to day experience of living in it, the caregivers' commitment to it, and how they cope within it. Temporarily leaving or getting out of this dominating caregiver world is one of the many coping strategies used by the caregivers. Factors which influence the caregivers' ability to move out of the world of caregiving are prominantly positioned in the model to illustrate their pivotal role in caregivers attempting to "get out" temporarily.

Because the caregivers described the experience of respite as a cognitive process which seemed to imply an action or movement occurring at a deeply personal level, the model includes a motion component called "moving to your own world." Within the model, this motion is toward the central feature of the model: the respite experience itself - the mental state of feeling free, being yourself, and doing your own thing. The element of time within the respite experience is featured as a separate component because of its importance to the understanding of the various respite experiences. Because leaving the world of caregiving is temporary the model includes the features and characteristics of the re-entry process.

To conclude, the findings give credence to the dominance of caregiving in the lives of the caregivers in this study. The findings also contextualize the respite experience as a coping strategy within this over-shadowing caregiver world. Further, from the caregivers' perspective, the experience of respite is the movement out of this world to a mental state of feeling free, the true essence of the respite. Factors which influence the movement out of the world of caregiving are presented to demonstrate their importance for the caregivers. Finally, the influencing factors and the characteristics of the re-entry process are included to highlight the impact the respite experience has on the caregivers' ongoing ability to manage in their situations. In the final analysis, the extent to which the respite experience can contribute to the ability of the caregivers to continue in their caregiving role is the ultimate test of the respite's value.

Chapter 5

DISCUSSION OF FINDINGS

In Chapter 2, social support theory was identified as the informing theory for the study. As the research process of the study evolved and the data were analyzed, it became increasingly evident that the caregivers' experiences of respite also seemed closely linked to the theories of stress and coping, particularly as outlined by Pearlin (1989) and Lazarus and Folkman (1984). Therefore, I will discuss the findings in relation to both of these informing and related theories. In addition, I will use a secondary review of the respite literature to enhance the relevance of the interpretative discussion process within this chapter.

The purpose of this study was to describe and gain insight into the respite experiences of family members caring for dementia persons. The caregivers provided rich contextual data about their complicated and difficult situations. These data formed the contextual backdrop for my interpretative discussion of the data related to the caregivers' experiences with respite. The findings indicated three distinct components or phases to these caregiver experiences. These phases included: getting out of the caregiver world; the actual experience of respite, i.e., the feeling of freedom associated with "being in your own personal world"; and returning to the caregiver world. In addition, various factors influenced each of these components of the caregiver respite experience. These three process components and the related influencing factors provide the theoretical structure to the discussion in this chapter. Since the relevance of stress and coping theory to this study was not initially apparent, a discussion of its various components and concepts was not included in Chapter 2. Therefore, I will now explore these concepts in relationship to the study findings.

Stress and Coping Theories

Rationale for Selecting this Framework

As I listened to the stories of the family caregivers in this study, as they told me about the caregiving problems they encountered, how they tried to solve these problems on an ongoing basis, how they developed strategies to get through each day, how they attempted to manage their emotions in dealing with their difficult and complex situations, and how they viewed respite for themselves in the context of these complexities, it became increasingly evident to me that the concept of "coping" seemed to portray how the caregivers proceeded with their lives. Social supports seemed important to them but the supports evident in the stories operated as resources which they could elect to use or not use in order to manage their unique circumstances. All the social support resources that were used seemed to have only one purpose and that purpose was to help the caregivers cope with their situations. In other words, the caregivers had to activate a coping strategy within themselves before the social supports, such as formal or informal respite help, could become available to them. The caregivers who could achieve a mental state of respite without outside assistance, were, in fact, coping with their situations without the help of a social support structure. The caregivers who could achieve this mental state of respite only with outside help used the social support system to assist them in better coping with their circumstances.

To interpret the family caregiver circumstances from a coping perspective and to position their experience of respite within that context seemed appropriate and logical. If the purpose of this study was to understand the caregiver experience of respite, then it was essential for me, as the researcher, to search out the essence of the respite experience from their stories. Their perspective must be clearly represented in my interpretation of what they told me. They told extensive stories of how they coped with their situations and what respite meant to them in their processes of coping. To stay with a social support informing theory for my discussion and interpretation would have misrepresented their stories. To my understanding, interpreting the experience of respite from a social support perspective, as I did in Chapter 2, represented a "system" perspective. To interpret the experience of respite from a coping perspective represents the caregivers' perspective.

Therefore, I will outline the main features of stress and coping theories in the following section. However, in this chapter, as I interpret the caregivers' stories, social support will be considered in the context of stress and coping theory. Viewing social support as a way of coping, as a theoretical subset of coping, is receiving increasing attention in the literature (Greenglass, 1993; Gottlieb & Gignac, in press). This, then, should provide a more accurate theoretical backdrop for the interpretation and discussion of the study findings.

Concept of Stress

Lazarus and Folkman (1984) define stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being." (p.19) This definition emphasizes the relationship between the person and the environment and takes into account characteristics of the person on the one hand and the nature of the environment on the other. A most important concept of this definition is that the judgement of whether a particular person-environment relationship is stressful hinges on the person's cognitive appraisal of the situation.

Pearlin and Lieberman (1981) and Pearlin (1989) enhance this definition by indicating that stress, which is more process oriented, has three main components: stressors, mediators, and outcomes. Stressors, defined as the experiential circumstances which give rise to stress, are seen as arising out of two broad circumstances: the occurrence of discrete life events or life event stressors and the presence of relatively continuous problems or chronic strain stressors. With life event stressors, stress arises because changes in life situations are involved. However, the stress does not necessarily arise out of change per se. Rather, it is the quality of change which is potentially damaging to people, particularly changes in life circumstances which are seen as undesirable, unscheduled, non-normative, and uncontrolled.

Chronic strain stressors are those types of stressors which arise out of relatively enduring problems, conflicts, and threats occurring in the daily lives of people. Pearlin (1989) specifically identifies role strain as a major contributor to this type of stress because, typically, considerable importance is attached to the major roles in our lives. This focus on role strain can reinforce the links between the conditions which largely structure people's activities, relationships, experiences and their well-being. He then outlines some examples of types of role strain which might contribute specifically to chronic strain. These include: role overload, a condition that exists when demands on energy and stamina exceed the individual's capacity; interpersonal conflicts within roles where problems and difficulties arise among those who interact within complementary roles, i.e., husband/wife, parent/child; inter-role conflict which entails the incompatible demands of multiple roles such as demands of work and family; role captivity which exists when one is an unwilling incumbent of a particular role, for example, a wife who feels forced to be the caregiver to her husband when she would prefer employment outside the home; and role restructuring where roles undergo inevitable change, for example, change associated with the aging process or with maturation.

It is, perhaps, in this last example related to role restructuring, that the convergence of life events and chronic strains is most evident. Pearlin (1989) maintains that events and strains converge in at least three ways in stressful experience: events lead to chronic strain; chronic strains lead to events; and strains and events provide meaningful contexts for each other. It is the nature of relevant conditions preceding the event that may influence whether an event is experienced as stressful.

Finally, Pearlin (1989) emphasized the importance of values in his conceptualization of stress. He stated that values regulate the effects of the experience by regulating the meaning and the importance of that experience. The degree of threat people experience from the circumstances they face depend, to large extent, on the values they hold; that is, what they define as important, desirable, or to be cherished. Certain values when combined with certain social conditions are especially conducive to generating stress. For example, in a situation where a wife was the primary caregiver to her dementing husband, the marital relationship was valued highly by her. Yet, because of the deteriorating mental condition of her husband, this relationship could not be sustained and, in fact, more resembled a parent-child relationship which could degenerate into a very stressful living situation for the wife. This type of stressful scenario was evident throughout the caregiver stories in this study.

Although to some extent, values influence the interpretation of an event as stressful/non-stressful, the greatest influence in how potentially stressful events are experienced are those factors identified by Pearlin (1989) as mediators. The two dominant mediators he outlined were coping and social support. Other mediating constructs, although not as clearly delineated as mediators in the literature, include the self-concept factors of self-esteem and mastery and personality factors such as hardiness and invulnerability. The focus of the discussion in this chapter will use the concepts of coping and social support. Social support was profiled in Chapter 2. In the following section, the concept of coping will be outlined more specifically.

Concept of Coping

Pearlin and Schooler (1978) and Perlin (1989) have described all coping as changing the situation from which the stressors arise, managing the meaning of the situation in a manner that reduces its threat, or keeping the symptoms of stress within manageable bounds. Lazarus and Folkman (1984) expanded this to define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." (p.141) In this definition, coping is process oriented focusing on the efforts made to manage the stress rather than on the outcome of those efforts. It is also management oriented so that additional strategies such as minimizing, avoiding, tolerating and accepting stressful conditions can be included as well as mastery of the stressful environment. Fundamental to this definition is that coping is determined by cognitive appraisal. That is, how a person copes with a particular event is contingent on the interpretation by the person of that stressful event or situation.

Further, these authors differentiate between problem-focused coping directed at managing or altering the problem causing the distress and emotion-focused coping directed at regulating emotional responses to the problem. In problem-focused coping the strategies were similar to problem-solving and were directed at defining the problem, generating alternate solutions, weighing the alternatives in terms of their costs and benefits, choosing among them, and acting. These strategies could also be directed inward or at the self to include such strategies as motivational change, shifting the level of expectation, or reducing ego involvement. In emotion-focused coping all the stress reducing strategies involve a diminution of the threat by changing the meaning of the situation. Strategies such as avoiding, minimizing, distancing, selective attention, positive or downward comparisons, and finding positive value from negative events are examples of this type of coping.

People use both problem and emotion focused coping to deal with the demands created by stressful situations in their lives. From the caregivers' descriptions of respite in the context of their complicated caregiving lives described in this study, it seemed that the emotion-focused strategies of avoiding and distancing were the operational coping forces which helped them get out of their caregiving world. These concepts of avoidance and escape, in the context of the caregiver respite experiences in this study and of coping theory, will be discussed in greater detail in subsequent sections.

Further, the resources available to the person when managing a stressful event is another concept significant to coping. Resources which are primarily properties of the person include such factors as the person's health and energy, their system of beliefs, their problem-solving skills, their personality traits, and their social skills. Resources linked with the person's environment include material (goods and services that money can buy) and social resources. The social support available to the person is pivotal in this area and its buffering effect on stressful situations is well established (Stewart, 1993).

The evidence that the caregivers in this study viewed respite assistance as a resource for themselves was strong throughout their stories. They saw it as a resource outside of themselves and their caregiving circumstances, although it was a resource which, if they could access it, was much desired and highly valued. Their experience of respite, however, was not necessarily contingent on this resource being available to them. The experience of respite was a deeply personal one which could be achieved without social support resources, although it was facilitated for many by outside respite help. It was this insight, that respite help as a resource to the caregiver and the caregiver personal experience of respite was not the same concept, that led me to reorient my thinking to consider coping rather than social support as the dominant informing theory for this study.

Further, Lazuras and Folkman (1984) say that, regardless of the availability and adequacy of resources, there were times and situations when constraints impede their full use. These constraints might be operating at personal levels which arise out cultural values and beliefs. For example, there may be many different forms of social support available but the person may be unable to use them because of how these supports are construed. These constraints may also arise out of the environment where there is competition for the same limited resources and choices have to be made in allocating them. The constraints could also arise out of the actual level or degree of threat the person is encountering. Excessive threat could be so overwhelming that it could interfere with problem-focused coping. The person's cognitive functioning and the capacity for information processing might be impaired because of the high threat in the situation. In this study, the cognitive difficulties a number of the caregivers experienced in getting themselves to use respite resources provided evidence of this notion. The idea of values and attitudes interfering with the caregivers' ability to access respite resources will be discussed again in subsequent sections.

A final point of clarification in defining coping, is to consider the concept of control. Coping with a situation means attempting to control it. Lazarus and Folkman (1984) differentiate between control in how stressful situations are interpreted or appraised and control as actual coping. Control as cognitive appraisal is grounded in how the threatening event is interpreted and in the meaning or significance of that event to the individual. It is rooted in the person's beliefs and commitments. Control as cognitive appraisal can be seen in the work of Moch (1988) where she outlines the concept of "personal uncontrol" (p.120). The cognitive appraisal operational in this concept is one of letting go, an acceptance that one does not have the power over all, or even many events, people or conditions that affects one's life. Having the belief that allows one to give up control to a greater force is a way of appraising that situation to facilitate coping.

On the other hand, Lazuras and Folkman (1984) state that, for the concept of control to be linked to actual coping, it must be linked to evidence of effort on the part of the individual facing a threatening situation. It can't be a passive state of accepting the conditions of one's life. Averill (1973, cited in Moch, 1988) distinguishes between three types of personal control which require effort: behavioral control, a response which may directly influence or modify the characteristics of a threatening event; cognitive control, the way a potentially threatening event is interpreted and incorporated into the individual's way of thinking; and decisional control, the opportunity to choose among various courses of action. In activating these processes, effort is required by the person in attempting to regulate, direct or dominate a situation or event and is, therefore, related to actual coping. Of the three types of control identified, the notion of cognitive control seems the most evident in how the caregivers in this study experienced respite. The mental state of feeling the freedom of respite seemed to be a cognitive process over which they felt they had some control; as Peter said, "we give ourselves our own respite."

In the next section, this theoretical backdrop of coping will be used to explore the findings of the study, as described in Chapter 4. I will also discuss the study findings in relation to the current respite literature. Each component of the respite model and the relating factors of that component will be discussed separately. Before I can proceed with this discussion, however, the process of temporarily leaving the caregiver world or, experiencing respite, must be established as a coping strategy. It can, therefore, serve as a "pull-down menu" for the subsequent discussion and interpretation of the caregiver experience of respite in the remainder of the chapter.

Temporarily Leaving the Caregiver World as a Coping Strategy

The caregivers, in their descriptions of the respite experience, created an image of two spheres of existence. One very large and dominating sphere was the caregiving world while a much smaller but very special sphere was that part of their lives where they were NOT the caregiver. Different caregivers used different phrases to describe this part but generally it seemed to be a mental space which they considered as "their own world." To be in this personal space of their own world was the quintessential meaning of respite to the caregivers. Is then the process of "temporarily leaving the caregiver world" in order to be in "their own world" a coping strategy for caregivers?

Previously I noted that Lazarus and Folkman (1984) delineate two main categories of coping strategies which they call problem-focused coping and emotion-focused coping. Further, these authors identify "avoiding" behaviours as an example of emotion-focused coping. Coping by avoiding is a technique used by people to get away from the source of stress and can include such activities as vacation, hobbies, and physical activities such as jogging (Folkman & Lazarus, 1991). These strategies are successful in that they temporarily draw the attention of the person away from the stressful situation. They also tend to neutralize the distress emotions and help the person's emotional state improve (p.215).

The caregivers' cognitive processes of leaving or escaping from the caregiver world seem congruent with this notion of coping. The caregivers were not seeking to abandon their situation, to run away from it. They were merely attempting to divert their attention from their situations for short periods of time so that they could feel better within themselves. In this improved emotional state they anticipated they would be able to continue with the responsibilities of their demanding circumstances.

An examination of this process of coping by avoidance in relation to the caregivers' stories in this study, reveals its complexity. According to the caregivers, this coping strategy was not a single act or thought process. There seemed to be at least three dimensions evident in their descriptions and these included: recognizing the need to get out of the caregiver world; giving themselves permission to actually "escape" from it temporarily; and having the social support resources available to facilitate the "escape." Each behaviour represented a behavioural dimension congruent with coping in that each was an attempt to deal with stressful life circumstances. However, recognizing the need to "get out" was conceptually and practically different from the caregivers permitting themselves to actually engage in the "escaping" behaviour. As well, while all of these behaviours were internal cognitive and emotional caregiver processes, the third dimension, the availability of social support resources, was linked to both internal emotional and external environmental resources. Each of these three dimensions will be discussed separately in the following sections.

Recognizing the Need to "Get Out"

The "recognizing" behaviour was an active, conscious cognitive appraisal process that seemed to arise out of the realization that past strategies were not adequate and not working. This is congruent with the notion of the cost-benefit action theory perspective of coping (Frese, 1991, p.185). This theory posits that since coping is always linked with stress, the methods used to manage this stress are not highly practiced and automatic. Therefore, coping involves effort that will arise only out of necessity when the person realizes the "old" coping strategies are no longer effective. This is similar to a process of cognitive appraisal which Lazarus and Folkman (1984) call primary stress appraisal. It is an evaluative process of categorizing a stressful situation or event by identifying the meaning and significance of it. It is the first step in recognizing the harm or potential threat or challenge in a situation or event.

This first step, "recognizing" behaviour, was evident in the quote from Rhea's story: "Then you realize, hey, I'm not managing as well as I should. You know that's when you admit to yourself that [you need relief]." It was also evident in Betty's story although she was not using formal service at the time of the interviews. When asked whether she felt the need for relief she said, "We're not to that point yet...so you know I have that in reserve if that time ever comes...but it isn't to that point." The recognizing behaviour is a first step in the cognitive appraisal of acknowledging the possible threat to the ongoing equilibrium and stability of their situation. In the first example, the caregiver was recognizing that her situation was precarious and that some harm might have already occurred, while in the second case, the recognition was of possible future instability and threat.

However, the recognition of the need for relief or respite does not necessarily result in the mobilization of coping efforts by the caregivers. What the recognition behaviour did do was to alert the caregivers in this study that different coping efforts were required to maintain stability in their situation. The coping strategies that were being used did not seem adequate and not as effective as they once were. This recognition is a type of "wake up call," often triggered by dismay at the caregivers' own inappropriate coping behaviour, that a change in the way they have been managing the situation is needed.

Another aspect of the "recognizing" behaviour is the element of caregiver control. As I stated earlier, coping with a situation means attempting to control it (Lazarus & Folkman, 1984). In the Chapter 4 description of the caregivers' circumstances, there was evidence of many different coping behaviours which seemed to provide the caregivers with a measure of perceived control. Examples of these coping strategies included: having a sense of humour; having a specific and regular schedule; having patience; engaging in physical activity; engaging in recreational activities; having supportive friends and family; having spiritual beliefs and a supportive church; being able to solve specific problems which helped to reduce the worry or constant vigilance; knowing about and having access to resources in the community; having adequate financial resources; having a realistic outlook on their situation; acknowledging the ongoing decline in their dementia family member; redefining and reframing the interpretation of their situation; and mental self talk. All of these strategies were coping efforts to maintain control of their situation. It seemed that, in the recognizing process there was an acknowledgement that their situation might not be controllable. Recognizing that there was a need for respite required the realization that, at least to some extent, the coping efforts they had been using were not totally effective in maintaining stability in their environment. It required an admission, even if just to themselves, that they were not as much in control as they might like to be.

This seemed to be the essence of Betty's comment when she said that she did not need respite or relief just yet. She could still manage; she was still in control, although she acknowledged that she might probably use respite in the future. It is a type of cognitive rehearsal (Houston, 1987). Betty was going over in her mind in some detail what may happen in the future and rehearsing her response to it. By naming the possible uncertainty of the future and by suggesting coping options for herself, Betty was attempting to anticipate her future situation and to maintain control of it.

Giving Themselves Permission to "Get Out"

The "recognizing" behaviour does not necessarily translate into the active behavioural and/or cognitive process of "getting out" of the caregiver world. The second dimension of getting relief, is the caregivers admitting to themselves that it is "okay" for them to get away from the responsibilities of caregiving for a while, coming to an emotional resolution that this type of self serving behaviour is, indeed, appropriate behaviour for them. It seems to be a process of giving themselves permission to actually "escape" from the caregiver world. For some of the caregivers in the study this was a difficult and emotional process, while for others it was relatively easy. This reluctance in caregivers to give themselves permission for respite is congruent with the observations made by Rosenheimer and Francis (1992) in their California survey of families using an Alzheimer's respite program. These authors talk of the guilt the caregivers felt in leaving their dependent family members at their program and actually use the word "permission": "they were reluctant to give themselves permission for 'time off'" (p.199).

Why is this permission process so difficult for some and relatively easy for others? One possible answer might relate to the concept of commitment and how it affects the perception of stress. Lazarus and Folkman (1984) state that the greater the strength of the commitment the more vulnerable the person is to psychological stress. The strength of commitment also impels a person toward a course of action that can reduce threat and help sustain coping efforts in the face of obstacles.

Although all the study caregivers indicated a strong commitment to caring for their dementing family member as is illustrated in Chapter 4 in the section on the commitment to caregiving. This theme was perhaps most strongly evident in the story of Marilyn. She talked of how lucky she was to still have her husband even though his mind was not that clear and he was a lot of work for her. She would have it no other way. She saw no other purpose to her life but to look after him now. For her, this process of allowing herself to get some relief from her caregiving was somewhat problematic because of this commitment. She really enjoyed playing bridge with her friends but, because he seemed discontented when she went out in the evening without him, she was cutting back on this respite activity. The only reason she was able to get some relief when he attended a day program, was because he enjoyed the program and being with the people there. If he had not liked it, she would not have been able to get this relief. It is because of the strength of the Marilyn's commitment to her relationship with her husband that she made these decisions with little resentment.

Although the commitment theme was strong throughout all the interview data, there remained considerable discrepancy between the caregivers in how they considered their own need for respite. They all articulated a deep commitment to their dependent family member which might account for the stress they were experiencing in their circumstances. It did not, however, seem to explain the differences in the way they perceived and used respite.

The concept of coping efficacy (Lazarus & Folkman, 1984; Pearlin, 1978) might provide some clarification on this point. Coping efficacy focuses on the effectiveness of a coping strategy, i.e., how well does a particular strategy result in alleviating or managing the stressful life event. Additionally, Bandura's conceptualization of self-efficacy focuses on the idea of efficacy expectations, the beliefs about how capable a person is in performing certain behaviours which lead to the desired outcome (Strecher, DeVillis, Becker, & Rosenstock, 1986). Coping efficacy focuses on the strategy itself while self efficacy highlights the individual's belief in their own ability to use that strategy.

These two concepts together provide some insight into how the caregivers in the present study gave themselves permission to escape from the caregiver world. It seemed that the caregivers who had confidence articulating their need for relief, in acknowledging that respite was a useful strategy to manage their situation, and in acting on these beliefs were the ones who had the least difficulty in cognitively giving themselves permission to escape their world of caregiving. This confidence was evident in the stories of Betty and Gladys. The evidence was strengthened by the fact that Betty was not using respite services at the time of the interviews while Gladys was using them regularly. Betty conveyed a sense of confidence in her ability to make judgements and decisions affecting her husband and how she reacted to him. Gladys conveyed a sense of competence in making decisions that led her to use respite services regularly as a coping strategy. Both had a strong sense of self-efficacy in recognizing how they could cope effectively with their situations.

What then of the other caregivers who had difficulty in permitting themselves the escape that respite might provide? Is it that they had lower self-efficacy in acknowledging their need for relief? Is it the fact that they had not experienced the effectiveness of this coping strategy for themselves? Perhaps, beliefs and values were other factors which need to be considered in this discussion. According to Lazarus and Folkman (1984), beliefs are personally formed or culturally shared notions about reality. They form a perceptual lens for the interpretation of an event or situation and shape the understanding of its meaning. People are generally unaware of their influence; the impact of beliefs and values is often realized only upon a sudden loss of belief or a conversion to a new belief system.

Values related to role expectation as wives was a powerful theme throughout the data in this study. For Marilyn the role of wife was paramount in her value system. If the living out of that role resulted in her being a full-time caregiver to a disabled husband, so be it, she said. She accepted the hassles and personal limitations associated with that situation without much difficulty. As a result she did not require much for herself in the way of relief; two mornings a week to herself when her husband attended an adult day program and a little bridge with her friends once a week was enough for her to continue in her situation with a reasonable sense of contentment.

For Betty the role of wife was also important but, in addition, she held other values and beliefs which strongly influenced her approach to her caregiving. She highly valued her personal identity apart from that of wife and did not let the caregiving role dominate her entire life. She also valued the independent identity of her husband. So she did not hesitate to let her husband go out on his own even though his safety might be compromised. She also held strong beliefs about how she managed the stress related to this behaviour; she started to worry and act only after a designated time period had expired. And she articulated clearly that there was room in her belief system for mistakes. Therefore, although she was not using formal respite, she conveyed a strong sense that she already had respite built into her approach to caregiving. She considered respite an attitude which could be generated only from within the caregiver. This was congruent with the values and beliefs she so clearly described. Respite as a mental attitude will be discussed in more detail subsequently in this chapter. With this system of values and beliefs in place, Betty did not seem to have difficulty in acknowledging her need for respite or in permitting herself to have access to this respite, although she was not using any formal service at the time of the research interviews.

Rhea's values and beliefs in relation to role expectation revealed yet a different perspective. She, like Marilyn and Betty, valued the role of wife and what was expected of her as a wife. This was evident in the fact that she retired early from her teaching profession at the time of her husband's stroke in order to look after him full-time. As she reflected back on this decision, she resented having made it because she had lost the professional and independent identity she valued so much. Initially, she pursued what she thought was expected of her as a wife. Now she felt she had sacrificed too much personally and wished she had done things differently. Because she did what she felt was expected of her at the onset of her husband's illness, she now felt that she did not have the independence to make decisions about the use of respite services which might benefit her more than her husband. She desperately felt the need for relief from her caregiving responsibilities yet felt trapped, unable to make the decisions which would give her this relief. Her husband expected her to look after him, did not want to go to respite programs, and did not recognize his wife's need for relief. She felt she could not go against his feelings because she had never done that in the past. Because of these feelings of being trapped, Rhea had great difficulty in permitting herself to escape from her caregiving world. She had acted on her values and beliefs at the initial stage of her husband's illness. She still felt strongly that her place was beside her husband. However, juxtaposed against these powerful beliefs about her role as supportive and dutiful wife were her strong values in relation to her personal and professional identity and her belief that she also needed some nurturance. This resulted in a deep internal conflict which seemed to add to her stress and led to her difficulty in accessing respite services which might conceivably benefit only her. It is interesting to note that she was probably the most articulate of all the caregivers in this study, delineating her need for respite and describing how she felt when she got relief.

Gladys, too, valued her role as wife but, unlike Rhea and more like Betty, she maintained an independence in her identity in relation to her husband throughout their marriage. She was able, at the onset and throughout his illness, to maintain this sense of separateness from her husband in her personal identity. So she cared for him, made extensive sacrifices doing it, but she never seemed to lose sight of her need to get out of the world of caregiving for short periods of time. She used respite services regularly and without feelings of guilt or concern. She realized that if she did not escape regularly, she would not be able to live out her values related to being a caring wife. Like Betty, she possessed the value system which allowed for the idea that respite is a state of mind. Accessing respite within this value system was completely acceptable to Gladys. As well, because Gladys had used the respite services frequently with positive results she had a strong coping efficacy in the use of this strategy. She had confidence that this approach would give her the relief she needed to continue in her caregiver situation.

The stories of Marilyn, Betty, Rhea, and Gladys reflected the themes identified by the other caregivers in the study, i.e., how values and beliefs permitted them to have relief from their caregiving responsibilities. However, the story of Anna requires some discussion here as well. In Chapter 4, there was an extensive quote outlining her struggle with the permitting herself to use a respite service. The marriage in this situation had been conflictual and unsatisfactory. Anna had taken responsibility for all aspects of the family; she had raised the children and worked outside the home to support the family unit. She stated that she had always made decisions in her life to maximize the benefit for everyone else in the family; she had never given consideration to herself. She stayed in this marital relationship because of the role expectation that women stayed with their husbands; at one point she said it was the marriage vows which kept her in the marriage, "for better or worse, I promised." Now, faced with caring for a demented husband who had given her a difficult life, she was resentful and bitter. And yet, she was almost immobilized in making the decision to use respite. It was only after considerable pressure from many sources that she proceeded to use a respite arrangement. Perhaps the values related to the spousal role expectation and her perception of the wife's duties in the marriage relationship and her feelings of subservience to other family members were so strong and so entrenched that she could not make the decision without considerable encouragement and support. Also, in a related theme, she had not used respite services before so she did not have a sense of the effectiveness of this coping strategy for her. So, the combination of Anna's values and beliefs concerning her role expectation together with a low level of coping efficacy in relation to the use of respite (Pearlin, 1978) are possible explanations for her ambivalence and distress in making the decision to allow herself the help she needed so much.

Availability of Social Support Resources

The third dimension operational in the process of caregivers using respite as a coping strategy is the caregiver perception of the availability of social support resources. Social support resources refer to what is available to people in their environments to help them develop their coping repertoires (Pearlin & Schooler, 1978). Social support resources are present in the interpersonal networks of people's lives which can become the source for crucial support in times of stress. Pearlin and Lieberman (1981) further state that it is the quality of the interpersonal networks, not just their existence, which is significant in assisting people to cope with difficult life situations. They identify the exchange of intimate communications and the presence of solidarity and trust as most important. Stewart (1993) points out that social networks influence help-seeking behaviours from formal and informal sources. The presence of quality social networks also influences the ability to appraise the causes of and solutions to the stressors. These social support factors together influence the coping process. The influence of social resources was perhaps most evident in Anna's situation. If Anna had been left to her own devices, she might not have overcome her ambivalent feelings and used the respite service. It was only with the support from the formal system, encouragement from the home care nurse and the family doctor, and the informal support from a trusted daughter that she finally decided to use the respite service.

A second example was evident in Rhea's story. The lack of support from the social network might be a reason for Rhea's difficulty in making the decisions allowing her to get out of the caregiver world for a while. It was only when her sister offered to keep Rhea's husband for the weekend that Rhea could attend a highly anticipated event without concern or worry. Rhea considered this event quintessential respite for herself because she felt she was her own person during the event and she felt renewed and refreshed having attended it. It was the presence of a quality social network which created the environment so that Rhea felt comfortable with the decision to attend the event.

Concluding Comments about "Getting Out of the Caregiver World" as a Coping Strategy

To conclude, the emphasis in the preceding discussion has been on establishing that the caregiver process of "getting out of the caregiver world" is a coping mechanism for the caregivers in this study. Three dimensions of this process of getting respite were identified and included: caregivers recognizing their need to get out of the caregiver world, giving themselves permission to actually "escape" from it temporarily, and having the social resources available to facilitate the "escape." These dimensions were then linked to the concepts of coping theory as outlined by Pearlin (1978) and Lazarus and Folkman (1984) and were discussed in relation to caregiver stories and the general findings in the study.

It also seemed that the process of "getting out of the caregiver world" was linked with the avoidance strategies of emotion-focused coping (Folkman & Lazarus, 1991). It required a recognition of the need for "escape" by the caregivers, then an emotional or psychological process of saying it was "okay" to try and get respite for themselves, and finally either a physical or a mental action by the caregiver which might result in respite actually being achieved.

It seems clear that the "process of getting out of the caregiver world" is a coping strategy among many other strategies used by caregivers to manage their trying circumstances. Therefore, the subsequent discussions and interpretations of the caregiver respite experience are enveloped within this "getting out" process. In other words, the following discussion attempts to illuminate the components within the "getting out" process of respite which, because it has been established as a coping strategy, can now serve as a "pull-down menu" for the subsequent discussion and interpretation of the caregiver experience of respite in the remainder of this chapter.

Factors Influencing the Caregivers' Ability To Get Out of the Caregiving World

The examination of the caregivers' understanding of respite reveals a number of factors which influence the caregivers' ability to actually "get out of" or escape from the caregiving world. As outlined in the respite model in Chapter 4, these factors include the nature of the pre-illness relationship, personality-based factors, length of time in the caregiving role, the stage of the dementia illness, role expectation, and the attributes of the respite help. These factors either facilitated or impeded the escape.

Nature of Pre-Illness Relationship

In reflecting on the nature of the relationship between the caregiver and the dementia person prior to the onset of the dementia symptoms a number of interpretations come to mind. Kuhlman et al. (1991) point out that caregiving takes place within a current and historic context; one cannot separate the past from the present. Biegel, Sales, and Schulz (1991) also link the nature of this pre-illness relationship with the course of the caregiver experience. These authors suggest that those caregivers who have received more positive gratification in their prior relationship with the care recipient may feel more motivated to provide care.

The data in the present study seem to support this notion as well. There was evidence, in Marilyn's story, of strong past relationships sustaining and mitigating the present difficult caregiver circumstances. There was also evidence, in Anna's story, where the past conflictual and difficult relationships were directly and negatively influencing the present demands of caregiving.

These past relationships also seem to influence the caregiver ability to get out of the caregiver world. The data in this study suggest that the caregivers who experienced conflictual relationships in the past had greater difficulty in permitting themselves to escape from their world of caregiving. The caregivers who experienced more stable and affectionate relationships seemed more readily able to escape from their world of responsibility without extensive emotional distress. The two contrasting examples of Gladys and Anna demonstrate this difference quite clearly. This difference in caregiver reaction linked to the past relationship with the care recipient is congruent with the findings of the study by Morgan and Laing (1991) which explored the impact of an Alzheimer's disease diagnosis on the caregiving spouse. They note that the quality of the couple's previous relationship influences a number of aspects of caregiving: the motivation for providing care; the ability to tolerate and manage their spouses' care; and the use of support services. They report that if the relationship had been a close and loving one, the caregivers seemed more motivated to care for their spouse, were more tolerant and better able to manage their spouses' difficult behaviours, and were more open to using support services than were the caregivers from less intimate and more unstable relationships.

This seemed apparent in the quality of the relationships evident in this study. The stories of Jeanette and Anna most clearly represented the influence of difficult past relationships while the stories of Peter, Wally and Gladys exemplified the influence of positive past relationships. Jeanette had struggled with the use of respite for herself in the past but was now fully committed to it while Anna was in the process of the struggle during the research interview. Peter, Wally, and Gladys all used respite services liberally and without guilt feelings.

Personality-Based Factors

Linking the influence of personality-based factors to the caregivers' ability to get out of the caregiving world is an interesting but tentative one. It is a concept perhaps most closely linked with Kobasa's conceptualization of personal hardiness (Kobasa, 1979; Pollock, 1989) as a coping resource. These authors see hardiness as personality-based with three intertwining components. Hardy people, they say, have a high level of commitment to whatever they are doing, have a sense of control over events, and have an attitude that life is a challenge to be experienced as a growth phenomenon. They suggest that the hardy personality type would adapt and cope more readily to stressful situations than the less hardy personality.

It seems that there might be some application of this concept to the caregiver temperaments portrayed in this study. Betty, Gladys and Jeanette conveyed a sense of hardiness in their demeanour as they talked about their outlooks and attitudes toward caring for their husbands. The three seemed to have a sense of commitment and control in how they managed their lives. Rhea and, to a lesser extent Marilyn, were not as confident or in control of their lives. Marilyn was content with her situation but reduced her bridge outings, which she enjoyed, without too much questioning because her husband was unhappy when she went out at night.

Rhea did not seem to be as confident or in control of her coping and adaptation to her life situation as either Betty, Gladys or Jeanette. Rhea, by her own admission, had always deferred to her husband. Now that she was supposed to be in control and make decisions which might not be well received by her husband, she had great difficulty. This was also the case when she sought respite.

Tartasky (1993) cautions against linking hardiness and coping too quickly by stating that the linkages between hardiness and its stress buffering effects have been unclear in the research to date. Therefore, there is only a tentative link between the hardiness of caregivers and how it influences them in "getting out of" their caregiver world. Little research has been conducted on the hardiness traits of informal caregivers. It seems that hardiness and temperament are variables which need further exploratory research in relation to the caregiver experience of respite.

Additionally, there is now some research which attempts to link the personality type of the family caregiver to perceived levels of caregiver burden and stress (Hooker, Monahan, Shifren, & Hutchinson, 1992; O'Reilly-Wenegrat, Gallagher-Thompson, Rose, & Bliwise, 1994). Both of these studies suggest that personality is a predictor of perceived caregiver stress. Personality characteristics such as optimism and humour seem to influence the caregivers' mental health positively and reduce their perception of the stressfulness of their caregiving experience. However, this same association between personality trait, mental health and perception of caregiver burden cannot be made between caregivers' personalities and their ability to seek help. This provides additional evidence of the need for further research exploring the linkage between hardiness, caregiver coping, and caregiver respite.

Length of Time in Caregiving Role

Another factor which influenced the ability of the study caregivers to escape from their caregiving world was the length of time they had been the primary caregiver. Wilson (1989a, 1989b), in a grounded theory study exploring the caregiver experience of coping with negative choices, outlines three stages in a difficult process she names, "surviving on the brink." She labels these three stages as "taking it on," "going through it," and "turning it over."

The "taking it on" phase is characterized by an imperative to take action, a context of uncertainty and unpredictability, and an overpowering sense of moral duty. In this phase of taking on the responsibility of caregiving there is a perception of a lack of resources and information about the condition with which they are dealing. In their attempt to cope with these conditions of uncertainty, the caregivers in Wilson's study expressed feelings that they were the best and perhaps the only one who could manage the situation.

The "going through it" phase is characterized by a long and formidable list of problems including such things as the constant nature of caregiving, the breakdown of shared meaning, and family conflict. The result of the constant and unrelenting demands of this phase are caregiver fatigue, physical and emotional exhaustion, and a sense of putting one's own life "on hold." Wilson identifies "selective resourcing" and "protective governing" as coping strategies associated with this phase. The third "turning it over" phase of the caregiver career, is characterized by a gradual process of giving up control. This phase involves processes of the caregivers coming to terms with their difficult situation, relinquishing the control they have, and entrusting the care of their loved one to someone else.

Wilson's conceptualization of the stages of the caregiver experience provides some insight into the notion that the length of time the caregiver is in this role influences their ability to recognize a need for respite. In the first phase, the caregivers in Wilson's study were taking on the responsibility of caregiving. They felt they were the best person to do it; no one else could do it like they could; no one else knew the family member as they did. Therefore, they could manage, they didn't need help, and they couldn't let someone else take on the care.

This pattern was exemplified in Rhea's story. Immediately after her husband's stroke she retired from her career as a teacher and took on the responsibility of caring for her husband full time. She didn't consider asking for help and, even when it was offered, tended to refuse it because she felt she could manage on her own. She said, it took her three years of being totally involved in the care of her husband to recognize that she needed some help, some type of respite.

This seems congruent with Wilson's (1989a, 1989b) "going through it" second phase where the caregivers recognized the increasing demands on their time and resources and of their need for help if they were to survive. Rhea's recognition of a need for help and her careful searching for appropriate help after three years of full time caregiving was a good example of Wilson's second phase of "selective resourcing" as a caregiver coping strategy.

Wilson's third phase of "turning it over" is linked closely with the caregivers' full recognition that they need help and that they can't continue on their own. This recognition is associated with an active reaching for help. Wilson states that this phase is the precursor to the ultimate step of entrusting care to an institution. This phase was most evident in the stories of Gladys, Peter, and Jeanette. All three were using a number of different services to help them with the care of their dependent family members and to provide themselves with respite. All three fully understood their need for respite services and did not seem to feel guilty or have remorse in using the services and supports available. Also, in keeping with Wilson's speculation that this phase is a precursor to institutionalization, two of these dependent family members were, indeed, in long term care institutions at the time of the second interview and Jeanette was aware that the institutionalization for her spouse was inevitable.

In another qualitative study exploring the social processes of caring for a relative with a dementia condition, Willoughby and Keating (1991), identify a series of four stages in the career of caregiver. These stages include: emerging recognition; taking control: making their own decisions; losing control: accepting decisions of other; and adjusting to the institutional placement of the relative. The authors state that the emerging recognition by caregivers of the seriousness of their relative's changing behaviour is a solitary undertaking, a very private and internal process. It seems a precursor to Wilson's (1989a, 1989b) phase of "taking it on." If this process of becoming fully aware of their relative's condition is a private and deeply personal one, then it would appear that caregivers in this stage might not be emotionally or cognitively ready to reach out for help. They might still be in the very private and lonely process of fully recognizing the problem they are facing. There was some evidence of this in Betty's story. Although she recognized that her husband had a dementia problem, she did not yet seem ready to reach out to resources external to the immediate family for relief. She seemed to be at the end of this stage of "emerging recognition."

Willoughby and Keating's (1991) second stage of "taking control - making my own decisions," seems congruent with Wilson's phase of "going through it." The characteristics of attempting to achieve and maintain control in this stage might also interfere with the caregiver's ability to seek respite help. Caregivers in this stage could interpret seeking respite services as not being in control, as not being able to manage. This was evident in Anna's difficult struggle to let herself go on a vacation for two weeks. She had taken on the responsibility of caregiver and she perceived herself to be in control. Even when everyone around her encouraged her, she remained uncertain about her decision to use respite services. It was also evident in Betty's situation. She felt she was still in control and did not need help.

Willoughby and Keating (1991) further state that the cognitive shift from relative independence to "acknowledging that I need more help" is associated with entry into the third stage of "losing control: accepting decisions of others." Rhea talked of this as she recognized her need for help after three difficult years of trying to do it on her own. Gladys recognized this need early in her caregiving career and seemed to manage her situation with greater ease. Anna was actually going through the process of recognizing this during the research interview. Betty, at the beginning phase of her caregiver career relative to the other caregivers in the study, was just starting the phase of "going through it" (Wilson, 1989a) or the stage of "taking control' (Willougby & Keating, 1991). She was not ready to acknowledge her need for respite. She was still managing on her own. She still had personal strategies which provided her with enough assistance in order to manage her circumstances.

The language of "acknowledging that I need more help" and of "feeling free" in the respite experience seems to represent conflicting perspectives for caregivers. On the one hand the caregivers have to come to terms with the realization that they can't manage and that they need help to continue. On the other hand they want a mental state which is personal, self absorbing, and not directed towards the benefit of the dependent relative. For the caregivers, searching for this state of feeling free might be considered a selfish act, a personal luxury. The dilemma for them is that this mental state is exactly what they require in order to continue. It seems that the resolution of this dilemma within the caregivers is required in order for them to proceed with their request for help.

To conclude, it seems evident that the stage or phase of the caregiver career determines how ready the caregiver is to recognize the need for and to receive help. Respite has been readily suggested by researchers and the helping professionals as an intervention to assist caregivers with the burden of their difficult circumstances (Rosenheimer & Francis, 1992; Zarit, Todd, & Zarit, 1986). However, I suggest that if this help is offered at a time when caregivers are not ready to acknowledge their need for help, the help might well be rejected. Additionally, recognizing the stage of caregiving might explain the low utilization rates of some respite programs reported in the literature (Chappell, 1992; Clarke & Watson, 1991; Lawton, et al., 1991). Therefore, it seems that the recognition by health professionals of this stage of readiness and non-readiness to accept help is important in the process of assisting caregivers with the stress and burden of caregiving. Further research to investigate this relationship between the stage or phase of the caregiving experience and the caregiver's readiness to accept respite help in greater detail is required.

Stage of the Dementia Illness

Another factor which seemed to influence the caregivers' ability to get out of their caregiver worlds is the stage of the dependent relative's dementia illness. There is considerable evidence in the literature that the stress and burden of caring for a person with dementia varies over time. Zarit, Todd, and Zarit (1986), in a two year longitudinal study, found that the caregivers' perceived burden decreased. These authors suggest that this downward trend in stress levels is related to the caregivers' increased ability to tolerate problems as the disease progresses, i.e., the caregivers had learned to manage the problems more effectively. Also, as the family member's dementia worsened, some of the troublesome behaviours diminished in frequency or ceased all together.

This interpretation is congruent with Lararus and Folkman's (1984) model of stress and coping. These authors propose that the impact of harmful events is mitigated by a person's perception of harm and by the person's own coping responses. This pattern of interpreting stress and burden was most evident with Wally who cared at home for his wife until just nine months before her death and with Jeanette still caring at home for her husband who had advanced Alzheimer's disease. Both indicated a perception of reduced stress in caring for their deteriorating spouse as the disease progressed because their spouses' behaviour became more manageable. It did not, however, seem to influence their decision to use respite services. Both continued the ongoing use of fairly intensive respite help. Wally used a mixture of adult day care, some in-home help, and intermittent institutional respite admissions. Jeanette used in-home sitter services five days per week and eight hours each day. On the other hand, Betty was at the beginning of her caregiver career compared to the other caregivers with her husband demonstrating some difficult behaviours; i.e., wandering, getting lost, driving the car in unsafe circumstances, etc. From the description of his behaviours it seemed likely that her husband was still in the initial phase of the disease, although perhaps approaching the middle stage. However, despite the difficulties associated with his trying behaviours, she was not ready to acknowledge the need for respite help.

Cleary (1989), in her qualitative study of 15 caregivers of Alzheimer persons found, at the middle stage of the disease, that family caregivers experienced a complete role reversal with a parent or spouse becoming child-like and the caregiver essentially becoming the parent. Caregivers with family members in late-stage dementia, faced the demand of complete care but generally found their caregiving more predictable and controllable. There was more intense caregiver burden expressed in the middle stage of the disease than at either the first or last stage. It might be, that the ability of the caregiver to reach out for respite help is precipitated by this middle stage of the disease when the stress and burden of caring are the greatest. Betty was still at the first stage of her husband's illness and was not using respite assistance. The other caregivers were certainly in the middle or last stages of their family members' dementing illnesses and were starting to or fully using respite services.

To conclude, it remains unclear whether the stage of the dementia illness influences the caregiver's ability to escape from the caregiver world. Again, it is an area requiring further research. It seems, however, from the data in this study that the stage or phase of caregiving is more directly linked to the caregiver ability to seek respite than to the stage of the dependent family member's dementia.

Role Expectation

Another factor influencing the caregivers' ability to temporarily get out of the caregiver world is role expectation. Biegel, Sales, and Schulz (1991) point out that illnesses such as Alzheimer's and other dementias have a more severe impact on spouses than on non-spouse family caregivers. However, these authors also say that while spouses showed more physical and mental health symptoms than did non-spouse caregivers, they also felt less burdened by the demands of caregiving. This implies that perhaps spouses are less resentful of the care demands imposed by the illness. Young and Kahana (1987) suggest that spouses define their roles to encompass looking after the other "in sickness and in health."

All of the caregivers in this study indicated a strong commitment to their dependent family member. The spouses particularly, talked about being the caregiver because it was expected of them. As Anna said "for better or for worst, I promised," they were the spouse to the dementia person and it was their fate to follow through with whatever that role demanded of them. Both Marilyn and Rhea clearly demonstrated this. Marilyn would not consider doing anything else right now. She said she was relatively content with her "lot in life." Rhea had second thoughts about the sacrifices she had had to make because of her caregiving role but also could not think of doing anything else right now.

The data in this study further suggest that this spousal role expectation influences caregivers' ability to get out of the caregiver world. The attitude that this was "my lot in life" and "how can I leave him/her and go off to have a good time" acted as a powerful restraining force keeping them in the caregiving world. This role expectation was frequently manifested in self-denying behaviours and guilt about having a good time. Marilyn cut back on her bridge nights because her husband was unhappy when she was not at home with him. Rhea was reluctant to use institutional respite because her husband didn't like to go there. Even Anna, with her troublesome marriage, denied herself the pleasure of respite and experienced the same guilt as the other wives; she was the one who most clearly linked her caregiving to spousal role expectation. The struggle to allow themselves to use respite was evident to a greater or lesser degree, in all of them. Some, like Gladys, had overcome the struggle and were using respite regularly. Others, like Rhea and Anna, were still in the process of the struggle and the guilt.

These findings are congruent with the work of Lawton, Brody and Saperstein (1991), in their Philadelphia study of a respite service demonstration project. These authors discuss how cultural attitudes and caregiver ideology, such as "we take care of our own" and "its my job," negatively influence the caregivers' ability to use respite services. They also identify guilt as a profound barrier to caregivers gaining access to respite services: "people struggle to be 'good' caregivers and do the 'right' thing for their relatives" (p.53). It seems that role expectation, significantly and profoundly, influences the spousal caregivers' ability to get out of their caregiver world.

It was difficult to determine whether these same forces influenced Peter. The notion of reciprocity rather than role expectation seemed more prominent in the interviews with him. There was a strong commitment to return "in kind" the benefits gained from the father when Peter was young. Social exchange theory has suggested that reciprocity implies an exchange of resources (Stewart, 1993) and, in long-term relationships, such as that of father-son, the sense that reciprocity will be achieved eventually is a strong motivating force in the giving and receiving of support. This commitment to reciprocity did not, however, seem to influence the son's decision to use respite help. He saw the regular use of respite help as perhaps the only way he could fulfil his obligations to his father.

The Attributes of Respite Help

In addition to the personal factors, the nature of the respite help itself also affected the caregivers' ability to escape from their caregiving world. The caregivers' in this study indicated that certain qualities of respite were very important to them if they were to use the help and if they were to experience the feeling of freedom from their caregiving responsibilities. These included their perceptions that the respite service must be acceptable to their dementia family member; the dependent family member's willingness to use the help; its acceptability to the caregivers; and the respite's beneficialness to the dementia person.

The literature identifies a number of factors which might affect the utilization of respite services. Beck et al. (1990) suggest that lack of awareness, family reluctance to seek respite help, and older people's wariness to use services as some reasons for low participation rates in respite programs. These suggestions are similar to what the caregivers' in this study were saying. For some of the caregivers, specifically Marilyn and Rhea, their reluctance to seek respite help and their wariness of using respite services were linked to the qualities of the respite service. If their spouses did not like the respite help, these two caregivers were reluctant to use them.

Chappell (1992), Montgomery (1995), and Strang, Greschuk, McIlveen, and Gadacz (1992) note that families are in such stressful circumstances that the respite services are being used as a last resort, reducing the possible benefits of that respite help for the caregivers. Rabowski and Clark (1985) also report that the families are experiencing such stress that they have a limited picture of the future and lack the energy to seek out external resources. It was difficult to determine whether these suggestions were appropriate to the caregiver stories in this study. It was noteworthy that two different family members were institutionalized during the time of the study data collection period. The caregivers in the study did, however, articulate clearly the conditions which inhibited them from using respite help.

Perhaps, the suggestion by Lawton et al. (1991) and Chappell (1992), that the very system providing the service acts as a major barrier to the utilization of that service, best explains what the caregivers' are telling us about respite help. These authors state that in many situations, respite is discontinuous and fragmented with each program having its unique eligibility criteria and programming patterns, making it difficult for caregivers to appropriately gain access to the service. The data from this study clearly suggest that the caregivers must feel the respite is appropriate for their family member, that their family member is treated with respect and dignity, and that there should be some identifiable benefit for their dependent family member. The respite help must also be sensitive to the dementia person's perceptions. Again, the caregivers have clearly indicated that, if their dementia family member does not want to go to a respite program or in some other way resists the respite help, the caregivers will not seek it.

These respite characteristics are an initial attempt at delineating the caregivers' perspective in this area but more research is needed. Within the service sector, respite is increasingly seen as a panacea for caregiver stress and burden (Alberta

Health, 1994; Nolan & Grant, 1993). In order to provide more sensitive respite, service providers and researchers must more clearly understand which service qualities are important to caregivers.

Concluding Reflections

To conclude this discussion about factors influencing the caregivers' ability to leave the world of caregiving, a few additional comments need to be made. Identifying these factors is fundamental to the theoretical clarification of respite. It is in understanding these impeding and/or facilitating factors, as the caregivers perceive them, that we gain a conceptual grasp of the caregivers' experience of respite.

As well, identifying these factors is a critical first step in helping us understand why respite may be so difficult for some caregivers to gain access to and use. Also, more extensive research is needed to determine whether there are additional factors which need to be identified and considered in this area. If the formal system is to enhance its abilities to help caregivers with their stressful situations and if it is to provide appropriate respite services, then we must more clearly understand those factors which act as barriers to the caregivers' ability to "get out" of their caregiver world.

Moving to Your Own World

In keeping with the respite model presented in Chapter 4, caregivers start moving toward their own world after they have made the decision to temporarily "get out" of the caregiver world. The caregivers in this study identified this process of moving to their own world as a cognitive process at a deeply personal level which might, but need not, be associated with using a service the formal system calls respite. Some of them were able to achieve the mental state of respite on their own without the aid of formal respite services. Others could also achieve it without help but preferred to have the assistance of formal respite services. Still others could achieve it only with the assistance of formal respite services.

This notion of respite being a caregiver attitude is different from the respite definitions found in the literature. For example, Crossman, London, & Barry (1981) indicate that respite is any service which provides intervals of rest and relief for the caregiver. Berman et al. (1987) and Seltzer et al. (1988) state that respite is the temporary supervision or care provided to a disabled or ill person, specifically to relieve that individual's primary caregiver. The definitions by Lawton, Brody, & Saperstein (1991) and Chappell (1992) are perhaps closer to that of the caregivers in this study. Lawton et al. (1991) describes respite as a service or group of services that provide caregivers with temporary periods of relief and rest away from the care of their dementia family member. Chappell (1992) simply states that respite is time off from caregiving. None of these authors, however, mention the notion of respite being a mental process occurring within the caregiver.

In the literature to date, there seems to be an assumption that if a respite service is used, the caregiver will experience respite or relief. This did not seem to be the case, at least not for the caregivers in this study. Some of them, particularly Gladys and Betty, talked of respite happening at a personal and attitudinal level. They could achieve respite, a state of mind, where they were cognitively and emotionally away from their caregiving responsibilities and related stressors. Betty, who did not use formal respite services, stated clearly that, for her, the only type of respite was this cognitive state of being away from caregiving. In addition, Gladys related a story where she had placed her husband in a respite service but where she did not achieve this mental state of respite. As a result, she did not experience the benefit she usually experienced when she used respite. As pointed out earlier in this chapter, the concept of avoidance in the emotion-focused dimension of coping (Folkman & Lazarus, 1991) seems to be the most appropriate explanation for this caregiver behaviour. These mental processes appear to be examples of coping activities which divert attention from the source of the distress.

Referring to the problem-focused and emotion-focused coping strategies outlined by Lazurus and Folkman (1984), it seems that the cognitive process of achieving a mental state of respite has elements of both coping strategies.

Particularly, it has an overtone of coping by avoidance. In the problem-focused coping domain, achieving a respite attitude is an active strategy requiring doing something about the stressful situation. The problem, from this perspective, is the stressful caregiver situation. The solution to this problem is "to get out" of the situation for a while so that emotional equilibrium can be re-established. Peter and Wally concentrated their problem-focused coping on using formal social supports to achieve a mental state of avoidance. Others, like Betty and Gladys, more readily used emotion-focused avoidance coping strategies. Betty used this type of coping by escaping on her own without help from formal respite programs.

> Betty: ...but even in the home....I just detach myself from him and just let him be....I'm my own person at that time....it isn't that I totally don't pay any attention....but I don't get involved and often when there is something lost I kind of say in my mind I'll let him hunt this long for whatever it is and then I'll go about my business and if he is still hunting then I'll give him a hand.

Her solution to her stressful situation was to "detach" herself mentally from that behaviour and not let it bother her. Also, in detaching herself from her husband's behaviour, she was able to redefine the situation by taking the emotionality out of it. In a more rational and collected way she was then able to proceed with her own activities. She had been able to transform the original stressful emotion of the situation so that she could manage it more effectively.

Gladys also demonstrated the emotion-focused, avoidance coping strategy by changing the meaning of the situation for herself.

> Gladys: ...when I'm outside I have some freedom. I know that I'm going out for an hour and I know he's going to be alright for an hour and I'm not going to think about his needs for an hour. It's a mind set...my mind is completely on something that I am doing and not subliminally on...somebody's needs.

By changing the meaning of the situation she was able to achieve what she perceived as an attitude of respite. She was able to modify the meaning of the situation for herself and put her needs and desires first for that short period of time when she was out in the yard. This helped her to re-establish her equilibrium so that she could continue to manage her situation.

To conclude, the concept of respite as being a cognitive process occurring at a deeply personal level within the caregiver is unique from the literature on respite. It to date has, almost exclusively, discussed respite from the service system perspective shown in the literature review in Chapter 2. This study is a first attempt at presenting the caregivers' perspectives on the meanings of respite. It is an area requiring further research with larger sample sizes, particularly using interpretative qualitative methods. It is only through active, open, and intensive dialogue with many caregivers that we can expand our understandings of how they experience respite and how this experience contributes to their ability to manage their caregiving situations.

Being in Your Own World

In keeping with the respite model presented in Chapter 4, the motion toward the personal world of the caregiver results in arriving at and "being in your own world." For the caregivers in this study, being in their own personal world was the quintessential experience of respite. This was the place where they could get refreshed and energized. The phrase, "being in their own world," was used to present an image of the caregiver being in a different place, either physically or mentally, from the world of caregiving. In the interviews, the word "freedom" was most frequently used by the caregivers to describe this personal place or mental state. The freedom they spoke about was associated with freedom from the worry, from the daily "grind," and from the ongoing responsibility of caregiving. This personal world was a place where they could be themselves, where they could do the things they liked to do, where they could be with their friends and people of their own choosing, and where, most of all, they were NOT the caregiver.

The literature has only recently begun to discuss respite from the more personal caregiver level. In studies attempting to identify the caregiver benefits of respite programs, there have been references to the caregivers feeling free, being able to do the things they want to do, and of being able to do the chores they could not otherwise do when their dependent family member is at home. For example, Miller and Goldman (1989), in a survey of 48 family caregivers who had used institutional respite services, indicated that the caregivers wanted to repeat their respite experience. Reasons given by these caregivers included a need for "time out" and "peace of mind"; phrases which have similar emotive meaning to the word "freedom" used by the caregivers in this study. Scharlach and Frenzel (1986), in their evaluative study of institutional respite, indicated that the vast majority (81%) of the caregivers in their study cited emotional and physical rest as reasons for using respite services. Strang and Neufeld (1990), in an evaluative study of a small adult day program, stated that the caregivers in their study found "peace of mind" and "a break from worrying" as respite benefits of the program. Gottlieb and Johnson (1995), in their evaluative study of 16 adult day programs in southern Ontario used word themes similar to those in this study. These authors identified the respite benefit themes voiced by their caregivers as, having "a sense of freedom and a release from role captivity" when their dependent family member participated in an adult day program.

However, numerous references continue to discuss respite as THE intervention to counter caregiver burden and stress and do not consider that the caregiver experience of respite might be quite different from that pictured by service providers and researchers. For example, Mohide et al. (1990) and Lawton et al. (1991) attempted to measure levels of depression or the quality of life as outcomes of respite services. It was not surprising that they were able to demonstrate little positive respite effect on caregivers. Based on what the caregivers in the present study said, the above authors did not seem to be using the appropriate concepts to define respite. It seems that measuring the extent to which caregivers "feel free" as a result of a respite intervention might yield more accurate findings.

Authors such as Theis and Deitrick (1987) and Gaynor (1989) outlined the various burdensome activities and difficult lives of caregivers and suggested that respite is an appropriate intervention for caregivers. No reference, however, is made to what respite might look like or what it might mean to these caregivers. Berry, Zarit and Rabatin (1991) talk of the importance of considering respite outcomes, determining the need and timing of respite, educating the caregiver about respite and use of free time. Again, they do not consider what the caregiver might deem appropriate as respite outcomes. Although the considerations identified by Berry et al. (1991) are important, it remains paramount to understand respite at a personal level of the caregiver first. This better understanding of the caregiver experience of respite, can then more accurately inform and enhance the delivery of formal respite programs.

Being in Your Own World (Respite Interval) and Time

To expand the discussion of the caregivers' experience of respite, it is important to consider the time when caregivers were in their own world, i.e., when they were experiencing respite. As indicated in Chapter 4, three time elements seemed to emerge from the data: length, quality and use of respite time. Time in relation to the experience of respite was a consideration with all the caregivers in this study but was particularly evident in the four stories of Marilyn, Betty, Rhea, and Gladys.

The length, quality, and use of the respite time interval varied with the different caregivers. To Marilyn the total of 12 hours her husband spent weekly at an adult day program gave her enough time for herself and she considered that time "sacred." Although she would have liked more time to get out in the evening for bridge with her friends, these two days a week were sufficient for her. She would not even consider having her husband go to an institutional respite placement giving her a longer respite interval. Betty's respite interval was quite different from the others and could range from a momentary interval to an extended period of time. Her time in her own world was frequently a cognitive exercise not lasting long in actual physical time. At different periods, however, her respite time was similar to the other caregivers because she went about her activities as if her husband was not there. For Betty, the respite interval could range from a momentary cognitive reorientation to a longer time perhaps equivalent to the six hours associated with the use of an adult day program. Because this respite interval was not dependent on an external service or program, however, Betty could experience respite frequently. In terms of quantity, then, Betty probably experienced the most respite time of all the caregivers because she could tap into this personal coping strategy when she needed it.

Rhea, on the other hand, managed to get only about six hours per week when her husband attended an adult day program. She fervently wished for more time but, because of her husband's reluctance, made do with the six hours. She successfully used an institutional respite placement for her husband once but felt she could not repeat this arrangement, again because of her husband's reluctance to attend such a program. She talked fondly of one weekend in the summer when her husband stayed with her sister and she went to a class reunion. Then she experienced the "freedom" of the respite experience. Although this was a relatively short respite time interval, she experienced respite because of the quality of the time away from her husband.

Gladys used both adult day programming two days per week for a total of about 12 hours, and regular intervals of institutional respite placement of about two weeks at a time. As well, Gladys was able to achieve that feeling of "freedom" for short intervals by using the detachment cognitive process similar to Betty's approach. However, she was not able to achieve this momentary mental disengagement often because of the extent of her husband's disabilities. Like Rhea, Gladys also talked of a relatively short experience of respite associated with a peak weekend event.

Different authors have reflected on the diversity of respite service models and on the medley of programs called respite (Lawton et al. 1991; Montgomery, 1992; Kane & Penrod, 1995). Time was one fundamental variation in this plethora of services. Therefore it needed to be considered in relation to the respite experience of the caregivers in this study. How the caregivers used the time when their family members were at a respite service, the length of the respite interval, and the quality of the caregivers' experiences during the respite interval seemed to influence whether the caregivers felt the freedom they associate with respite.

It seemed that how the respite time was used by the caregivers was dependent on the type of respite being used. The shorter respite interval associated with the use of adult day programs was most often used for chores and errands. This finding is similar to the findings of Berry, Zarit, and Rabatin (1991), Gottlieb and Johnson (1995), Miller and Goldman (1989), Scharlach and Frenzel (1986), and Strang and Neufeld (1992). It seemed that short periods of so called "respite" are used by the caregivers almost exclusively to cope with the day to day activities related to managing their situations. Although some short intervals of time were used for personal "escape" activities, such as Rhea's and Betty's sewing, Marilyn's bridge, and Milly's golfing, the majority of the time was spent doing tasks and chores which could not be done when the dependent family member was at home. When this is considered in the context of the feeling of freedom the caregivers in this study associated with respite, it seems that a brief interval such as that associated with adult day care utilization, is not a true respite experience. This time is, however, a useful coping strategy for caregivers in that it gives them time to manage their day to day activities. This is congruent with the findings of Strang et al. (1992) in their evaluation of a small adult day program. These authors state that the program was effective in that it helped caregivers cope with the day to day activities of their lives although it did not make a respite impact in their overall experience of caregiving.

Gladys was particularly articulate in voicing this insight. Because she was one caregiver who used a number of different respite strategies she could differentiate how she used each one and the impact each had on her caregiving experience. She used the adult day program time almost exclusively to do her chores, although she did from time to time use it for personal freedom type activities, such as being outdoors. This helped her manage her situation but to her this short interval was not respite. It just gave her the time to do the things she needed to do. For her, the experience of respite, or freedom, was associated with the extended period of an institutional respite placement for her husband. It was also associated with a relatively short interval of a weekend when she had a peak quality experience similar to Rhea's experience of respite. But interestingly, for Gladys it was also associated with the very short intervals when she detached herself cognitively from her caregiving responsibilities and was totally absorbed in her enjoyment of being outdoors.

To conclude, the respite literature does differentiate between the length and quality of caregiver time as related to the experience of respite, although Berry, Zarit, and Rabatin (1991) state that the need for and the timing of respite must be considered in determining future services and research. This type of time differentiation and how caregivers experience their respite time is important because of the vast array of programs and the diversity of approaches which the formal system and the research literature call respite services. It is critical to understand this relationship between length of respite time and the caregiver experience of freedom if respite services are to be effective. This study has made an initial attempt at articulating the idea that time is a critical factor in the caregiver experience of respite. In light of the increasing prominence of respite services in the formal support system, further research is urgently required to investigate this association.

Re-entry into the Caregiver World

If, from the perspective of the family caregivers in this study, respite means temporarily getting out of the caregiver world mentally and/or physically, then re-entry into the world of caregiving is always the reality for them. As outlined in Chapter 4, the re-entry has characteristics with certain factors influencing these characteristics. How the caregivers re-enter their specific caregiver worlds seemed to influence their ability to continue in their ongoing caregiver roles. There is no respite literature to date which outlines the processes or characteristics of caregivers resuming their caregiver responsibilities after brief absences. This study is an initial attempt at identifying some of the factors influencing the caregivers' re-entry experience. The factors identified in this study include the amount and quality of the caregivers' respite interval, the condition of the dependent family member at re-entry, and the nature of the respite service itself. Depending on these components, the outcomes for the caregivers at re-entry could include an initial period of despondency, feelings of refreshment and renewed energy, or feelings of guilt and devastation.

Time and Re-entry into the Caregiver World

Both the amount and the quality of the caregiver respite interval seems to influence how caregivers re-entered their world of caregiving. And, it seemed that the quality rather than the quantity of the respite, is a factor in how the initial re-entry period is experienced. Both Gladys and Rhea told stories about "peak" high quality respite experiences and Gladys, particularly, spoke of an emotional slump on returning from this experience.

Why there seems to be an initial period of despondency upon re-entry when the caregiver respite is of high quality but of short duration, can be explained in a number of different ways. It might be that the contrast of the two worlds, the personal world and the caregiver world, is so stark at that moment of re-entry that the depressive or despondent emotions are the only appropriate responses available to the caregivers. Gladys' use of the word "prison" to describe her feeling of coming back home to her caregiver responsibilities after her peak respite experience graphically showed the bleakness of her emotions at that moment. The fact that this emotion lasted only a short time is possibly related to factors such as the commitment of the caregiver to the situation and the nature of the relationship between the caregiver and recipient. Obviously, more research is required to clarify the nature of these relationships between quality of respite and resuming the responsibilities of caregiving.

The initial feeling of despondency could also be similar to the feelings in the work force commonly known as the "Monday morning blues." If, indeed, the work of caregiving is seen as a career (Gerald, 1993), then a respite interval might be analogous to an off duty week-end or vacation time. The re-entry into the career related work of caregiving might then be viewed with the same "down" feeling of being back "at the job" with all the problems and responsibilities associated with it.

It is interesting to note that the despondent reaction at re-entry seems to be linked only to the quality of the respite. This might further support the analogy of a respite interval with the off duty time in the labor force. The "down" feeling after having a wonderful time away from work seems a common experience. The despondent feeling of the caregivers might be similar to this "down" feeling. Perhaps the "peak" and infrequent respite interval is different from other respite intervals for the caregivers, just like a "peak" and unique holiday would be for anyone in a work environment. This analogy linking caregivers' experience of respite to leisure and its effect on work needs to be explored further. It has the potential to provide respite service providers and researchers with different and refreshing approaches to the challenges of articulating and measuring possible respite outcomes.

Another time factor affecting the re-entry is the length of the respite experience. Short respite intervals seem most often to be associated with running errands, doing chores around the house, and other activities generally related to the day to day management of the caregiving situation, while longer respite intervals seem more associated with personal freedom type caregiver activities. After a short interval of respite re-entry seems to be low-key and less emotionally eventful than the re-entry after a longer interval of respite. After the short interval, however, the re-entry seems to be linked with similar types of activities as those associated with caregiving itself. For example, for the caregivers where adult day programs provided the respite experience, the re-entry is associated with such activities and concerns as being home early enough to meet the bus and trying to match their personal activities with the unpredictability of DATS bus schedules. Since the length of free time is not long, possibly ranging from four to six hours at a time, the way that time is used matches the ebb and flow of the caregivers' daily lives. It is a short interval that allows for some planned personally satisfying activities, such as sewing, bridge, and golf but usually it allows only enough time to do the essential chores of daily living. There is not enough time for the "freedom type" of respite experience more associated with the longer interval or with peak quality respite time. This seems congruent with Blume et al. (1990), in their Florida study of an Alzheimer's Respite Care Project, who state that "the caregivers did not feel four hours a week was sufficient to provide a breather" (p.81).

Although the caregivers' re-entry from the short interval of respite is usually uneventful and considered part of the contextual pattern of their daily lives, it can still be associated with feelings of refreshment and renewed energy. Marilyn's comment that the adult day care time was "sacred" to her attests to this. Rhea's determined effort to get her husband to go to the day program highlighted the importance of it for her. For others, however, the short interval was not associated with the personal freedom associated with respite. For example, in the research interviews, when I asked about the meaning of respite to them, the caregivers rarely considered adult day programs as respite, even though they might be using such a program. It was only after I prompted them about their use of the adult day program that they discussed it in relation to their respite experience. They saw these short interval programs as providing some time, and in many cases not enough time, to do the chores they were not able to do in the presence of their dependent family member. This is congruent with the findings of a national Canadian respite survey conducted by Canadian Long Term Care Foundation and Home Support Canada (1994), which stated that only seven percent of responses from seniors defined Adult Day Care as respite (p.35).

On the other hand, longer intervals of respite, such as institutional respite services, seems to provide more of the personal freedom time that the caregivers of this study associated with respite. However, the re-entry into the caregiver world from this type of respite experience seems varied and more positive emotionally. It does not seem to be associated with the despondency period that is part of the "peak" short interval of respite. The caregivers, who had used this longer interval of respite, talked of being glad to see their relative again, feeling good about being home, and of conversing with their family member about their different experiences while they were apart. They talked of feeling better emotionally about their caregiver world, of having more energy to do the daily activities, of being more accepting of their circumstances, not getting angry as quickly, and of being more tolerant and patient with their loved one. The re-entry, then, is usually associated with positive emotions. The longer respite time seems to provide the caregivers with the renewed energy and revitalization they require to carry on with their caregiver responsibilities.

Additionally, the effect of the respite length on the quality of the relationship between the caregiver and the dementia person needs to be addressed. It seems that both short and long intervals of respite improved the relationships between caregivers and their dependent family members. Gladys having her husband's favourite rice pudding waiting for him when he came home from the adult day program is an example of the effect that a brief respite period had on that relationship. There was also repeated mention that caregivers having something to talk about with the dependent family member positively influenced the caregiver/care-recipient relationships. Even Anna, who had ambivalent feelings about her husband and their long marriage, felt more tolerant and accepting of her relationship with her husband and of her caregiver situation after her excursion to Vancouver.

These observations are congruent with the findings of Gottlieb and Johnson (1995), Strang and Neufeld (1990), and Strang et al. (1992). These authors all say that one of the benefits of respite is the caregiver perception of improved relationships between caregivers and their care-recipients. This is one key outcome of respite for caregivers which might be a useful indicator for researchers and service providers when evaluating the benefits of respite services.

The Dementia Person's Condition and Re-entry into Caregiver World

However, certain factors can quickly negate these feelings of caregiver refreshment and renewal: the condition of the dementia person at re-entry and the caregivers' perception of the quality of the respite help. The story of Peter and the emotional devastation of that family when they returned from their respite time to find their father in a deteriorated condition, provide a prime example of how both of these influenced their re-entry. Their bitterness and anger at the institution providing the respite service poignantly reflected the idea that the respite, which can feel so wonderful and free, can quickly turn to feelings of guilt and despair. None of the other caregivers in this study had similar experiences with respite services so it is difficult to identify a common focus in this area. However, what seems clear is that the quality of the respite service and how the caregivers perceive that quality affected the care-recipient, is important in identifying the benefit of the respite period in terms of the caregiver's emotional refreshment and their ongoing ability to cope.

There is considerable speculation in the literature about the low utilization rates of respite programs even though caregivers consistently identify respite as a much needed service (Bowen, LaPerriere & Thornton, 1994; Chappell, 1992; Gottlieb et al., 1995; Lawton et al., 1991; Seltzer et al., 1988). Seltzer et al. (1988) cites one of the reasons for this lack of use as the deterioration in the elderly client after relocation into the respite facility. In this study this deterioration certainly was evident in Peter's story. This kind of negative experience generates among caregivers fear of care-recipient deterioration among caregivers which could result in a reticence to use respite services. This concern about the quality of the respite service and deterioration of the dependent family member was evident in Wally's story as well. Each time he used a respite service he spent a few days carefully checking it out to reassure himself that the service met his expectations and that his wife would be happy while he was away. It was only after he had reassured himself of the quality of the service that he could go away and have a good time and be free of worry.

The area of how respite help affects the dependent family member and how that affects the caregivers' experience of respite is an area needing further exploratory research. It is critical to identify those factors which result in negative emotional outcomes for caregivers at the point of their re-entry into the caregiver world. Clarification of these factors can then provide guidance to service providers in the development of respite services which might be more attuned to the caregivers' perception of benefit.

The Attributes of the Respite Help and Re-entry into the Caregiver World

Another factor which influences or even negates the positive effects of the respite experience is the quality of the respite help itself. Again referring to Peter's story, the relationship between the nature of the respite help and how the caregiver re-entered the caregiver world is evident. In this story, the respite help was rigid and lacked attention to the needs of the caregivers. The respite service took the father for a designated period of time only, much longer than the family felt they needed. The respite service paid little attention to the family's wishes and requests about how the father should be treated. And the part that seemed most galling to the family was the disrespectful attitude of the staff toward the father.

The story provides a prime example of how the formal system creates real barriers to respite service utilization. This family did not have the opportunity to access respite services again; their worst fear about using respite services was realized. Their father stayed in the institution when they came back from their vacation. This is congruent with the work of Lawton et al. (1991) and Chappell (1992) who point out that low utilization of respite services might be linked to the numerous barriers created by the formal system. Further, Bowen, LaPerriere and Thornton (1994), in a national Canadian survey of seniors about respite services, indicate that seniors are generally dissatisfied with the formal support system and how respite is offered to them. From these seniors' perspective, the respite services are not established to be "user friendly."

To conclude, the nature of the respite help, how the caregivers perceive it is experienced by the dementia person, and how these two factors affect the caregivers' re-entry into the world of caregiver responsibility are critical areas for ongoing research. Here the philosophies and policies of the formal system can directly influence the program methods and worker attitudes to enhance the quality of respite services for family caregivers. If the purpose of respite services is to help caregivers experience respite or "feeling free," then service providers must be more sensitive to how caregivers perceive the respite service and how that service influences the caregivers' ongoing ability to continue in their role.

Concluding Reflections on the Meaning of Respite:
Work and Leisure

In concluding these reflections on the experience of respite for the caregivers in this study, the similarity between the respite experience in caregiving and the leisure experience in everyday work life needs to be revisited. Increasingly, the activities and responsibilities of caregiving, particularly of caring for frail elderly people, are being described as "work" using phrases such as the "work of caregiving" or the "caregiver career" (Corcoran, 1992; Ward, 1990; Ward & Brown, 1994). And it is seen as predominantly "woman's work." Ward (1990) argues that, because the majority of caregivers are women and because the nature of caregiving work is seen as an extension of housework, the traditional domain of women's work, the work of caregiving is a "quintessential piece of women's unpaid work" (p.224).

Housework, including caregiving or the taking care of kin, has largely been unrecognized as productive labor (Parker, 1983; Ward, 1990) because of its never ending and repetitive nature, the fact that it is delivered in the context of the family, and that it is infrequently done by men (Osborne, 1991). Caregiver tasks fall within the parameters of what women are socialized to do, especially because the workplace of caregiving is the home (Corcoran, 1992). It is women's duty and obligation to care for their frail family members. The caring is done because of women's commitment to nurturing within the family.

These themes were strongly represented in the stories of the caregivers in this study. The majority of them were elderly women and there was a strong sense of commitment to the "job" of caregiving and to the meeting of societal obligations of "caring for your own." It was a role they had been socialized into and it provided meaning to their lives.

On the other hand, describing what respite meant for themselves, the caregivers frequently used terms such as "freedom," "to be their own person," and to be away from the responsibilities of caregiving. To experience respite they needed to feel free and unconstrained by their caregiving work. Parker (1983) defines leisure as "time free from obligations to self or to others - time in which to do as one chooses" (p.64). In this definition leisure is more than just a period of time; it implies relative freedom from constraint. The similarities between the definition of leisure and the caregiver descriptions of respite are striking. Interpreting the experience of respite as an experience of leisure is a new and unique way of viewing respite. If the role of caregiver is increasingly represented as an occupation or a job, then it seems productive to examine the concept of respite as an experience of leisure. It makes sense, then, to talk of respite as a vacation, a time which is free from the constraints of caregiving.

Further, Neulinger (1976) offers a paradigm of leisure which distinguishes between pure leisure and work leisure. In pure leisure the activities are freely engaged in and done in the absence of constraints and obligations. In work leisure the activities are engaged in under constraint but are still satisfying and enjoyable. This type of differentiation is useful when examining respite care from a leisure perspective. In a previous section of this chapter, called "Being in Your Own World and Time," I outlined an apparent difference in the way caregivers experience short interval, long interval, and quality respite. The short interval respite was more often associated with having free time mainly to do chores and perhaps to do a few personal enjoyment activities but under the time constraints of their returning family member. This seems congruent with Neulinger's concept of work leisure. The long interval or quality respite seems more associated with the freedom and the absence of constraint which Neulinger identifies as pure leisure.

The analogy of the caregiver experience of respite care to leisure is embryonic. However, further investigating this association in future research has the potential for developing a unique and useful interpretation of the caregivers' experience of respite care. It might illuminate the reluctance of caregivers to use respite care services. Because of the potent values related to work and because the work of women is often perceived as not earning the right to leisure because they were not engaged in economically valued work (Henderson, Bialeschki, Shaw, & Freysinger, 1989), caregivers might be viewing respite time as a luxury to which they are not entitled. There was some evidence of this caregiver perception of the use of respite time in this study.

Summary

In review, although the study began from a social support theoretical orientation, coping theory proved to be more fruitful as an underlying framework for exploring the meaning of respite to caregivers. Therefore, coping theory was the primary informing theory for the interpretation of the study findings while social support became its theoretical subset. In the interpretation process, I outlined my rationale for including coping theory as the predominant framework for my reflections on the stories of the caregivers and delineated two spheres of experience the caregivers in this study described to me. These included the large, dominating, and energy consuming world of caregiving and the much smaller world which they considered their "own personal world." I identified a process of caregivers moving out of their caregiver world into this personal world away from the responsibilities and worries of being the caregiver. This process of "temporarily leaving the caregiver world" included three dimensions: recognizing the need to "get out," giving themselves permission to "get out," and the availability of social support resources.

Being in their personal world, the mental state of feeling free from the duties and hassles of caregiving, was the essence of the respite experience. I also described the caregivers' re-entry into the world of caregiving and outlined numerous factors influencing the various components of the processes associated with the "getting out of" and re-entry to the caregiver world. As I reflected on these findings about how caregivers experienced respite in relation to the respite literature, I gained new insights and found possible unique associations which might be useful for future research.

Chapter 6

SUMMARY, CONCLUSIONS AND DIRECTIONS FOR THE FUTURE

In this chapter I summarize the main themes and findings of the study. I also reflect on the processes of the study and address its limitations. In addition, I include a discussion of the implications of the findings and interpretations for respite practice and for future research.

Overview of the Study

The purpose of this study was to explore respite from the perspective of family caregivers of dementia persons and to gain an increased understanding of what respite means to them. The main research question in this study was: what is the experience of respite for caregivers of dementia persons?

Because of the lack of conceptual clarity in the literature about respite, an interpretivist, qualitative, open, and exploratory approach seemed to be the best research process for this study. This method allowed the caregivers to freely describe and interpret their unique experiences, insights, and understandings about respite. This method also provided the rare opportunity to discover the components of respite and the relationships among these components from the caregivers' perspective. Two specific qualitative methods of data collection were used: the development of narratives and grounded theory. Both are associated with interpretivist enquiry. Using these methods in tandem, provided the advantage of pursuing the essential theoretical development of grounded theory and the opportunity to add a richness to the analysis process. They also give credence to the individuality and uniqueness of the caregiver stories. The participants were eight women and two men who at the time of the interviews or just before, were caring for a dementia family member. The intensive interviews and data analysis processes associated with interpretativist qualitative research also facilitated new connections and discoveries about the meaning of respite in the context of caregiving. These discoveries challenged the existing literature and theories about respite.

Summary of Findings

Although, the study began from a social support theoretical orientation, coping theory proved to be more fruitful as an underlying framework for exploring the meaning of respite to caregivers in this study. Therefore, coping theory was the primary informing theory for the interpretation of the study findings while social support became a theoretical subset in the interpretative process. Social support as a theoretical subset of coping is receiving increasing attention in the literature (Gottlieb & Gignac, in press; Greenglass, 1993).

Judging by the caregivers' richly descriptive stories of their daily lives, they saw caregiving as integral to their everyday world; that is, it was an all consuming activity absorbing enormous amounts of their life energy. Caregiving as an integral component of everyday life was identified in the study as the caregiver world. In this all consuming world of caregiving, the respite experience was described as a brief interval where the caregivers are out of this stressful caregiver world, mentally feeling free to be themselves and in their own personal world. After this respite interval re-entry into the caregiver world was presented as an integral component of the respite experience.

In portraying the caregiving world, the caregivers in this study gave poignant and detailed descriptions of their daily lives, stories which, as the data collection and analysis evolved and intensified, formed the context for exploring their experiences of respite. Their individual stories were filled with an abundance of practical insights and rich descriptions of their individual caregiving experiences. Their narratives contained detailed accounts of the coping strategies they had learned to use in dealing with their various and difficult situations. They talked of the physical and the emotional aspects of their present situations. The physical aspects included the actual physical personal care, the constant vigilance of monitoring the dementia person's activities, the daily hassles of adapting and adjusting to the routines of their dementia person, and the coordination of the many activities and responsibilities associated with caregiving. The emotional aspects included their feelings of guilt, worry, fear, grief, embarrassment, conflict, anger, frustration, helplessness, sadness and loneliness. Particularly touching, was the underlying desire of the caregivers to maintain the integrity, dignity and humanness of the dementia person in their care and of a reluctance to use any assistance which might demean that person.

A deep commitment to their dementia family member, the high quality of their past relationship, fulfilling social norms and roles expectations, and living out one's values, were reasons given for continuing in their present situations. Some caregivers could also identify that caregiving had assisted them in reorienting their personal values and the purpose of their own lives. There was a profound commitment to maintaining the quality of life for their dependent family member.

Within this busy and bitter-sweet world of caregiving, the caregivers identified many different coping mechanisms: having a sense of humour; having a regular schedule; and being able to solve specific problems which reduced their worry or constant vigilance. The attitude of the caregivers themselves and the way they viewed their individual situations were also strong forces helping them cope with their circumstances. These mental processes included feeling self reliant and comparing themselves with other people less fortunate than themselves. They also saw their ability to recognize their need for respite and to allow themselves to get relief from the demands and drudgery of their daily lives as one of these coping strategies. Within the context of coping theory, this respite seeking behaviour was discussed as an avoidance emotion-focused strategy (Folkman & Lazarus, 1991; Lazarus & Folkman, 1984).

The process of getting respite from their caregiver responsibilities, of temporarily leaving the caregiver world, was a complex one for the caregivers of this study. Three dimensions of this process included the caregivers recognizing their need to get out; giving themselves permission to actually 'escape' from it temporarily; and, having the social support resources to facilitate the 'escape'. These dimensions were linked to the concepts of coping theory as outlined by Lazarus and Folkman (1984) and Pearlin (1978). It was argued that the "recognition" dimension is a cognitive appraisal behavior which acts as a "wake up call" alerting the caregivers that a change in coping strategy is needed. Further, this recognizing dimension requires caregiver acknowledgement of the uncontrolability of their situations. The "giving self permission to escape" dimension was discussed in the context of coping efficacy and of how beliefs and values influence coping behaviour (Pearlin, 1978; Lazarus & Folkman, 1984). The "availability of social support" dimension was presented as a means of facilitating the "escape". And, the influence of social networks, both informal and formal, on this process was considered (Stewart, 1993).

A number of factors influencing the caregivers' ability to leave their world of caregiving emerged. These included: the nature of the relationship between the caregiver and the dementia person prior to the onset of the dementia symptoms; caregiver personality-based factors; length of time in the caregiving role; stage of the dementia illness, caregiver role expectation, and the attributes of the available respite help. The pre-illness relationship of the caregiver and the dementia person influenced help seeking behaviour was congruent with the works of Biegel, Sales, and Schulz (1991) and Morgan and Laing (1991). Further, it was argued that the personality-based factors evident in the caregivers of this study were linked to the conceptualization of the hardy personality and coping as outlined by Kobasa (1979) and Pollock (1989). It was further contented that the stage (Willoughby & Keating, 1991) or phase (Wilson. 1989a; 1989b) of caregiving was more directly linked to the caregiver's ability to seek respite than was the stage of the dependent family member's dementia illness itself. As well, it seemed that role expectations profoundly influenced the spousal caregiver's ability to seek respite help and was congruent with the works of Lawton, Brody and Saperstein (1991).

The attributes of the respite help elicited considerable caregiver comment. They identified that quality respite services include the following: the dementia person must be willing to use the respite help; it should be evident to the caregiver that the respite help is acceptable to, respectful of, and beneficial to the dementia person; and, the respite help must be legitimated by someone in authority. These characteristics were comparable to factors identified by numerous authors (Beck et al., 1990; Chappell, 1992; Lawton et al., 1991; Strang, et al., 1992) as influencing utilization patterns of respite.

The actual process of getting out of the caregiver world was identified as a cognitive process, an attitude which could be achieved by various means. This notion was identified as different from other respite definitions found in the literature (Berman et al., 1987; Chappell, 1992; Lawton, Brody & Saperstein, 1991; Seltzer et al., 1988;) which have, almost exclusively, discussed respite from a service system perspective. The representation in the present study was an initial attempt at representing the caregivers' own perspectives on the meaning of respite. Some of the caregivers of this study could achieve the respite attitude on their own without assistance. Others could achieve the respite attitude on their own but preferred the assistance of some respite help, while still others, the mental state of respite could be achieved only with the help of some external respite help.

The caregivers described the respite experience as being in their own world where they were free from the worries, responsibilities and hassles of being a caregiver. They were free to be themselves, to do the things they enjoyed, and, most of all, to NOT be the caregiver. For the caregivers in this study, being in their own world was the quintessential experience of respite. This was a unique interpretation of the caregiver respite experience because the literature has only recently begun to discuss respite from the more personal level of the caregiver (Miller & Goldman, 1989; Strang & Neufeld, 1990; Gottlieb & Johnson, 1995). However, none have been as specific in their descriptions as has this study. Most importantly, the caregivers in this study indicated that, if they did not achieve this mental state of "feeling free," they did not achieve respite even if their family member was using a respite service.

As well, caregivers' feeling of respite or freedom was linked with the element of time, specifically, the length, quality and the use of time when they were "in their own world." Although the many available respite programs and services vary in time length, there was no evidence in the literature of an association between the element of time and how respite was experienced by caregivers. The findings of this study are an initial attempt at articulating the idea that time is a critical factor to be considered in the context of caregivers' "freedom" respite experience. Future research to explore these relationships in greater depth is urgently required.

In this study, how the caregivers re-entered the caregiver world was seen as an integral component of the respite experience and was influenced by a number of factors: the length and quality of the respite time, the characteristics of the respite help used, and the condition of their dementia family member when the caregiver resumed the caregiver role. When the respite time was experienced as a "peak" quality interval, the re-entry seemed to be characterized by an initial brief period of despondency from which the caregiver quickly recovered. This brief period of despondency was compared to the notion of "Monday morning blues" within the regular work force. If the respite time had been short, a period of perhaps four to six hours, the re-entry seemed to be part of the regular rhythm of daily life and was frequently not identified by the caregivers as respite time. It was time to do the chores and other tasks which the caregiver could not do while the dependent family member was at home. These findings seemed congruent with recent work by Bowen, LaPerriere, and Thornton (1994) and Gottlieb and Johnson (1995). If the respite interval was longer, lasting a few days or perhaps a few weeks, the re-entry was characterized by joyful reunion with the family member and feelings of being refreshed and having renewed energy to cope with the caregiving responsibilities. There was no evidence of supporting literature in this conceptualization of caregivers re-entry into their caregiver worlds after respite experiences and of identification of the factors which influence this process.

However, this positive caregiver re-entry changed to a very negative experience when the condition of the dependent family member had deteriorated or the family member had not experienced the interval positively. This resulted in feelings of guilt, emotional devastation, and a reduced ability to cope with the caregiving obligations. These findings were linked with the literature on low utilization rates of respite services and on barriers within the service system contributing to client deterioration and caregiver reticence to use them again (Bowen et al., 1994; Gottlieb & Johnson, 1995; Lawton et al., 1991; Seltzer et al., 1988).

To conclude, it was argued that if the experience of respite is to have a positive impact on the on-going caregiver ability to manage and cope with their circumstances, then this notion of caregiver re-entry after a respite time interval needs more intense research. The factors influencing this re-entry process, which have been identified in this study, are an important initial step in this research.

Major Insights Gained

A number of important discoveries influenced my deliberations throughout the process of conducting this study. They will continue to influence profoundly my thinking about caregivers and respite in the future. The first such discovery related to the paradigm shift in my thinking regarding the informing theoretical framework I used to interpret the data. In listening to the stories of the caregivers and in analyzing the content and meaning of their stories in relation to their respite experience I realized that, to make sense of what they were telling me, the informing theory should be more closely aligned with the coping theories of Lazarus and Folkman (1984) and Pearlman (1989) than with the social support orientation of Chappell (1992) and Stewart (1993) which I had adopted in the initial stages of the study. The process of getting out of the caregiver world, which the caregivers described to me, seemed closely linked to the emotion-focused coping strategy Folkman and Lazurus (1991) call avoidance, a type of distancing behaviour used by the caregivers for restorative and recovery purposes so that they can continue to cope and manage their stressful circumstances. To me, it seemed that to continue to view respite from the social support theoretical perspective (Chappell, 1992; Stewart, 1993) would have kept the study in the same conceptual confusion that the present literature on respite demonstrates. The interpretation of the caregiver stories and their experiences with respite seemed to provide enough evidence of the validity of this theoretical perspective. Additionally, viewing the respite experience from this informing theoretical foundation has been receiving increasing support in the literature (Gottlieb & Monique, in press; Monique & Gottlieb, 1995).

A second and related discovery also brought a paradigm shift in my thinking about the meaning of respite to caregivers: that is, the discovery that, from the caregivers' perspective, the experience of respite was a cognitive and deeply personal process resulting in a mental state of feeling free. The stories of Betty, Rhea and Gladys particularly, brought this insight sharply into focus. As I confirmed this discovery with other caregivers in the study, I began to realize the importance of it for me. It represented a major shift in my conceptual orientation to respite, for I, too, had been viewing respite from the formal service perspective. With this shift in my thinking about respite, I realized that the effort made by caregivers to get respite was, indeed, only one strategy among many others in the caregivers' repertoire of coping strategies. Respite was not a panacea which would necessarily eliminate the stress and burden in the caregivers' situations. Lawton et al. (1991) states that it is unrealistic to expect respite to result in an overall improvement of caregiver well-being and mental health (p.140). However, hearing the caregivers in this study point this understanding out to me specifically had a profound influence on my changing perceptions about respite and the impact that respite services can have for caregivers. The caregivers in this study saw respite as very important. However, from research and practice perspectives, I realized that it must always be viewed in the context of the other caregiver management strategies and the complexities within their lives.

A third breakthrough for me was the delineation of the element of time in relation to the caregiver respite experience. In the initial Chapter 2 discussions about the respite models as outlined by Montgomery (1992; 1995), time was identified as one dimension in how respite services are organized. However, rather than using "time" to define the caregivers' respite interval, these discussions used terms related to the intensity or frequency of respite service. In the data analysis process, I increasingly came to realize that time factors affect the caregiver experiences of respite. For example, in recognizing a difference between longer versus shorter intervals in the respite experience, I began to realize that caregivers use the various types of services, which the formal system has called respite, in different ways. Shorter interval respite programs seem to be used for the management of the day to day activities within the caregivers lives while the longer interval or "peak" shorter respite intervals are more closely associated with the true "feeling free" respite experience. Because of the importance of respite services within the health care reform movement (Capital Health Authority, 1994) and because of the many types of respite services emerging in the community (Montgomery, 1995), I saw this differentiation as fundamental to advancing our understanding of the impact of these services for caregivers. As well, it was most refreshing to encounter the work of Gottlieb and Johnson (1995) who are also making initial attempts at delineating the impact of the shorter respite interval, i.e., adult day programs, on caregivers.

A fourth insight I made linked the concept of respite to that of leisure. This connection came late in the analysis process of the study in a rather incidental manner. It was in the process of attempting to interpret the data related to the initial period of despondency some of the caregivers experienced on re-entry into the caregiver world that I started to reflect on the similarity of this experience to the work/leisure pattern of everyday life for many of us. As I started to search the literature in the leisure area I quickly realized that the language associated with defining leisure (Deem, 1986; Parker, 1983; Wimbush & Talbot, 1988) was similar to the language the caregivers in this study used to define respite for themselves. As well, the caregiver literature increasingly is describing caregiving as "work" or as a career of caring (Corcoran, 1992; Ward & Brown, 1994; Ward, 1990).

Further, linked with this idea of respite time as leisure time, was the notion of the respite experience nurturing self-esteem and maintaining personal identity, so evident in the stories of Betty, Rhea, and Gladys. Parker (1973) indicates that because the value modern society places on work, it acts as a primary source of self-identity for many people. In contrast, leisure was defined by this author as time in which the feelings of constraint are minimal and the sensations of relaxation, regeneration, and personal development are maximal. Applying these insights to the analogy of caregiving and work, the identity of people engaged in caring for a dependent family member is then determined by their work of caring for that other person. Therefore, the need for the caregivers to see respite time or leisure time as a means of maintaining their personal identity, separate from that dependent person, made considerable sense to me.

This study is only an initial and embryonic attempt at interpreting respite as leisure. I do think, however, that for future exploration this is a potentially fruitful way of examining and interpreting respite. It was the similarity in language, the freedom from the constraints of "work," that made this analogy so powerful for me.

Another discovery I made was also linked with the work-leisure dichotomy. This discovery, however, was from a feminist perspective related to the connection between the work of caregiving and the work of women (Corcoran, 1992). It is undeniable that caregiving, specifically the type of caregiving work described in this study, is in the predominant realm of women's experiences. It is also undeniable that the vast majority of caregiving is done by women (Hogan, 1990; McDaniel & Gee, 1993). However, there are small but significant numbers of caregivers who are men, as this study demonstrated. In our attempts to understand the caregiver experience feminine attributes and difficulties have been emphasized and the male caregivers have all but been forgotten (Harris, 1993). There are studies now emerging which identify apparent gender differences in the caregiving approaches and in how services are used differently by men and women (Harris, 1993; Zarit, Todd & Zarit, 1986). Therefore, it seemed to me that to differentiate the gender approaches to caregiving and to gain insights into gender-based caregiver coping strategies was productive in expanding our insights about coping strategies such as attaining a feeling of respite. The feminist perspective was useful in that it helped to illuminate the nature and the attitudes associated with the caregiver experience. It is true that caregiving work is seen as woman's work but this woman's work of caregiving is not done exclusively by women. The research should reflect that men also are engaged in this work. By including both women and men in the research a more comprehensive perspective about how each cope with their difficult circumstances can be achieved.

Implications for Practice

At the beginning of this dissertation, I stated that the new insights gained in this study should result in a clearer definition and conceptualization of respite from the dementia family caregiver perspective. From this foundation more specific and appropriate outcome indicators for respite could be identified. These outcome indicators could then be more confidently used to identify the effectiveness of specific respite programs and could be used for future respite program development for the caregivers of dementia persons. I believe this study has been successful in articulating a more definitive approach to the understanding of respite from the caregivers' perspective and that this clearer conceptualization will be useful to respite practitioners.

On a general level, providing practitioners with a caregiver respite conceptual framework gives them a fresh new perspective on respite. As indicated in Chapter 4, this study challenges the basic assumption that if a dependent family member is in a respite program then the caregiver experiences respite. The caregivers in this study provided evidence of the inaccuracy of this assumption. They also provided rich data indicating the numerous factors which determine the caregiver's ability and opportunity to experience the personal freedom of respite. It is important that respite practitioners be aware of these influencing factors so that services can more appropriately incorporate them. And, most importantly, the recognition that each case has at least two clients, the caregiver and the dementia person, for each respite service attendee who may benefit from the service, must be fully acknowledged in respite program planning.

Additionally, conceptualizing respite as a deeply personal caregiver experience challenges the use of the term "respite care" by practitioners. To identify a program as a respite service continues the conceptual disarray about the caregiver experience of respite. An initial step to clarify this confusion might be to rename services where the intended outcome is a caregiver respite experience. I do not say this to discredit the value of these services. The caregivers in this study have provided ample evidence of the worth of these "respite services" to them. The value in renaming these services lies in more clearly articulating the supportive nature these programs provide to the caregivers rather than defining them in terms of the mental state of respite only the caregivers can experience.

Each component of the experiential respite model developed in this study has implications for respite practitioners. At the first stage of the model, the factors influencing the caregivers' ability to move out of the caregiver world provide insight into why some caregivers have difficulty in acknowledging their need for respite and in accessing respite services. If practitioners recognize and incorporate these components into their practice, their services might become more sensitive to caregivers. For example, when caregivers reach out to the formal service system for help, providing new caregivers with education and counselling about the factors which might impede their use of respite services might help caregivers acknowledge their need for these services sooner. As well, the model provides insight into some attributes of a respite service which influence the caregivers' ability to get out of the caregiver world. These are important considerations for service providers in developing appropriate and caregiver sensitive respite programs.

At the center of the model is the caregivers' expression of their respite experience and the influencing dimension of time. This conceptualization is important to practitioners for several reasons. First, for a respite service to be successful, practitioners must recognize that their service must provide the caregiver with a "freedom" respite experience. They must further recognize that how this type of respite is achieved varies between caregivers. Second, the finding that the quality and length of the respite time interval is significant in how caregivers interpret their experiences of respite and in how respite services are planned. For example, differentiating the caregiver respite experience with adult day program (shorter time interval) from caregiver respite experience with institutional respite (longer time interval), is significant in determining the goals and outcomes of these programs. It might be that institutional respite is the service most appropriate to providing caregivers with a "freedom" respite experience. The goals and outcomes of adult day programs, on the other hand, might be better stated in terms of assisting caregivers to cope with the day to day management of their situations rather than providing caregivers with respite per se.

At the third stage of the model is the caregivers' re-entry into their world of caregiving and the factors influencing this re-entry. Recognition of the factors influencing this re-entry is important because it is the caregivers' ability to continue managing in this complex world which is the desired outcome of the respite experience. Caregivers seek out respite experiences so they can feel refreshed and continue in their situations. If the respite experience does not provide this for them and they re-enter the caregiver world with depleted energy or a deteriorated dementia person as a result of conditions in the respite service, then that experience has been ineffective and has, in fact, exacerbated the stress of the caregiver situation.

It is fundamental that respite practitioners recognize this relationship of the quality of the respite service, the condition of the dementia person at the termination of this service and the impact these have on the caregivers' ability to re-enter and continue effectively in their caregiver situation. It seems to me that, if respite practitioners do not recognize this pivotal relationship, then the caregivers' reluctance to use respite services, evident in this study and in the literature (Lawton et al., 1991; Chappell, 1992) will continue. Respite services will continue to be under-utilized by caregivers.

The possibility of continued under-utilization of respite services runs counter to the prominence of respite in government policies. It is in the best interests of everyone concerned -- caregivers, service providers, and government policy makers -- that the salience of the caregiver experience of respite be considered in conjunction with the delivery of respite services. Service providers cannot continue to consider only the respite program itself. They must, to a much greater extent, consider the perceptions of the caregivers and the impact that the program has on them.

Finally, the conceptual model developed in this study is also of value to the caregivers themselves. It provides them with the opportunity to gain further insight into the importance of respite experiences for themselves; to recognize the difficulties they might have in "giving themselves permission" to use respite, and to understand the numerous factors in their situations which can influence their respite experience. Additionally, the model might provide practitioners with a useful teaching and counselling tool in helping caregivers gain insight into their particular situations.

Implications for Future Research

The study has numerous implications for future research. Most significantly, it provides a foundational conceptual framework for the on-going study of respite. Each component within the framework needs to be explored in greater detail, both inductively and deductively, to strengthen and expand the relationships and connections within the model. As well, the conceptual link between respite, caregiver role, and leisure/work needs to be developed further. It is in the process of engaging in an open but systematic enquiry that new insights and associations into the area of respite can be made.

Within the model itself, some specific areas need to be mentioned. In exploring the factors influencing the caregivers' ability to leave the caregiver world, the concept of personality and the use of respite needs further exploration. As well, the hardiness characteristic in caregivers and its association with their ability to get out of the caregiver world is a tentative one in this study. Further research is required in this area as well.

In this same area of the model, linking the ability of caregivers to get out of their caregiving world with the stage of their caregiver experience is a potentially very useful research area. Also, exploring the notion that if respite help is offered at a time when the caregiver is not ready to admit the need for help, might provide insight into low utilization patterns of some respite programs reported in the literature (Chappell, 1992; Clarke & Watson, 1991). As well, the stage of the dementia illness and how it influences the caregivers' ability to temporarily leave the caregiver world also needs to be explored further. We must also have a clearer understanding of the characteristics of respite help and how these affect the caregivers' ability to leave the caregiver world. Identifying the factors which influence the caregivers' ability to step out of the caregiving world is a critical first step in helping us gain insight into why respite might be so difficult for some caregivers to access and use. More extensive research is needed to determine whether there are additional factors which need to be considered in this area.

In the model component called "being in your own world," the concept of freedom, the interval differentiation, and how caregivers experience their respite time are critical elements for further research. It is the understanding of this relationship between length of time and the caregiver experience of freedom that is so significant to the delivery of respite services. In light of the increasing prominence of respite services in the formal support system and the profusion of respite services, this is a "top priority" area of research. In addition, the area of how respite help affects the dependent family members and their relationships with their caregivers is an area which needs further exploration. It is important to investigate whether respite can facilitate an improved relationship between care-recipients and caregivers because of the implications for reduced caregiver stress levels in the situation.

In the model component called "factors influencing re-entry into the caregiver world," it is critical to identify those factors which result in negative emotional outcomes for caregivers at the point of their re-entry into the caregiver world. Clarification of these factors can provide guidance to service providers to develop respite services which are more attuned to the caregivers' perceptions of benefit for themselves and for their dependent family members.

Personal Observations

Exploring the concept of respite with the caregivers has been a wonderfully enlightening experience for me. It provided me with a different perspective of what caregivers perceive as a respite experience. It also gave me further insight into what the world of caregiving is like for the caregivers and of the significance that respite can have for them. Recognizing that the respite experience is, indeed, a caregiver coping strategy among many other strategies was another useful insight. Respite has been elevated to such heights as a panacea for caregiver burden and stress that to recognize its place among all the other coping strategies was a helpful process.

Finally, and, perhaps most significantly, this project is providing me with the foundational conceptual framework for my on-going research program in the area of respite. In this thesis, considered Phase 1 of a continuing research project on respite, the conceptual model of caregiver respite was developed. In Phase 2, which has already begun, this respite model is being strengthened conceptually through a qualitative process of intensive interviews of additional caregivers of dementia persons in preparation of further research in the area of respite.

References

Adler, G. (1992). Dementia caregivers: Expectations of respite care. The American Journal of Alzheimer's Care and Related Disorders and Research, 7, 8-12.

Alberta Health - Core Health Services (1994). A government document prepared for Regional Health Authorities, Alberta Health, author.

Allen, J.K. & Wrege, C.D. (1991). Social model day care for demented elderly and their families: A lower cost alternative. The American Journal of Alzheimer's Care and Related Disorders and Research, 6, 30-34.

Antonucci, T.C. (1990). Social support and social relationships. In R.H. Binstock and L.K. George (Eds.), Aging and the Social Sciences, Orlando, Florida: Academic Press, 205-226.

Archibold, P. (1982). An analysis of parent caring by women. Home Health Care Services Quarterly, 3, 5-26.

Archibold, P. (1980). Impact of parent caring on middle-aged offspring. Journal of Gerontological Nursing, 6, 79-85.

Barusch, A.S. (1988). Problems and coping strategies of elderly spouse caregivers. The Gerontologist, 28, 677-685.

Beck, M., Quade, V., Roberts, E., Gordon, J., & Annin, P. (1990). Home away from home. Newsweek, 116, 56-58.

Berman, S., Delaney, N., Gallagher, D., Atkins, P., & Graeber, M.P. (1987). Respite care: A partnership between a veterans administration nursing home and families to care for frail elders at home. The Gerontologist, 27, 259-265.

Berry, G.L., Zarit, S.H. & Rabatin, V.X. (1991). Caregiver activity on respite and nonrespite days: A comparison of two service approach. The Gerontologist, 31, 830-835.

Biegel, D.E., Sales, E. & Schulz, R. (1991). Family Caregiving in Chronic Illness. Newbury Park, CA: Sage.

Binstock, R.H., Post, S.G. & Whitehouse, P.J. (1992). The challenges of dementia. In R.H. Binstock, S.G. Post & P.J. Whitehouse (Eds.), Dementia and Aging. Johns Hopkins University Press: Baltimore, 1-17.

Blume, L., Persily, N.A., Mirones, M., Swaby-Thorne, A. & Albury, S. (1990). Anatomy of the Alzheimer's respite care program (ARCP). Home Health Care Services Quarterly, 11, 75-89.

Borden, W. & Berlin, S. (1990). Gender, coping, and psychological well-being in spouses of older adults with chronic dementia. American Journal of Orthopsychiatry, 60, 603-610.

Bowen, P., LaPerriere, B., & Thornton, N. (1994). An Analytic Review of Respite Care in Canada. Ottawa: Canadian Long Term Care Foundation and Home Support Canada.

Brody, E.M. (1985). Parent care as a normative family stress. The Gerontologist, 25, 19-29.

Brody, E.M. (1981). Women in the middle and family help to older people. The Gerontologist, 21, 471-480.

Brodaty, H., & Hadzi-Pavlovic, D. (1990). Psychosocial effects on carers of living with persons with dementia. Australian and New Zealand Journal of Psychiatry, 24, 351-361.

Brown, L. J., Potter,, J. F. & Foster, B. G. (1990). Caregiver burden should be evaluated during geriatric assessment. Journal of the American Geriatrics Society, 38, 455-460.

Burdz, M.P. (1991). Longitudinal study on the impact of nursing home respite on caregivers and patients. Dissertation Abstracts International, 51, 11-B, 5567.

Burdz, M.P, Eaton, W.O. & Bond, J.B. (1988). Effect of respite care on dementia and nondementia patients and their caregivers. Psychology and Aging. 3, 38-42.

Capital Health Authority (1994). A New Direction for Health. Edmonton: author.

Cobb, S. (1976). Social support as a moderator of life stress. Psychometric Medicine. 38, 300-314.

Cohen, S. & Syme, S.L. (1985). Issues in the study and application of social support. In S. Cohen and S.L. Syme (Eds.), Social Support and Health. Orlando, Florida: Academic Press, 3-22.

Cohen, S. & Wills, T.A. (1985). Stress: Social support, and the buffering hypothesis. Psychology Bulletin, 98, 310-357.

Chappell, N.L. (1990). Aging and social care. In R.H. Binstock & L.K. George (Eds.), Handbook of Aging and the Social Sciences. Toronto: Academic Press, 438-454.

Chappell, N. L. & Blandford, A. A. (1987). Adult day care and medical and hospital claims. The Gerontologist, 27, 773-779.

Chappell, N.L. (1992). Social Support and Aging. Toronto: Butterworths.

Chappell, N.L. (1993). Implications of shifting health care policy for caregiving in Canada. Journal of Aging and Social Policy, 5, 39-55.

Clarke, C. & Watson, D. (1991). Informal carers of the dementing elderly: A study of relationships. Nursing Practice, 4, 17-21.

Cleary, B.L. (1989). Alzheimer's disease: stressors and strategies associated with caregiving. Unpublished PhD Dissertation, University of Texas, Austin.

Clipp, E.C. & George, L.K. (1993). Dementia and cancer: A comparison of spouse caregivers. The Gerontologist, 33, 534-541.

Conlin, M.M., Caranasos, G.J. & Davidson, R.A. (1992). Reduction of caregiver stress by respite care: A pilot study. Southern Medical Journal, 85, 1096-1099.

Corcoran, M.A. (1992). Gender differences in dementia management plans of spousal caregivers: implications for Occupational Therapy. The American Journal of Occupational Therapy. 46, 1006-1012.

Clandinin, D.J. & Connelly, F.M. (1994). Handbook of Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), Thousand Oaks, California: Sage, 236-247.

Connelly, F.M. & Clandinin, D.J. (1990). Stories of experience and narrative inquiry. Educational Researcher, June-July, 2-13.

Crossman, L., London, C., & Barry, C. (1981). Older women caring for disabled spouses: A model for supportive services. The Gerontologist, 21, 464-470.

Deimling, G.T. (1991). Respite care and caregiver well-being in families caring for stable and declining AD patients. Journal of Gerontological Social Work, 18, 117-134.

Denzin, N.K. & Lincoln, Y.S. (1994) Handbook of Qualitative Research. Thousand Oaks,CA: Sage.

Dillehay, R.C., & Sandys, M.R. (1990). Caregivers for Alzheimer's patients: What we are learning from research. International Journal on Aging and Human Development, 30, 263-285.

Dorian, B. & Garfinkel, P.E. (1987). Stress, immunity and illness - a review. Psychological Medicine, 17, 393-407.

Eagle, D.J., Guyatt, G. H., Patterson, C., Turpie, I., Sackett, B., & Singer, J. (1991). Effectiveness of a geriatric day hospital. Canadian Medical Association Journal, 144, 699-704.

Folkman, S. & Lazarus, R.S. (1991). Coping and emotion. In A. Monet & R.S. Lazarus (Eds.), Stress and Coping An Anthology, 3rd edition. New York: Columbia, 207-227.

Folkman, S. & Lazarus, R.S. (1988). The relationship between coping and emotion: Implications for theory and research. Social Science and Medicine, 26, 309-317.

Forbes, W.F. & Barham, J.F.H. (1991). Concerning the prevalence of dementia. Canadian Journal of Public Health, 82, 185-188.

Fortinsky, R.H. & Hathoway, T.J. (1990). Information and service needs among active and former family caregivers of persons with Alzheimer's Disease. The Gerontologist, 30, 604-609.

Frese, M. (1991). Coping as a moderator and mediator between stress at work and psychosomatic complaints. In M.H. Appley & R. Trumbull (Eds.), Dynamics of Stress Physiological, Psychological, and Social Perspectives. New York: Plenum, 183-206.

Friedman, R. & Newberger, J. (1993). Family caregiving and health care reform. Caring, 12, 44-47.

George, L. & Gwyther, L. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26, 253-59.

Gerald, L.B. (1993). Paid family caregiving: A review of progress and policies. Journal of Aging & Social Policy, 5, 73-89.

Gaynor, S. (1989). When the caregiver becomes the patient. Geriatric Nursing, May/June, 121-123.

Gignac, M.A. & Gottlieb, B.H. (1994). Caregivers appraisal of efficacy in coping with dementia. Unpublished paper, Gerontology Research Centre, University of Guelph.

Gottlieb, B.H. & Johnson, J. (1995). Impact of Day Programs on Family Caregivers of Persons with Dementia (Final Report). Gerontology Research Centre & Psychology Department, University of Guelph, Ontario.

Gottlieb, B.J. & Gignac, M.A. (in press). Content and domain specificity of coping among family caregivers of persons with dementia. Journal of Aging Studies.

Gonyea, J.G., Seltzer, G.B., Gerstein, C. & Young, M. (1988). Acceptance of hospital-based respite care by families and elders. Health and Social Work, 13, 201-208.

Grant, G. & Nolan, M. (1993). Informal carers: sources and concomitants of satisfaction. Health & Social Care in the Community, 1, 161-168.

Guba, E.G. & Lincoln, Y.S. (1982). Epistemological and methodological bases of naturalistic inquiry. Educational Communication and Technology Journal, 30, 233-252.

Guba, E.G. & Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of Qualitative Research. Thousand Oaks, California: Sage, 105-117.

Haley, W.E., Levine, E.G., Brown, S.L., & Bartolucci, A.A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. Psychology and Aging, 2, 323-330.

Harder, W.P., Gornick, J.C., & Burt, M.R. (1986). Adult day care: Substitute or supplement? The Millbank Quarterly, 64, 414-441.

Harper, S., & Lund, D. (1990). Wives, husbands, and daughters caring for institutionalized and noninstitutionalized dementia patients: Toward a model of caregiver burden. International Journal of Aging and Human Development, 30, 241-261.

Harris, P.B. (1993). The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer's Disease victims. The Gerontologist, 33, 551-556.

Health and Welfare Canada (1992). Future directions in continuing care. Ottawa: Minister of Supply and Services.

Henderson, K.A., Bialeschki, M.D., Shaw, S.S. & Freysinger, V.J. (1989). A Leisure of One's Own: A Feminist Perspective on Women's Leisure. State College, PA: Venture Publishing.

Hirsch, C.H., Davies, H.D., Boatwright, F. & Ochango, G. (1993). Effects of a nursing-home respite admission on veterans with advance dementia. The Gerontologist, 33, 523-528.

Hogan, S. (1990). Care for the caregiver: Social policies to ease their burden. Journal of Gerontological Nursing, 16, 12-17.

Hooker, K., Monahan, D., Shifren, K, & Hutchinson, C. (1992). Mental and physical health of spouse caregivers: The role of personality. Psychology and Aging, 7, 367-375.

Homer, A.C. & Gilleard, C.J. (1994). The effect of inpatient respite care on elderly patients and their carers. Age and Ageing, 23, 274-276.

House, J.S. & Kahn, R.L. (1985). Measures and concepts of social support. In S. Cohen and S.L. Syme (Eds.), Social Support and Health. Orlando, Florida: Academic Press, 83-108.

Houston, B.K. (1987). Stress and coping. In C.R. Snyder & C.E. Ford (Eds.), Coping with Negative Life Events. New York: Plenum, 373-399.

Hyndman, L. (1989). The Rainbow Report: Our Vision for Health. Edmonton, Alberta: Legislative Assembly of Alberta.

Jerrom, B., Mian, I., Rukanyake, N.G. & Prother, D. (1993). Stress on relative caregivers of dementia sufferers, and predictors of the breakdown of community care. International Journal of Geriatric Psychiatry, 8, 331-337.

Kane, R.A. & Penrod, J.D. (1995). Family Caregiving in an Aging Society. Thousand Island, CA: Sage.

Keating, N. & Gilewich, G. (1985). Alzheimer's disease: The burden of family caring. Alberta Psychology, 123, 1481-1489.

Keating, N. & Warren, S. (1988). Factors which may predict the institutionalization of Alzheimer's patients (Final report). Edmonton, Alberta: Senior Citizen's Secretariat.

Knight, B.G., Lutzky, S.M. & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. The Gerontologist, 33, 240-248.

Kobasa, S.C. (1979). Stressful life events, personality, and health. Journal of Personality and Social Psychology, 37, 1-11.

Kosberg, J.I., Cairl, R.E. & Keller, D.M. (1990). Components of burden: Interventive implications. The Gerontologist, 30, 236-242.

Kosloski, K. & Montgomery, R.J. (1993). Perceptions of respite services as predictors of utilization. Research on Aging, 15, 399-413.

Kuhlman, G.J., Wilson, H.S., Hutchinsson, S.A., & Wallhagen, M. (1991). Alzheimer's disease and family caregiving: Critical synthesis of the literature and research agenda. Nursing Research, 40, 331-337.

Larkin, J.P. & Hopcroft, B.A. (1993). In-hospital respite as a moderator of caregiver stress. Health and Social Work. 18, 132-138.

Lather, P. (1986). Issues of validity in openly ideological research: Between a rock and a soft place. Interchange, 17, 63-84.

Lawton, M.P., Brody, E.M., & Saperstein, A.R. (1989). A controlled study of respite service for caregivers of Alzheimer's patients. The Gerontologist, 29, 8-16.

Lawton, M.P., Brody, E.M., & Saperstein, A.R. (1991). Respite for caregivers of Alzheimer patients: Research and practice. New York: Springer Publishing.

Lawton, M.P., Moss, M., Kleban, M., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. Journal of Gerontology: Psychological Sciences, 46, 181-189.

Lazarus, R.S. & Folkman, S. (1984). Stress, Appraisal and Coping. New York: Springer.

Levine, J. & Lawlor, B.A. (1991). Family counselling and legal issues in Alzheimer's disease. Psychiatric Clinics of North America, 14, 385-397.

Lincoln Y.S. & Guba, E.A. (1985). Naturalistic Inquiry. Newbury Park: Sage.

Lindgren, C.L. (1993). The caregiver career. Image, 25, 214-219.

Lindeman, D.A., Corby, N.H., Downing, R., & Sanborn, B. (1991). Alzheimer's day care - A basic guide. New York: Hemisphere Publishing Corporation.

Mace, N.L., & Rabins, P.V. (1984). Day care & dementia. Generations, Winter, 41-44.

McDaniel, S.A. (1986). Canada's Aging Population. Toronto: Butterworths.

McDaniel, S.A. & Gee, E.M. (1993). Social policies regarding caregiving to elders: Canadian contradictions. Journal of Aging and Social Policy. 5, 57-72.

Miller, D.B. & Goldman, L. (1989). Perceptions of caregivers about special respite services for the elderly. The Gerontologist,. 29, 408-410.

Milne, C., Sacco, C., Cetinski, G., Browne, G., & Roberts, J. (1992). Correlates of Caregiver Wellbeing, With and Without the Use of a Day Program for Cognitively Impaired Elderly. Hamilton, Ontario: McMaster University.

Mirosh, D. (1988). A New Vision for Long Term Care - Meeting the Need. Edmonton, Alberta: Legislative Assembly of Alberta.

Mohide, E.A., Pringle, D.M., Streiner, D.L., Gilbert, J.R., Muir, G. & Tew, M. (1991). A randomized trial of family caregiver support in the home management of dementia. Journal of the American Geriatrics Society, 38, 446-454.

Morgan, D.G. & Laing, G. (1991). The diagnosis of Alzheimer's disease: Spouse's perspectives. Qualitative Health Research, 1, 370-387.

Moch, S.D. (1988). Toward a personal control/uncontrol balance. Journal of Advanced Nursing, 13, 119-123.

Montgomery, R.J.V. (1995). Examining respite: Its promise and limits. In Eds R.A. Kane & J.D. Penrod (Eds.), Family Caregiving in an Aging Society Policy Perspectives. Thousand Oaks, CA: Sage, 29-45.

Montgomery, R.J.V. (1992). Examining respite: Its promise and limits. In Eds M.G. Ory & A.P.Duncker (Eds.), In-Home Care for Older People. Newbury Park, CA: Sage, 75-96.

National Advisory Council on Aging (1990a). The NACA position on community services in health care for seniors. Ottawa: Minister of Supply and Services Canada.

National Advisory Council on Aging (1990b). The NACA position on informal caregiving: Support and enhancement. Ottawa: Minister of Supply and Services Canada.

Neulinger, J. (1976). The need for and the implications of a psychological conception of leisure. The Ontario Psychologist, 8, 15-17.

Nolan, M. & Grant, G. (1992). Respite care: Challenging tradition. British Journal of Nursing, 1, 129-131.

Novak, M., & Guest, C. (1989). Application of a multi-dimensional caregiver burden inventory. The Gerontologist, 29, 798-803.

Oktay, J.S. and Volland, P.J. (1990). Post-hospital support program for the frail elderly and their caregivers: A quasi-experimental evaluation. American Journal of Public Health, 80, 39-46.

O'Reilly-Wenegrat, A., Gallagher-Thompson, D., Rose, J. & Bliwise, N. (1994). Defense styles and emotional distress in women caregivers to cognitively impaired elders. Paper presented at the American Society on Aging 1994 Conference, San Francisco.

Ory, M.G. & Duncker, A.P. (1992). In-Home Care for Older People: Health and Supportive Services. Newbury Park, CA: Sage.

Osborne, K. (1991). Women's work...is never done. In J. Firth-Cozens & M.A. West (Eds.), Women at Work. Philadelphia: Open University Press, 3-12.

Owens, R.G. (1982). Methodological rigor in naturalistic inquiry: Some issues and answers. Educational Administration Quarterly, 18, 1-21.

Pallett, P. J. (1990). A conceptual framework for studying family caregiver burden in Alzheimer's-type dementia. Image, 22, 52-58.

Panella, J.J., Jr., Lilliston, B.A., Brush, D., & McDowell, F.H. (1984). Day care for dementia patients: An analysis of a four-year program. Journal of the American Geriatrics Society, 32, 883-886.

Parker, S. (1983). Leisure and Work. Boston: George Allen & Unwin.

Pearlin L.I. & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behaviour, 19, 2-21.

Pearlin L.I. & Lieberman, M.A. (1981). The stress process. Journal of Health and Social Behaviour, 22, 337-356.

Pearlin, L.I. (1985). Social structure and processes of social support. In S. Cohen & S.L. Syme (Eds.), Social Support and Health. Orlando, Florida: Academic Press, 43-60.

Pearlin, L.I. (1989). The sociological study of stress. Journal of Health and Social Behaviour, 30, 241-156.

Pollock, S.E. (1989). The hardiness characteristic: A motivating factor in adaptation. Advances in Nursing Science, 11, 53-62.

Pratt, C., Wright, S., & Schmall, V. (1987). Burden, coping and health status: A comparison of family caregivers to community dwelling and institutionalized Alzheimer's patients. Gerontological Social Work with Families, 10, 99-113.

Rabowski, W. & Clark, N.M. (1985). Future outlook, caregiving, and care-receiving in the family context. The Gerontologist, 25, 618-23.

Rankin, E.D., Haut, M.W. & Keefover, R.W. (1992). Clinical assessment of family caregivers in dementia. The Gerontologist, 32, 813-821.

Riggs, J.A. (1991). Family caregiver support act. Caring, 10, 18-21.

Robertson, D, Rockwood, K, & Stolee, P. (1989). The prevalence of cognitive impairment in an elderly Canadian population. Acta Psychiatrica, 80, 303-309.

Robinson, K. (1990). The relationships between social skills, social support, self-esteem and burden in adult caregivers. Journal of Advanced Nursing, 15, 788-795.

Rosenheimer, L. & Francis, E.M. (1992) Feasible without subsidy? Overnight respite for Alzheimer's. Journal of Gerontological Nursing, 18, 21-29.

Sands, D., & Suzuki, T. (1983). Adult day care for Alzheimer's patients and their families. The Gerontologist, 23, 21-23.

Schene, A. H. (1990). Objective and subjective dimensions of family burden: Towards an integrative framework for research. Social Psychiatry and Psychiatric Epidemiology, 25, 289-297.

Scharlach, A. & Frenzel, C. (1986). An evaluation of institution-based respite care. The Gerontologist, 26, 77-82.

Schwandt, T.A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of Qualitative Research. Thousand Oaks, California: Sage, 118-137.

Seltzer, B., Rheaume, Y, Volicer, L., Fabiszewski, K.J., Lyon, P.C., Brown, J.E. & Volicer, B. (1988). The short-term effects of in-hospital respite on the patient with Alzheimer's Disease. The Gerontologist, 28, 121-124.

Shapiro, E. & Roos, N.P. (1987). Predictors, patterns,and consequences of nursing-home use in one Canadian province. In V.W. Marshall (Ed.), Aging in Canada: Social Perspective (2nd Ed), Richmond Hill, ON: Fitzhenry & Whiteside.

Skelly, M.C., McAdoo, C.M. & Ostergard, S.M. (1993). Caregiver burden at McGuire Veterans Administration Medical Center. Journal of Gerontological Social Work, 19, 3-13.

Skaff, M.M. & Pearlin, L.I. (1992). Caregiving: Role engulfment and the loss of self. The Gerontologist, 32, 656-664.

Spradley, J.P. (1980). Participant Observation. Toronto: Holt, Rinehart, and Winston.

Stephens, M.A., Kinney, J.M., & Ogrocki, P.K. (1991). Stressors and well-being among caregivers to older adults with dementia: The in-home versus nursing home experience. The Gerontologist, 31, 217-223.

Stewart, M. (1993). Integrating Social Support in Nursing. Newbury Park, CA: Sage.

Strecher, V.J., DeVellis, B.M., Becker, M.H., & Rosenstock, I.M. (1986). The role of self-efficacy in achieving health behaviour change. Health Education Quarterly, 13, 73-91.

Strang, V., Greschuk, J., McIlveen K. & Gadacz, R.R. (1992). Adult day care programs - An Evaluation Study (Final Report). Victorian Order of Nurses, Edmonton.

Strang, V., & Neufeld, A. (1990). Adult day care programs: A source for respite. Journal of Gerontological Nursing, 16, 16-19.

Strauss, A.L. (1987). Qualitative Analysis for Social Scientists. New York: Cambridge University Press.

Strauss, A., & Corbin, J. (1990). Basics of Qualitative Research. Newbury Park, CA: Sage.

Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of Qualitative Research. Thousand Oaks, CA: Sage, 273-285.

Tartasky, D.S. (1993). Hardiness: Conceptual and methodological issues. Image, 25, 225-229.

Theis, S.L. & Deitrick, E.P. (1987). Respite care: A community needs survey. Journal of Community Health Nursing, 4, 85-92.

Wallsten, S.M. (1993) Comparing patterns of stress in daily experiences of elderly caregivers and noncaregivers. International Journal of Aging and Human Development. 37, 55-68.

Ward, D. & Brown, M.A. (1994). Labor and cost in AIDS family caregiving. Western Journal of Nursing Research, 16, 10-25.

Ward, D. (1990). Gender, time, and money in caregiving. Scholarly Inquiry for Nursing Practice: An International Journal, 4, 223-239.

Ward, R.L. (1983). Limitations of the family as a supportive institution in the lives of the aged. In D.B. Gutknecht, E.W. Butler, L. Criswell, & J. Meints (Eds.), Family, Self, and Society: Emerging Issues, Alternatives, and Interventions. Lanham, Md: University Press of America.

Wells, Y.D., Jorm, A.F., Jordan, F., & Lefroy, R. (1990). Effects on care-givers of special day care programmes for dementia sufferers. Australian and New Zealand Journal of Psychiatry, 24, 82-90.

Wilson, H.S. (1989a). Family caregiving for a relative with Alzheimer's dementia: Coping with negative choices. Nursing Research, 38, 94-98.

Wilson, H.S. (1989b). Family caregivers: The experience of Alzheimer's Disease. Applied Nursing Research, 2, 40-45.

Wolcott, H.F. (1994). Transforming Qualitative Data. Thousand Oaks, CA: Sage.

Young, R. & Kahana, E. (1987). Conceptualizing stress, coping and illness management in heart disease caregiving. The Hospice Journal, 2, 53-73.

Zarit, S.H., Reever, K.E. & Bach-Peterson, J. (1980). Relatives of impaired elderly: Correlates of feelings of burden. The Gerontologist, 20, 649-655.

Zarit, S.H., & Zarit, J.M. (1983). Families under stress: Interventions for caregivers of senile dementia patients. Psychotherapy: Theory, Research and Practice, 19, 461-471.

Zarit, S.H., Todd, P.A., & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist, 26, 260-266.

APPENDIX A

INFORMATION SHEET

The Experiential Understanding of Respite Care for Caregivers of Persons with Dementia

I am recruiting volunteers to participate in this research study. The volunteers should be caregivers of persons with dementia. Also, they should be using some type of help expected to give the caregiver relief from their caregiving duties.

The purpose of the study is to see how family caregivers of dementia persons experience relief from their caregiving activities. The following are some of the questions I am asking in the study. What is the caregiving experience like? What part of the caregiving experience is the most and the least stressful? What is helpful and not helpful in caring for a dependent family member? What gives the caregiver relief? How does the caregiver feel about the respite arrangement being used? What is the value of the respite care to the caregiver?

The results of the study may help us to better understand how caregivers of dementia persons feel about getting relief from their caregiving activities. It might also help to provide a better type of service that will provide the type of relief needed by caregivers.

If you volunteer to be part of the study, I will interview you two or three times. Each of these interviews will last about 60 minutes. I will make an appointment with you by telephone for the first interview. I will ask you to talk about your caregiving situation and your feelings about getting relief. I will contact you again later to arrange for the second and third interviews. I will ask for a third interview with you only if needed. In these interviews, I will check with you to see what I thought you said was correct. I will ask you to talk further about how you feel about getting relief from your caregiver situation. All the interviews will be audio-tape recorded.

The information you provide will be kept confidential. I will write a report about this study. I might also present it to the public at some time. You will be free to stop your participation in the study at any time. Just tell me.

If interested in being part of the study, contact me, Vicki Strang RN, at **492-6333**. I am the researcher in this study. I am an Assistant Professor with the Faculty of Nursing at the University of Alberta. I am also a graduate student (PhD) with the Faculty of Education at the University of Alberta. I look forward to hearing from you.

APPENDIX B

INTERVIEW GUIDE

HOW CAREGIVERS OF PERSONS WITH DEMENTIA EXPERIENCE RESPITE CARE

DEMOGRAPHICS

1. What gender are you? male ____ female ____

2. In what year were you born? ________

3. What is your relationship to your dependent family member (spouse, adult child)?

____

4. What is your occupation now (what was it before your retirement)?

____

5. What was the highest level of education you achieved? ____________________

6. Do you have any health problems?_______________If yes, please describe

____

7. Besides your family member's dementia problem, does s/he have any other health problem?___________________ If yes, please describe___________________________

8. How is your family member affected by the dementia? _________________________

CAREGIVER SEMI-STRUCTURED INTERVIEW GUIDE

1. What is the caregiving experience like for you? (What is a typical day like for you?)

2. What part of your caregiving experience is most stressful for you?

3. What part of your caregiving experience is least stressful for you?

4. What situations do you find helpful in caring for your family member?

5. What situations do you find not helpful in caring for you family member?

6. What does respite mean to you? Describe what it feels like when you are getting relief.

7. What gives you relief from your caregiving activities?

8. Describe to me, how you go about getting this relief for yourself.

9. If you have some arrangement to get relief for yourself, how do you feel about it?

10. How do you experience the time getting ready to use this arrangement and the time after it is finished.

11. When you are using this arrangement, how do you experience the time when you are separated from you family member?

12. How important is it to you to get some relief from your caregiving activities?

13. If you have had a respite experience, how do you feel when you come back to your responsibilities of being the caregiver.

14. Is there anything else you would like to tell me about your situation?

Thank-you for taking the time to share your thoughts and feelings about respite care with me in this research study.

APPENDIX C

ETHICAL REVIEW DOCUMENTS

CONSENT FORM

CAREGIVER CONSENT FORM

CODE NUMBER ______

Project Title: THE EXPERIENTIAL UNDERSTANDING OF RESPITE CARE FOR CAREGIVERS OF PERSONS WITH DEMENTIA

Researcher: Vicki Strang - Assistant Professor, Faculty of Nursing
University of Alberta.
- PhD student, Faculty of Education
University of Alberta

PURPOSE - The purpose of this study is to see how you, as a caregiver of a dementia person, experience relief from your caregiving activities. In order to do this, you will be asked a number of questions. A sample of these questions are:

1. What is the caregiving experience like for you?
2. What part of the caregiving experience is most stressful for you?
3. What part of the caregiving experience is least stressful for you?
4. What situations do you find helpful in caring for your family member?
5. What situations do you find not helpful in caring for you family member?
6. What gives you relief from your caregiving activities?
7. How do you feel about the arrangement you have now to get relief for yourself?
8. When you are using this arrangement, how do you experience the time when you are separated from you family member?
9. How important is it to you to get some relief from your caregiving activities?

The results of the study may help nurses and other health care workers to better understand how caregivers of dementia persons feel about getting relief from their caregiving responsibilities. It might also help to provide a better type of service that will provide the type of relief needed by caregivers.

PROCEDURE - You will be interviewed two or three times. Each of these interviews will last approximately 60 minutes. If you want to, you can talk longer. The first interview will happen after the researcher has made an appointment with you usually by telephone. At this first interview, you will be asked to sign a consent form. You will then be asked to talk about your caregiving situation. You will also be asked to talk about your feelings about getting relief. The researcher will contact you again later to arrange for the second and third interviews. In the second and the third, if needed, interviews you will asked to verify what the researcher thought you said in the first and second interviews. You will also be asked to talk further about how you feel about getting relief from your caregiver situation.

1. All the interviews will be audio-tape recorded. They will be transcribed later. Notes might also be taken during the interviews. Your name will not be on the tapes, the transcriptions, or the notes. Only a code number assigned to your name will be used.

2. Your name and your code number will be kept in a locked container. Only the researcher directly involved in the study will be able to get at this information.

3. All the tapes, transcriptions, and notes collected in this study will be held in a separate locked container. These materials will be kept in this locked storage for seven years.

4. The information collected in this study might be used in some other related research in the future. This will be done only after the appropriate ethics review committee has approved it.

5. A report will be written about this study. Your name will not be on it. This report may be presented to the public at some time.

6. You are free to stop your participation in the study at any time. Just tell the researcher. Your service will not be affected. If any aspect of the study changes you will be informed right away.

7. You may not benefit directly from the study.

8. There are no expected risks for you if you participate in the study.

9. If you have any further question about the project, you can contact Vicki Strang (492-6333).

CONSENT: I acknowledge that I have been informed about the procedures in this study. I have been given the chance to ask all the questions I want. I give permission to be interviewed by the researcher. I know that in these interviews I will be asked to talk about caring for my disabled family member. I know that I will be asked to talk about how I feel about getting relief from my caregiving responsibilities. I understand that there are no expected risks. There may be no direct benefit for me if I participate in the study. I understand that I am free to withdraw at any time. I understand that if any aspect of the study changes I will be informed promptly. I have been given a copy of this form to keep. I know that it will be kept in locked storage for five years after the study is finished.

____

signature of caregiver date

____

signature of researcher date

If you wish to receive a summary of the study when it is finished, please complete the next section:

Name:____

Address:____

University of Alberta
Edmonton
Canada T6G 2G3

Faculty of Nursing
3rd Floor Clinical Sciences Building

Certification of Ethical Acceptability for Research Involving Human Subjects

---

NAME OF APPLICANT(S): **Vicki Strang, RN, MN**

TITLE OF PROJECT: **"The Experiential Understanding of Respite Care for Caregivers of Dementia Persons"**

The members of the review committee, having examined the application for the above-named project, consider the procedures, as outlined by the applicant, to be acceptable on ethical grounds for research involving human subjects.

February 23 1994
Date

D. Lynn Skillen
D. Lynn Skillen, RN, PhD
Chair
Ethics Review Committee

The Ethics Review Committee is a Joint Committee of
The Faculty of Nursing, University of Alberta
and
The Nursing Division, University of Alberta Hospitals

EBH
EDMONTON
BOARD OF
HEALTH

Suite 500, 10216 - 124 Street
Edmonton, Alberta T5N 4A3

Phone:(403) 482-1965
Fax: (403) 482-4194

1994 05 20

Vicki Strang RN, MN
3rd Floor, Clinical Sciences Building
University of Alberta
Edmonton, Alberta
T6G 2G3

Dear Ms. Strang:

Thank you for submitting your proposal titled, "**The Experiential Understanding of Respite Care for Caregivers of Persons with Dementia**" and for meeting with the Research and Ethics Review Committee to discuss the study. Thank you as well, for providing us with a revised copy of your consent form so promptly; the changes therein address our concern that participants should be informed that services being received would not be affected should they choose to withdraw from the study at any point.

I am pleased to report that the Committee approved participation of the Edmonton Board of Health in your study. Dr. Predy will contact Dawn MacNeil who will then assist you with the recruitment of subjects.

We wish you success with your study and look forward to receiving a copy of the final report.

Sincerely,

for/Joy Edwards, Chairman
Research and Ethics Review Committee