INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700 800/521-0600

University of Alberta

Experiencing Control in Caregiving

by

Vivian Ann Szabo

A thesis submitted to the Faculty of Graduate Studies and Research in partial
fulfillment of the requirements for the degree of Master of Nursing

Faculty of Nursing

Edmonton, Alberta

Spring, 1997

National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisitions et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced with the author's permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-21269-6

Canadä

University of Alberta

Library Release Form

Name of Author: **Vivian Ann Szabo**

Title of Thesis: **Experiencing Control in Caregiving**

Degree: **Master of Nursing**

Year this Degree Granted: **1997**

Vivian Szabo

619-First Avenue NW
Calgary, Alberta, Canada T2N 0A2

Date January 27, 1997

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 **Experiencing Control in Caregiving** submitted by **Vivian Ann Szabo** in partial fulfillment of the requirements for the degree of **Master of Nursing.**

V. Strang

Dr. V. Strang (Supervisor)

Anne Neufeld

Dr. A. Neufeld

M Haughey

Dr. M. Haughey

Date January 20, 1997

Dedication

This thesis is dedicated to the late Karen Hansen Szabo, an extraordinary caregiver.

Abstract

The purpose of this study was to explore the experience of control as perceived by family caregivers in caring for relatives with dementia. The sample included 21 family caregivers of relatives with dementia, four of whom were men and the remainder women. Grounded theory techniques were used for analysis of data from a previous study on caregivers. An explanatory model of experiencing control in managing caregiving was developed from the data analysis.

The caregivers experienced control in the dimensions 'maintaining control' and 'lacking control'. Maintaining control included five properties: (1) confident language, (2) positive internal resources, (3) ability to recognize the need for and to ask for help, (4) anticipation of the future, and (5) seeing impending loss of control and acting on it. Lacking control included three properties: (1) negative internal resources, (2) inability to recognize the need for or ask for help, and (3) no future anticipation.

The movement occurring between the two dimensions consisted of 'losing control' and 'regaining control'. The experience of control was related to the way in which the caregivers coped with their caregiving situations on a daily basis.

The explanatory model of experiencing control in managing caregiving will enable nurses to have a clearer understanding of control in caregiving and help them to intervene effectively with family caregivers. Nurses may then be more equipped to assist caregivers who lack control to plan for the future and to support those caregivers who are managing well. The model also provides direction for further longitudinal research on linking control and caregiver coping.

Acknowledgements

I would like to acknowledge those individuals who assisted me in completing this research. I am grateful for the support, guidance, and encouragement I received from Dr. V. Strang, my supervisor. She not only provided me with data for this secondary analysis, she also gave generously of her time and listening skills in all phases of this research. I appreciate her enthusiasm for my topic and her wise words.

I would like to thank my committee members Dr. A. Neufeld and Dr. M. Haughey for their thoughtful questioning and feedback throughout this study.

I would also like to thank my colleagues in the graduate program who listened to the development of the topic for this research and especially those who provided feedback during the presentation of my findings. Your input helped to clarify my thinking and writing.

I am also grateful to those caregivers who were a part of the original study and who graciously consented to secondary analysis of their narratives. Although I never met any of them, I appreciate the offering that they gave of their time and insight into their lives as caregivers.

Finally, I would like to thank my family for their support and encouragement since the beginning of this journey. In particular, my husband and friend Mark has listened, loved, and lived with this work. I am grateful.

The original study was supported by funding from the National Health and Research Development Program (NHRDP). The secondary study was supported by scholarships from the Lorraine Lawton-Andersen Memorial Fund for Gerontological Nursing and the C. Dianne Davidson Memorial Fund for Mental Health Nursing.

Table of Contents

I. Introduction 1

  Purpose of the Study 3

  Thesis Format 4

II. Literature Review 5

  The Experience of Caregiving 5

  The Stress of Caregiving 7

  Factors Influencing Stress Management 9

    Control 9

    Perceived Control 11

    Social Support and Control 12

    Coping and Control 13

    Personality and Control 15

    Summary 16

  Control and Caregivers 17

    Control as a Key Finding in Caregiving Research 17

    Studies on Control and Caregivers 21

  Summary 23

III. Method 27

  Methodological Approach 27

    Grounded Theory 27

    Secondary Analysis 29

      Primary Data 32

Fit With New Question 33
Sample Characteristics 34
Data Management 37
Data Analysis 40
Rigor 42
Ethical Considerations 44
IV. Findings 45
The Caregivers 45
The Caregivers as Individuals 45
Caregiver Groupings 46
The Experience of Control in Managing Caregiving 49
Summary of the Model 50
Model of Experiencing Control in Managing Caregiving 55
Explanation of the Dimensions and Properties of the Model 57
Dimension: Maintaining Control 57
Properties of maintaining control. 57
Dimension: Lacking Control 67
Properties of lacking control. 68
The missing properties. 75
Movement Within and Between the Dimensions 76
Losing control 76
Regaining control 80
Conclusion 85

V. Discussion and Interpretation 86

Related Literature 86

Coping and Perceived Control 87

Psychological resources 94

Coping responses 96

Movement 100

Conclusion 105

VI. Implications 107

Substantive Summary 107

Insights Gained from the Study 111

Limitations of the Study 112

Implications for Practice 113

Implications for Future Research 116

Conclusion 118

REFERENCES 119

APPENDIX A 127

APPENDIX B 130

APPENDIX C 133

APPENDIX D 136

APPENDIX E 138

APPENDIX F 147

APPENDIX G 153

List of Figures

Figure 1. Explanatory Model of Experiencing Control in Managing Caregiving...Page 56

CHAPTER I

Although the Canadian population is aging, the impact on the health care system has yet to be fully realized (National Advisory Council on Aging, 1994). One of the conditions associated with aging is senile dementia; it results in progressive mental and physical deterioration ending in death (Maas & Buckwalter, 1991). The majority of those afflicted live in the community and are cared for by family members (Baumgarten, Battista, Infante-Rivard, Hanley, Becker & Gauthier, 1992; Collins, Given, & Given, 1994; Parks & Pilisuk, 1991; Wuest, Ericson, & Stern, 1994). The number of family caregivers will increase as the population ages and as a result of cutbacks in health care services due to health care reform (National Advisory Council on Aging, 1995).

Within the last 15 years, family caregivers of persons with dementia has become a major area of research. Research has focused on the roles, experience, and burdens of caregiving (Maas & Buckwalter, 1991). In caring for a relative with dementia, it is not only the cognitive deterioration associated with dementia that caregivers find stressful, there is also a progressive physical degeneration (Maas & Buckwalter, 1991). In spite of the stressful nature of caring for a relative with dementia, some caregivers do function better than would be expected, given their demanding situation. Although the difficult nature of family caregiving is well established (Archbold, Stewart, Greenlick, & Harvath, 1990; Baumgarten, 1989; Cohen & Eisdorfer, 1988; Given, Collins, & Given, 1988; George & Gwyther, 1986; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986) there are wide variations in caregivers reactions and adaptations to caregiving. Studies investigating reasons for the differences in caregiver reactions have provided inconsistent results (Baumgarten, et al., 1992).

It would be helpful to know the factors that influence these caregivers who manage well in their caregiving roles so that these factors can be studied and applied to other caregivers. These factors are often not related to the state of the person with dementia but due to characteristics of the caregiver (George & Gwyther, 1986; Zarit et al., 1986). A number of factors such as social support, coping, and personality factors have been explored in hopes of shedding some light on these factors. Control is also seen as one factor which strongly influences the caregiver's ability to manage the stress and burden of caring for family members with dementia (Harris, 1993; Wallhagen & Kagan, 1993; Willoughby & Keating, 1991). Control has been linked with social support, coping, and personality frameworks.

Resources such as social support may be used to mediate the stressors of caregiving; when caregivers perceive of their social support systems as available, this enhances their perception of having control over their caregiving situation (Rothbaum, Weisz, & Snyder, 1982). Coping mediates the stress response and control is viewed as one of the basic processes which explains how coping mediates the stress response (Barusch, 1988; Krause & Stryker, 1984; Miller, 1979, 1980; Thompson, 1981). Personality literature indicates that personality may influence the appraisal of stressors and describes control as a trait of individuals where individuals are described as having either an internal or external locus of control. The complex relationships between control and social support, coping, and personality have led to confusion about the specific influence that control has within the caregiving experience.

These different theoretical perspectives of perceived control do not provide a clear idea of what perceived control is in relation to the caregiving experience. It is important not to link the study of perceived control with theoretical perspectives such as social support, coping, or personality at least initially in order to avoid continuing the conceptual confusion. In this way, a clearer understanding of how control is perceived in the caregiving situation can emerge.

A limited amount of research has been done on caregivers and control (Harris, 1993; Miller, 1987; Wallhagen, 1993; Wallhagen & Kagan, 1993; Willoughby & Keating, 1991; Wuest et al., 1994) and there is still no clear understanding of perceived control within the caregiving experience. Therefore, in this study, I will explore how caregivers perceive control within their experience of caring for relatives with dementia.

Purpose of the Study

The purpose of this study was to explore how caregivers perceive control within their experience of caring for persons with dementia. The concept of control is linked with managing stress and it seems to be a significant factor in how caregivers manage their stressful lives. However, there has been no specific delimitation of its meaning, role, and influence in caring for a relative with dementia. With a clearer understanding of control in caregiving, nurses will be able to be in a position to work more effectively with family caregivers.

The main research question for this study is as follows:

What is the experience of control as perceived by caregivers of relatives with dementia?

Additional questions to be examined are as follows: 1) Is control a process experienced over time with particular stages in caregiving? and 2) If control is a dynamic entity, is there evidence of movement within the experience of control?

The intent of these questions is to *explore*, that is, to remain conceptually open, as well as to *describe* and *explain* what control is for family caregivers of relatives with dementia. The perspective to be obtained is from the caregivers, within their experiences of caregiving.

Thesis Format

There are six chapters included in this research report. The relevant literature on caregivers and control is reviewed in the next chapter. The method, data analysis, and ethical considerations are discussed in Chapter 3. The findings and explanatory model of the study are introduced in Chapter 4. In Chapter 5, the literature which the findings are related to is first reviewed. The findings are then interpreted in light of this literature. The study is summarized in Chapter 6 and the thesis concludes with the implications of the findings for practice and research.

Chapter II

LITERATURE REVIEW

The purpose of this literature review is to establish a foundation for the study of the perceived control in family members caring for persons with dementia. First, the literature related to the caregiver experience and its stressful nature will be reviewed. This will be followed by a discussion of caregivers' perception of control. The extent to which the concept of control has been developed in the literature will be included. The influence of social support, coping, and personality on how caregivers perceive control in their situations will be addressed. It will become clear that despite the research on caregivers and on perceived control, to date, there has been limited research linking the two areas. This literature review will demonstrate that further study to determine how family caregivers perceive control within their experiences of caregiving was appropriate and timely.

The Experience of Caregiving

Cohen and Eisdorfer (1988) define informal caregivers as the individuals who are related to the patient and who provide the majority of assistance on a daily basis. For the purposes of this study, caregiver will mean family caregivers providing the majority of assistance to their relative with dementia. It is estimated that up to 80 percent of care given to persons with dementia is home-based care from relatives (Brody, 1981; Marshall, 1987; Parks & Pilisuk, 1991). The average length of home-based care is usually reported as around three years (Willoughby & Keating, 1991; Zarit, 1989) but the caregiving experience may last for many more years. Most informal caregivers are women and caregiving usually begins insidiously, starting with assistance in completing daily living tasks and this assistance increasing with the progression of the disease (Brody, 1981). The initial stage of the experience of caregiving surrounds the time of diagnosis of dementia, but caregiving has often begun long before that point with the onset of symptoms (Motenko, 1989). The caregiving experience progresses from the time surrounding diagnosis, through the stage of progressive deterioration of the person with dementia, with this stage often leading to institutionalization, and the final stage of the caregiving experience is the death of the person with dementia.

Caregivers have no difficulty describing their caregiving experiences because caregiving envelopes every aspect of their lives. It is important to understand the caregiving experience from the perspective of the caregiver. Caregivers describe the physical aspects of caregiving as: "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" (Strang, 1995, p. 85). Caregivers are often not prepared for the amount of physical care required by the relative with dementia and refer to themselves as jugglers, trying to keep a myriad of objects in motion in the air at once (Maas & Buckwalter, 1991; Strang, 1995). Yet caregivers continue to give care to their loved one in spite of the overwhelming number of mental and physical care needs associated with the dementia disease process. The commitment of caregivers to continue to provide care contributes to the emotional aspects of caregiving, which caregivers describe as being: "feelings of guilt, worry, fear, grief, embarrassment, conflict, anger, frustration, helplessness, sadness and loneliness" (Strang, 1995, p. 86). Throughout the experience of caregiving caregivers also endeavour to maintain the dignity and humanness of their loved one (Mace & Rabins, 1981; Strang, 1995).

This overview of the caregiving experience sets the stage for the context of this study. Stress and burden are major factors influencing the experience of caregiving. The burden associated with caregiving and the related stress management factors will now be discussed.

The Stress of Caregiving

One of the areas that has been studied extensively is the stress or burden experienced by caregivers within their experience of being a caregiver (Archbold et al., 1990; Baumgarten, 1989; Cohen & Eisdorfer, 1988; Given et al., 1988; George & Gwyther, 1986; Zarit et al., 1980; Zarit et al., 1986). The stressfulness of caring for persons with dementia is a result of its novelty, unpredictability, long duration, and ambiguity (Zarit et al., 1986).

The physical and psychological burden of caregiving has been studied extensively. It is well established that the prevalence of health problems among caregivers is high (Baumgarten et al., 1992; Fitting, Rabins, Lucas, & Eastham, 1986; George & Gwyther, 1986; Motenko, 1989). The majority of literature dealing with the impact of the caregiving experience has focused on caregiver burden. Those caring for persons with dementia are more likely to have chronic health problems and feel burdened by the constancy of the caregiving experience (Canadian Study of Health and Aging, 1994). Archbold et al. (1990) described the stressors of caregiving as being: strain from direct care, managed care, caregiving role expectations, communication, lack of resources, economic burden, tension in relationship, manipulation, role conflict, and global strain. Zarit et al. (1980) created the term 'caregiver burden' and carried out research in this area. They conceptualized all of the stress that a caregiver experiences under the term 'burden' and then developed the Burden Interview to measure the stressors that caregivers experience. The Burden Interview is a 29-item self-report questionnaire that measures the extent to which caregivers perceive burdens from caregiving in various areas of their lives. Zarit et al. (1980) determined whether any mediating factors such as the degree of illness of the person with dementia, provision of formal social or health services, or family visits influenced the degree of burden. The researchers interviewed 29 caregivers of elderly with dementia using the Burden Interview and asked the caregivers about the frequency of family visits and the use of social and health services. They found that only the frequency of family visits had a significant effect on the degree of burden. This research was followed with another study by Zarit et al. (1986) which looked at the changes in caregivers' burden over time and the influence of burdens on nursing home placement. The caregivers were contacted two years after the initial study and interviewed in the same manner, however, caregivers who had placed their relative in an institution were asked specific questions related to placement. They found that placement was associated with subjective factors such as the perception of burden rather than the objective indicators of the severity of dementia.

George and Gwyther (1986) also concluded that there was no direct relationship between the level of impairment in the person cared for and the caregiver s reported burden. Novak and Guest (1989) further maintained that caregiver burden could not be predicted by the level of impairment or abilities of the dementia person or the length of time as a caregiver. This underscores the need to study the characteristics of caregivers themselves to determine their perceptions of the caregiving situation. With the context for this study now set as being within the experience of caregiving which is associated with stress, I will now review factors that influence the management of this stress and explain how control may be associated with this management.

Factors Influencing Stress Management

There are great variations among caregivers in adaptation to the stressors of caregiving that are not related to the state of the person with dementia but due to characteristics of the caregiver (George & Gwyther, 1986; Zarit et al., 1986). Control is seen as one factor which strongly influences the caregiver's ability to manage the stress and burden of caring for family members with dementia (Harris, 1993; Wallhagen & Kagan, 1993; Willoughby & Keating, 1991). In the literature, social support, coping skills, and personality factors have been associated with caregivers ability to maintain control in managing their stressful situations. In the following section, the concepts of control and perceived control will be developed. Perceived control will then be discussed in relation to the social support, coping, and personality literature. To conclude, the concept of perceived control will be linked to the caregiver situation.

Control

Control is a concept that has been referred to as a "sensitizing concept" (Syme, 1991, p. 21) because it "seems to provide a parsimonious integration that incorporates into one thought, a variety of lesser and apparently unconnected ideas" (Syme, 1991, p. 21). In other words, the concept of control has a wide range of applicability; it is a term that provides explanation for a number of observations.

The concept of control has been studied in a number of disciplines, including psychology, sociology, medicine, and nursing. Control is referred to as a "hallmark of the human condition" (Hershberger, 1990, p. 55) where "to control is to behave intentionally" (Hershberger, 1990, p. 57). Control in this case is used to describe a property or trait of an individual. An individual is determined to have control if their actions are intentional.

Control has also been described as decisional. Bergmark and Oscarson (1987) argued that "control implies nothing more than determinism; any action, event, or system is controlled by its antecedent conditions" (p. 1206). This use reflects a causative position, where the question to be answered is not how an action happened, but rather why it happened (Bergmark & Oscarson, 1987). This position implies a retrospective review of situations to determine which preceding factors the property of control influenced to a certain outcome.

In addition to being used to describe a trait and an aspect of decision-making, the concept of control has been described as a process. Hickson, Housley and Boyle (1988) defined control as a "dynamic process which changes over time, and is moderated by environment, events, and developmental changes" (p. 197). According to Folkman (1984), "control can be viewed as a cognitive mediator of a stressful transaction and its adaptational outcome" (p. 850). This example again points to the use of control as a process between a situation and its outcome.

Perceived Control

Perceived control is an important aspect of the concept of control. Control has been described as being able to be perceived by an individual. It is a cognitive process whereby the individual believes that the way they think and act is within their own power (Bullers, 1994; Montbriand & Laing, 1991). According to Schorr and Rodin (1982), it is the control that an individual perceives themselves to have rather than the actual predictability of the situation that is important.

A general definition that encompasses many of the uses already discussed is that of Thompson (1981), who defined control as "the belief that one has at one's disposal a response that can influence the aversiveness of an event" (p. 84). This definition is general and "recognizes that the control does not need to be exercised for it to be effective and that it does not even need to be real, just perceived, for it to have effects" (Thompson, 1981, p. 84).

Perceived control has been defined by Wallhagen (1993) as the "perception that salient or valued aspects of one's life are manageable" (p. 220). In addition, perceived control is a critical component that influences adaptation and it has a role in coping with stress and well-being because it may act as a buffer within the caregiving experience (Wallhagen, 1993). The notion that perceived control is influenced by a particular situation is congruent with Hickson et al. (1988) who maintained that control is a "dynamic process which changes over time, and is moderated by environment, events, and developmental changes" (p. 197).

Once there exists within the individual the capacity for control, the consequence of the presence of control will be the ability to act. The consequence of control being present may be behavioral, such as the achievement of objectives or goal attainment. However, it is the perception of control as the antecedent of the behavior that must be studied. For the purposes of this study any further references to control may be assumed to imply the perception of control.

Social Support and Control

Social support is a resource used to mediate the stressors of caregiving by helping family members cope with caregiving (Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991). Social support also has a role in health promotion, coping, and moderating stressors (Stewart, 1995). Resources such as social support are "relatively stable conditions and supplies that are appraised by the person as available for use in meeting life changes" (Murrell & Norris, 1983, p. 477). Support systems consist of "a subset of the individual s overall network of social contacts, thus involving multiple variables, including type of support, size of social network, and perceived satisfaction with the support obtained" (Kuhlman et al., 1991, p. 333). It is the appraisal of social support systems as being available that enables social support to act as a mediator between the perception of caregiver burden and the consequences of caregiving (Pearlin & Schooler, 1978). When caregivers perceive of their social support systems as being available, this enhances their perception of having control over their caregiving situation (Rothbaum, et al., 1982). Caregivers look at their known resources in a particular light in order to gain control or mastery over their caregiving experience (Taylor, 1983).

Research done to explain the influence of social support on adaptation of caregivers to their caregiving role has resulted in inconsistent results concerning the effect of social support on caregiver well-being (Baumgarten, 1989; Kuhlman et al., 1991). This may be due to differences in the operationalization of social support, with definitions ranging from the presence of someone to confide in to instrumental help (Baumgarten, 1989). It is necessary to examine psychological aspects of caregiving such as caregivers' experiences of control in their caregiving situations; then it will be possible to understand how social aspects such as social support influence mastery and adaptation.

Coping and Control

Coping skills or responses also influence caregiver adaptation. Coping involves "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Coping processes are used to manage the relationship between a person and their environment (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) held that the individual must first appraise the situation before dealing with it. There are two forms of appraisal: primary and secondary. There are three kinds of primary appraisal: irrelevant appraisal, benign-positive appraisal, and stress appraisals (Lazarus & Folkman, 1984). A situation is appraised as irrelevant when it is viewed as meaningless and need not be dealt with; a situation is appraised as benign-positive when it is viewed as having an outcome which is positive; and a situation is appraised as stressful when it is viewed in terms of harm/loss, threat, or challenge (Lazarus & Folkman, 1984). Secondary appraisal is the assessment of resources in relation to the situation encountered. The assessment of resources includes those resources which are internal (competence and coping strategies) and external (social support) (Lazarus & Folkman, 1984). When the demands of the situation exceed the resources assessed by the individual the discrepancy may result in potential endangerment of the individual's well-being and therefore stress is experienced by the individual (Lazarus & Folkman, 1984). The individual must then deal with the demands of the situation through cognitive and behavioral efforts so that the threat is reduced, and this is known as coping (Lazarus & Folkman, 1984).

Control is viewed as one of the basic processes which explains how coping mediates the stress response (Barusch, 1988; Krause & Stryker, 1984; Miller, 1979, 1980; Thompson, 1981). Control augments the ability of individuals in coping with aversive events (Averill, 1973; Taylor, 1983; Thompson, 1981). Lefcourt (1976) stated that "whether people...believe they are actors and can determine their own fate within limits [is] of critical importance to the way in which they cope with stress and engage in challenges" (p. 2). However, the relationship between control, coping, and stress is complex and Averill (1973) emphasized that the effect of control depends on "the meaning of the control response for the individual; and what lends a response meaning is largely the context in which it is embedded" (p. 301). Therefore, it is important to study control within a particular context such as caregiving and to avoid linking it to coping initially in order to remain conceptually open to the way in which control operates as a factor in the caregiving experience. By remaining conceptually open in studying control in caregiving, the lens from which it is viewed will not be clouded by preconceived theoretical linkages, rather, a clearer understanding of the relationship of control with other concepts will be obtained.

Personality and Control

Personality has been hypothesized to influence the appraisal of stressors (Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Individuals assign meaning through an interactive process in which personality plays a part. It has been found in existing caregiving studies that personality does have a role in caregiving and it is worthy of further study with caregivers (Anthony-Bergstone, Zarit, & Gatz, 1988; Vitaliano et al., 1991). Vitaliano et al. (1991) suggested that gender, age, health problems, and personality may be factors that increase a caregiver s risk for burden within the experience of caregiving.

Control has been described as a personality factor or trait found in individuals; in this sense control is described as locus of control, a term which originated with the work of Rotter (1966). Locus of control refers to whether an individual s motivation is found internally or externally. If an individual has an internal locus of control, there is the belief that expectations are viewed as contingent on the individual's behavior; if there is an external locus of control, expectations are viewed as beyond the control of the individual and contingent on such things as fate, luck, or chance (Rotter, 1966).

There have been problems with the study of locus of control in nursing. Oberle (1991) reviewed the literature on the study locus of control in nursing over the last decade. It appears that there are basic methodological problems with most of the research, usually the problems are related to the design of the research. However, Antonovsky (1992) maintained that the problems and lack of progress discussed by Oberle concerning locus of control research in nursing are "primarily a function not of inadequate research design, but of inadequate conceptual clarification" (p. 1015). Cognitions such as perceived control are fluid and their meaning can vary according to the situation (Taylor, 1983); therefore control must be studied specifically rather than globally and within a specific context. Because of the conceptual confusion related to personality and control, it is time to inductively explore with caregivers how they experience control. In this way, clarification about personality and the process of perceived control within the particular situation of caregiving can be attempted.

Summary

The theoretical frameworks of social support, coping, and personality have each identified the concept of control as significant in how people manage stressful life events. However, each framework interprets control differently. Social support talks of control as being enhanced when caregivers perceive their social support systems as being available (Rothbaum et al., 1982). Coping mediates the stress response and control is viewed as one of the basic processes which explains how coping mediates the stress response (Barusch, 1988; Krause & Stryker, 1984; Miller, 1979, 1980; Thompson, 1981). Personality literature presents control as a trait of individuals where individuals are described as having either an internal or external locus of control (Rotter, 1966). Because of the theoretical variation in how control was described in relation to social support, coping, or personality, it was important to remain conceptually open in this study. If a deeper understanding and enhanced clarity of the family caregivers perception of control was to be achieved, then it was prudent to remain conceptually unattached to these theoretical perspectives, at least initially. Control in the caregiving situation could then be explored more independently and without the constraints of a particular theoretical influence. Based on the nature of the findings, suitable literature would then be reviewed and the findings explained as they relate to that literature.

Because control was the focus of this study, I will now focus on the literature related to control and caregiving. I will first review research which focussed on caregivers and where control became one of the key findings and I will then review the two studies that have specifically looked at control and caregivers.

Control and Caregivers

Control as a Key Finding in Caregiving Research

Control has been an important finding in research done on caregivers of persons with dementia. One study was done by Willoughby and Keating (1991). Using grounded theory, Willoughby and Keating (1991) studied caregivers who had placed their relative in an institution. Multiple unstructured interviews were done with ten family caregivers after institutionalization of their relative. The basic social process found in this study was taking on and relinquishing control. The process of gaining and relinquishing control within caregiving was found to encompass five stages: emerging recognition; taking control: making my own decisions; losing control: accepting the decisions of others; adjusting to the long-term care institution; and moving on. Stage 1 of the process was the recognition of a problem with the relative; it progressed to Stage 2 where the family member took control of the care of individual with dementia, thus becoming a caregiver. However, there came a point within the second stage where a cognitive shift occurred on the part of the caregiver with the acknowledgment that more help was needed to provide adequate care for the person with dementia. This resulted in Stage 3 which was a period of crisis where the caregiver experienced being out of control and had to make the cognitive shift to acknowledge the appropriateness of the decision to admit their relative. Stage 4 represented a time of change for the family with the person with dementia now institutionalized and the caregiving tasks taken over by the formal caregivers. In this stage the caregivers experienced less control over care management and felt isolated from their relative. The acknowledgment of the psychological loss of their relative was the cognitive shift experienced by the caregivers before moving into the final stage of the process. Stage 5 encompassed the time of institutionalization and death of the dementia person and the building of a life outside of caregiving for the caregiver. Although this study demonstrated some of the turning points within the experience of caregiving and provided an important foundation for further research into the role that control plays within the caregiving experience, it focussed on the overall process of caregiving. What needs to be understood now is the meaning of control within the day-to-day aspects of caregiving.

Another study which found control within caregiving was a study done by Harris (1993) on the male caregivers of spouses with Alzheimer disease. In-depth interviews were conducted with 15 male caregivers who were caring for their wives at home or just after placement of the relative with dementia in a nursing home. The most common themes expressed were: "commitment; social isolation/loss of companionship; coping strategies such as control...; a sense of accomplishment; the need for specialized services for men; and limited expectations of help from their children" (Harris, 1993, p. 553). One of the findings was that control was an important component in coping with the caregiving experience. The results showed that "keeping control of the caregiving situation for these men had meaning beyond an extension of their work roles" (Harris, 1993, p. 553). Control enabled the male caregivers to overcome the helplessness associated with the disease process. This study linked control with coping and emphasized the important role it plays within the caregiving experience. However, it is important to now look specifically at the role of control in caregiving and to not link control with coping. It is only in separating control from previous, assumed linkages that a clearer understanding of the particular influence that it has in caregiving will be known.

Caregivers may experience control by deciding not to be in control; that is, by letting go. Rothbaum et al. (1982) noted that "rather than changing the world, persons sometimes attempt to change themselves (specifically their views) so as to better accept the world" (p. 26) to maintain control. This may be evident in the caregiving period around the time of the demise of the relative with dementia. Jones and Martinson (1992) interviewed thirteen caregivers and used grounded theory to gain an understanding of the stages of bereavement; the first stage occurs during caregiving and the second occurs after the death of the relative. They found that throughout the caregiving experience, the process of detachment formed the first stage of bereavement. The caregivers decided to let go of the person with dementia due to their increased deterioration and impending death. Rather than being able to change their environment and the outcome of the dementia, the caregivers must now fit in with the environment (Rothbaum et al., 1982). After the physical death of the person with dementia, the caregivers experienced acute grief, followed by reflection and resolution of the bereavement process occurring over time.

Control as described by caregivers letting go was also found in a study done by Wuest et al. (1994) where grounded theory was used to explore the experience of caregivers and care recipients of Alzheimer disease as they become strangers in their interactions along a continuum of intimacy to alienation. Fifteen caregivers of persons with dementia were interviewed using unstructured interviews. The basic social process that emerged was becoming strangers; this process encompassed the stages of dawning, or becoming aware of change within the family member, holding on, and letting go of the former relationship with the dementia person. Holding on and letting go are two aspects of control where caregivers first try to maintain control by holding on to the familiar; they eventually realize that they will not be able to alter the outcome of the disease process and so choose to let go (Rothbaum et al., 1982). In letting go, the caregivers still maintain control over the situation by deciding not to be in control; it is they who have changed and not the situation (Rothbaum et al., 1982). This study focussed on the overall process of caregiving and found control to be a factor influencing the management of caregiving. What needs to be understood now is the meaning of control within the day-to-day aspects of caregiving.

These studies have demonstrated that control is one factor in caregiving.

Willoughby and Keating (1991) found that control described the turning points within the experience of caregiving but the focus was on the overall process of caregiving. Wuest et al. (1994) also looked at the whole continuum of caregiving and found that control was significant in caregivers learning how to 'let go' of their relative so that they could maintain control and move on with their lives. It is now important to shift the focus to examine control within caregiving on a day-to-day basis. In addition, Harris (1993) linked with control with coping and emphasized the important role it plays within the caregiving experience. However, a better understanding of control in caregiving will be obtained if control is looked at as a separate entity. Then the particular influence that control has in caregiving will be known.

Studies on Control and Caregivers

Two studies were found that looked specifically at control and caregiving. Miller (1987) interviewed spouse caregivers of persons who were cognitively impaired to determine whether men and women emphasized different dimensions of control within their caregiving experience. A semi-structured interview was conducted with the caregivers to gather information on their daily routine, the changes in their lives since the diagnosis of cognitive impairment, and the major problems encountered in caregiving. The sample included six husbands and nine wives. The investigator found that elements of control such as interpretation of the disease process, assumption of authority, control over the environment, and the use of social support were more problematic for wives. This descriptive study laid a foundation for further research on control within the experience of caregiving. However, Miller (1987) cautioned that the findings were exploratory and need to be replicated more rigorously. It is now important to specifically study control in caregiving, and to not limit the sample to spouse caregivers.

A second study on caregivers and control was done by Wallhagen (1993). Sixty caregivers were interviewed to test the hypothesis that perceived control would mediate the objective and subjective aspects of caregiving and caregiver adaptation. The objective aspects of caregiving included tasks of caregiving and the subjective aspects of caregiving referred to the difficulties of the tasks. Wallhagen developed the Perceived Control Questionnaire (alpha=0.93) to measure the participants' perception of control or manageability in relation to caregiving. The investigator found that perceived control had a direct relationship with life satisfaction and depression, and an indirect relationship with subjective symptoms of stress; wishful thinking coping behavior had a negative relationship with all adaptation variables. Caregivers who had a high level of perceived control had the necessary resources to deal with their situation and reported higher levels of life satisfaction. The investigator found that perceived control did not mediate the subjective and objective aspects of caregiving. Wallhagen suggested that this finding may mean that perceived control is a buffer rather than a mediator of the caregiving situation. However, she did not explain what the difference would be for control to buffer rather than mediate the caregiving situation. The investigator believed that the mediating effect was not found due to a redundancy of variables (Wallhagen, 1993).

In research related to the above work, Wallhagen and Kagan (1993) used semi-structured interviews as a part of the data collection tool from the Wallhagen (1993) study to explore the meaning of control with the participant caregivers. They concluded from this preliminary exploration of control with caregivers that this "research suggests a need to expand our conceptualization of control" (p.208). In addition, it needs to be viewed as an "active, prospective appraisal process" (p. 208) that is an "ongoing, ever changing characteristic of the lives of [these] caregivers" (p. 210) and must be studied as a process that occurs within the work of caregiving. This process must be studied using in-depth qualitative research because this method will offer a perspective that is inaccessible through traditional survey techniques (Kuhlman et al., 1991).

Summary

The review of the literature has established a foundation for the study of the perceived control in family members caring for dementia persons. I have set the context for this study within the experience of caregiving. I have outlined that caring for a person with dementia is an experience that is associated with burden or stress (Archbold et al., 1990; Baumgarten, 1989; Cohen & Eisdorfer, 1988; Given et al., 1988; George & Gwyther, 1986; Zarit et al., 1980; Zarit et al., 1986). Also, I have reviewed the literature showing that social support, coping, and personality are important factors that mediate some of the effects of the stress of caregiving. Resources such as social support may be used to mediate the stressors of caregiving; when caregivers perceive of their social support systems as being available, this enhances their perception of having control over their caregiving situation (Rothbaum et al., 1982). Coping mediates the stress response and control is viewed as one of the basic processes which explains how coping influences the stress response (Barusch, 1988; Krause & Stryker, 1984; Miller, 1979, 1980; Thompson, 1981). Personality literature indicates that personality may influence the appraisal of stressors and describes control as a trait of individuals where individuals are described as having either an internal or external locus of control.

The complex relationships between control and social support, coping, and personality have led to confusion about the specific influence that control has within the caregiving experience. These different theoretical perspectives of perceived control do not provide a clear idea of what perceived control is in relation to the caregiving experience. Because of these differences, it seems important not to link the study of perceived control with theoretical perspectives such as social support, coping, or personality in order to avoid continuing the conceptual confusion. In this way, a clearer understanding of how control is perceived in the caregiving situation can emerge.

The extent to which the concept of control was developed in the literature has been included. However, despite the research on caregivers and on perceived control there has been limited research linking the two areas. The concept of control seems to be a significant factor in how caregivers manage their stressful lives, but specific delimitation of its components remains elusive. There has only been a limited amount of research specifically examining control and caregivers. Willoughby and Keating (1991) found control as a process in caregiving; however, the sample consisted only of caregivers of institutionalized dementia persons. Harris' (1993) study hinted at decision-making as a result of caregivers having control; however, this process needs to be clarified further. Jones and Martinson (1992) and Wuest et al. (1994) found that the caregivers' decision to maintain control by 'letting go' of the dementia person was evident in the latter stages of the caregiving experience. Caregivers' decisions associated with the perception of control need to be explored in all stages of the caregiving experience. Miller (1987) provided a preliminary foundation for the study of control but the sample consisted solely of spouses. Wallhagen and Kagan (1993) provided information about control and caregivers but maintained that there was a need to expand on the research done in this area. The sample from this study was also almost exclusively (94%) spouses.

The ideas that need to be explored are the significance and meaning of control within caregiving; that is, what constitutes the experience of control for family caregivers, what is the specific influence that control has within the caregiving experience, and the way in which the perception of control changes throughout the caregiving experience. In addition, it has not been acknowledged that cognitions such as perceived control are fluid and their meaning can vary according to the individual s situation (Taylor, 1983). Therefore, perceived control in the context of individual caregiving situations needs to be explored in greater detail. This problem needs to be studied using qualitative methods to develop a clearer understanding of how this cognitive activity may have an impact on the experience of caregiving.

In this study, the question investigated is: What is the experience of control as perceived by caregivers of relatives with dementia? The intent of this question is to *explore*, that is, to remain conceptually open, as well as to *describe* and *explain* what control is for family caregivers of relatives with dementia. Others ideas which are related to the main research question will also be examined. These ideas include questions about the nature of the experience of control. These questions include: 1) Is control a process experienced over time with particular stages in caregiving? and 2) If control is a dynamic entity, is there evidence of movement within the experience of control? With a clearer understanding of control in caregiving, nurses will be able to be in a position to work more effectively with family caregivers.

Chapter III

METHOD

The purpose of this study was to explore how caregivers perceive control within their experience of caring for dementia persons. It is evident from the literature review that the perception of control in the caregiving experience needs to be studied using qualitative methods. A clearer understanding of how control influences caregiving needs to be gained if we are to be more sensitive in working with caregivers. In this chapter, the methodological approach utilized for this study will be discussed. The elements of the research design, including sample description, data management, data analysis, rigor, and ethical considerations will be presented.

Methodological Approach

Grounded Theory

Grounded theory is useful when the construct being studied is a dynamic process for which little is known (Sandelowski, Davis, & Harris, 1989). In addition, Kuhlman et al. (1991) maintained that grounded theory approaches are appropriate for future research on Alzheimer disease and family caregiving in order to capture the experiences of caregiving in context. Grounded theory is used to discover the informant's point of view and their way of processing the situation under study (Glaser & Strauss, 1967). The purpose of grounded theory is to provide explanatory models of human behaviour which are grounded in the data collected during the study.

Grounded theory has its roots in interpretivism which in turn, has its philosophical roots within symbolic interactionism. Symbolic interactionism is a theoretical orientation which contends that it is possible to study group behaviour in context because there is shared meaning in group actions and language is the expression of the symbols of this interaction (Baker, Wuest, & Stern, 1992). Study is undertaken at the symbolic level of language and at the interactional or behavioural level. Interpretivism stems from symbolic interactionism, where "interpretation comes via the understanding of group actions and interactions" (Miles & Huberman, 1994, p. 8). Within interpretivism, the researcher and informant enter into the study together and the interview is a collaboration between them, with the researcher gathering data and a deep understanding of the experiences of the informant (Miles & Huberman, 1994). The experiences of the informants are context-bound; that is, the researcher tries to "explicate the ways people in particular settings come to understand, account for, take action, and otherwise manage their day-to-day situations" (Miles & Huberman, 1994, p. 7).

Grounded theory provides useful 'tools' to study the experiences of informants within an interpretivist orientation. The assumption underlying grounded theory method is that groups share basic social problems that are resolved with basic social processes (Glaser, 1992). Grounded theory results in models of behaviour grounded in data (Morse & Field, 1995). Traditional grounded theory employs theoretical sampling; this type of sampling is ongoing and based on leads derived from coding of the data. Data collection, coding and analysis occur together in traditional grounded theory in a manner that is flexible and non-linear, allowing the focus to shift if needed and ending when there is theoretical saturation (Glaser & Strauss, 1967).

Therefore, an interpretivist orientation using grounded theory as a methodological approach to the data was selected to identify, describe, and propose a beginning theory of the experience of perceived control within family caregiving. In addition, using an interpretivist orientation and the tools of grounded theory allowed me to begin to develop an understanding of the experience of control as described by family caregivers of relatives with dementia. This approach enabled me to begin to address the lack of clarity concerning control within the context of family caregiving in the literature. Further, this approach suited the nature of my research question which is to explain the experience of control from the viewpoint of family caregivers of persons with dementia.

Secondary Analysis

Secondary analysis involves the analysis of data which was gathered for a previous research study (Herron, 1989; Jacobson, Hamilton, & Galloway, 1993; Lobo, 1986; McArt & McDougal, 1985; Miller, 1982). The analysis is done either by the original researcher or another researcher and either addresses new questions or looks at the same questions with different analysis methods (Glass, 1976; McArt & McDougal, 1985).

There is a scarcity of literature about secondary analysis (Abel & Sherman, 1991, Estabrooks & Romyn, 1995; McArt & McDougal, 1985). This may be due to the emphasis on research as being 'real' only if it involves original data collection (Herron, 1989). In nursing, secondary analysis "as an alternative mode of research in nursing has not yet received equal status with primary analysis" (McArt & McDougal, 1985, p. 55). However, secondary analysis is a valid mode of inquiry which needs to be utilized in nursing research (Estabrooks & Romyn, 1995; Gleit & Graham, 1989; McArt & McDougal, 1985).

The advantages most commonly associated with secondary analysis are the cost-effectiveness and convenience it provides to the secondary analyst (Glaser, 1963; Gleit & Graham, 1989; Herron, 1989; Miller, 1982; Reed, 1992). This advantage may contribute to more secondary analysis in the future due to decreases in research funding (Estabrooks & Romyn, 1995; McArt & McDougal, 1985). Secondary analysis is an important source of research education for students (Abel & Sherman, 1991; Estabrooks & Romyn, 1995; Glaser, 1963; Lobo, 1986; McArt & McDougal, 1985). Although it removes the research steps of sample selection and data collection, these skills can be obtained in seminars or research courses (Abel & Sherman, 1991). More effort is then placed on the other elements of the research process such as analysis and interpretation of findings.

There are several other advantages associated with the use of secondary analysis. Firstly, secondary analysis is a method of generating knowledge that will contribute to nursing (Herron, 1989; Estabrooks & Romyn, 1995; Jacobson et al., 1993; Lobo, 1986). Secondly, it provides for the maximum use of data (Glaser & Strauss, 1967). Thirdly, secondary analysts may not suffer from the closeness to the data which may affect the findings. Finally, sensitivity is needed regarding respondent burden (Estabrooks, Field, & Morse 1994; Estabrooks & Romyn, 1995); secondary analysis allows research to continue on topics such as informal caregivers without adding to the respondent burden of caregivers.

Secondary data analysis has a number of limitations. The "major limitation of secondary data analysis is lack of control over how a data set was conceived, generated, or recorded" (Jacobson et al., 1993, p. 484). There may have been problems or biases in the original research. It was advantageous for me in this study to have access to the original researcher to clarify questions about the contexts of the interviews and to provide addition background information as needed.

Another limitation of secondary analysis is the deviation necessary from grounded theory guidelines. A grounded theory study would employ theoretical sampling to determine the appropriate source for data on emerging aspects of control. Sampling would continue until all categories were saturated. With secondary analysis, theoretical sampling is possible only within the confines of the primary data set and this may impede the saturation of the categories and limit the emerging theory. I found that the sample size was large and broad enough to provide a rich source of information from a variety of caregivers. I was able to use theoretical sampling within the sample to saturate the categories without difficulty. A final limitation of secondary analysis is that it precludes the combined collection and analysis of data associated with grounded theory. In this study, the guidelines for use of grounded theory within the limitations of the secondary data set were followed.

In this study, I used secondary analysis for three reasons. Firstly, the primary study provided me with a rich data set which fit with my question. Secondly, I felt that it was important to be sensitive to the respondent burden of caregivers who are being asked to participate in a variety of studies. Thirdly, secondary analysis provided a convenient and efficient vehicle for obtaining useful research skills. In summary, in using secondary analysis I learned more about not only my own research process but I was also able to reflect and dialogue with my supervisor about the research process used in the primary study.

<u>Primary Data</u>

The data used in this study was from Phase 2 of a study on caregivers and their experiences and understanding of respite. Phase 1 of the study is reported in "The Experiential Understanding of Respite Care for Caregivers of Persons with Dementia" (Strang, 1995). The study used an interpretivist research orientation with grounded theory and narrative study employed as the methodological approaches. Both approaches are based in symbolic interactionism (Baker et al., 1992). As indicated earlier, grounded theory provides an understanding of the collective meaning of the informants' experiences. Narrative study provides the particular understanding of the individual caregiver's story of their unique experience.

The informants for Phase 2 were recruited through the Edmonton Home Care Program, the St. Albert Home Care Program, the Sherwood Park Home Care Program, the local Alzheimer Society, the senior administrator of Capital Health Care, the Mount Pleasant Care Centre, and the Stroke Club. Theoretical sampling was used in the primary study, with the final sample for Phase 2 including 21 caregivers of relatives with dementia. Inclusion criteria 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" (Strang, 1995, p. 39).

Informed consent was obtained from all informants and provision was made for the possibility of secondary analysis in the consent form (Appendix A). Data were collected from in-depth interviews which were semistructured and exploratory. The interview included questions about the caregivers' demographic profile, their experience of caregiving, and their experience of getting relief from the caregiving situation (Appendix B). The study received ethical approval from the Faculty of Nursing, University of Alberta, and the Edmonton Board of Health Ethical Review Committees (Appendix C).

Fit With New Question

As the secondary analyst, I had access to 26 interview audio tapes and transcripts (21 initial interviews and 5 repeat interviews), demographic data, and fieldnotes from Phase 2 of the original study. In any secondary analysis, "the fit between available data and the new research question is clearly the most important issue to resolve" (McArt & McDougal, 1985, p. 55-56). Both the primary and secondary studies were concerned with the experience of caregiving from the viewpoint of the caregiver, including what it involved, how they coped, what did and did not help in their situation, and why they continued to give care to their relative. The primary study also examined the meaning, value, and achievement of respite or relief for the caregivers. In the secondary study I looked at how factors such as perceived control within the caregiver enable them to manage their caregiving experience; the data obtained from the primary study on how caregivers move out of their caregiving world and experience relief provided a rich source of information suitable for secondary analysis.

The interviewing style used in the primary study enhanced the richness of the data available for the secondary study. The interviewing was done in a manner that created meaning and aided in the construction of the individual's story of his or her experience; in other words, the interviews were "active" (Holstein & Gubrium, 1995). The informants were not constrained by answering a rigid set of questions, instead, they were allowed to be storytellers with an avid and sensitive listener present to loosely guide the topic of discussion. This process is described by Holstein & Gubrium (1995) as activating narrative production. Qualitative research interviews of this type allow the caregivers to emphasize what is important to them in their experience (Kvale, 1984). Thus, the caregivers were able to give rich descriptions of their experiences of being a caregiver and explain how they manage the care of their family member with dementia in their unique, individual situation.

The primary researcher anticipated the possibility of secondary analysis and included this provision in the consent form. In addition, the "current status and feasibility of the data for secondary analysis must be determined through a discussion with the first researcher" (McArt & McDougal, 1985, p. 56). This discussion was ongoing throughout the research process with the primary researcher acting as the supervisor of the secondary researcher.

Sample Characteristics

The sample of caregiver informants revealed a range of characteristics that provided information on many types of caregivers and caregiving situations. The wide variation within the sample created a rich source of data for this study.

Age: The caregivers ranged in age from 45 to 85, with a mean age of approximately 67. Two of the caregivers' ages had to be estimated from the context of the interview. One caregiver also had her 18-year-old son present to help facilitate the exchange of information in the interview due to a language barrier.

Gender: Four of the informants were males and 17 were female.

Relationship to Person with Dementia: 13 of the informants were spouses, 7 were children, and one was the niece of the person with dementia.

Education of the Caregivers: The education level of the caregivers ranged from those who had not completed Junior High to those who had received University degrees and one who had pursued postgraduate education.

Length of Time as a Caregiver: This was not specifically asked in the original study because of the respite focus. Also, family members only gradually realize their expanding role as a caregiver and many have trouble identifying exactly when they become 'the caregiver'.

Living Arrangements: All except four of the informants cared for their family member with dementia in their own homes. One informant was not the usual caregiver but was caring for the family member during the vacation of the primary caregiver. Two of the informants had recently admitted their spouses to a long-term care facility. They were included in the study because of their recent experience as caregivers.

Health Problems of Persons with Dementia: The health problems of the persons with dementia are described by the caregivers as including the following: Alzheimer disease, multiple infarct dementia, diabetes, hypertension, spinal stenosis, seizure disorders, hypothyroid conditions, prostate problems, bowel cancer, diminished hearing, gout, peripheral vascular disease, and arthritis.

Health Problems of Caregivers: The caregivers described their own health problems as including: emphysema, bowel problems, depression, osteoarthritis, asthma, rheumatoid arthritis, hypertension, sciatica, gout, bronchitis, and congestive heart failure.

The characteristics of the caregivers who were informants in this study reflected the characteristics of the population of caregivers in Alberta (Warren, Keating, Janzen, & Wertenberger, 1996) and caregivers in general (Kuhlman et al., 1991). The majority of informants in this study were female, and were either wives or daughters. This reflects the population of caregivers in Alberta where wives and daughters are the primary caregivers for relatives with dementia (Warren et al., 1996). The characteristics of the informants varied in several areas. Length of time as a caregiver, family structure, and occupation differed greatly among the informants. These differences contributed to the richness of data available for analysis.

Even though the informants differed in these characteristics, they were homogeneous because they all spoke English and were willing and capable of expressing their experiences as caregivers. The results from the obtained sample may represent the experience of control for other caregivers of relatives with dementia or caregivers in general. The results are not generalizable to other samples but highlight areas which are worthy of further study with other samples.

Data Management

Data management included the types of data I obtained and the techniques I used to handle this data. Although the audiotapes and interviews analyzed in a secondary analysis were collected by a research assistant working with the primary researcher, data were also collected and analyzed as part of the secondary study. The data I managed in this study included interview audiotapes, transcripts of the audiotapes, original study fieldnotes, secondary study fieldnotes, methodological and theoretical memos, a personal journal, and diagrams of the emerging theory.

Interviews from the primary data were transcribed verbatim by a typist and checked for accuracy with the tape by the research assistant. It is important for secondary analysts to listen to all of the interview tapes not only to check the transcripts for errors and omissions, but also to add a dimension to the data analysis that is not possible to obtain from reading the transcripts alone. As Weber (1986) so aptly states:

> writing down verbatim someone's oral language transforms that language, robbing it at times of its power, clarity, and depth, even its meaning. Verbatim transcription makes little accommodation for tone of voice and emphasis, and little

> accommodation for the differences in style, words, and form that exists between oral and written modes of communication. (p. 71)

Following the initial review of each audiotape and transcript, I made a fieldnote of the interview. The fieldnote included a vignette of the individual caregiver's story, information about the context or environment of the interview, changes in emotion and tone of the informant's voice, and any other factors which were relevant for the study from that interview. The fieldnotes from the primary study provided a description of the visual dimension of the interview and served as a source of validation for hunches about the context of the interview. In addition, the research assistant from the original study was contacted for elaboration on the context for the interviews and to comment on the interviews with the informants.

Methodological and theoretical memos were compiled throughout the secondary analysis process. Methodological memos contained information about the research process itself. Theoretical memos captured my thinking process during contact with the data and contained ideas about connections within the data and the emerging theory.

Diagrams of analytical thoughts about relationships and patterns flowed from the memos. These diagrams became a visual depiction of the flow of ideas as they arose from the data. The drawing and redrawing of schematic diagrams was a useful way for me to visualize the developing theory.

I kept a personal journal to document feelings and experiences that occurred throughout the research process. In this way, I became aware of my personal preconceptions, values, and beliefs so that I was able to incorporate them into the analysis more appropriately. The personal journal was also useful for recording ongoing notes related to my role of researcher as a research tool and as a method of identifying theoretical biases. All data were dated and timed at the time of writing.

In secondary analysis, one of the data management questions that must be resolved is the accessibility of data (McArt & McDougal, 1985). Data from the original study was available on computer and was analyzed using QSR NUDIST™ (Non-numerical Unstructured Data Indexing Searching and Theorizing) software. Computers assist in the management of data through document handling systems; software such as NUDIST also allows the user to use an index system to create concepts and explore emerging ideas (Richards & Richards, 1994). After coding by hand on a hard copy, indexing or coding was done in NUDIST, creating a tree of hierarchically related concepts (conceptual framework). The coding and tree design are easily changed within the program as the understanding of the concepts evolve. I found it helpful to complete most of the hand coding before coding within NUDIST as it then allowed for consistent coding within the program. This is important because NUDIST allows for elaborate and sophisticated interpretation of the data based on the codes that have been entered. I was able to increase my understanding of how family caregivers perceive that they have control in their caregiving situations by using the advanced search functions within NUDIST.

The advantage of using a computer to aid in the management of qualitative data analysis is that more energy is available for the analytic process and programs such as NUDIST also facilitate conceptual activities (Taft, 1993). I found that NUDIST helped me more than a word processor alone. I was able to divide categories, rename them, put some of the same text in multiple categories, and look at related ideas from many interviews with ease. In summary, I found that using NUDIST to assist in the management of the data in this study facilitated the analysis of data.

Data Analysis

Data analysis tasks, techniques and processes associated with primary research are also applicable to secondary interpretive processes (Thorne, 1994). Some data collection in secondary analysis is already complete; however, coding and analysis still occur together in a manner that is flexible and non-linear, allowing the focus to shift if needed and ending when there is theoretical saturation (Glaser & Strauss, 1967).

Open coding was the initial step in the data analysis. In open coding I moved from the words of the informants; that is, substantive coding of the interview, to the generation of categories (Glaser, 1992; Stern, 1980). Categories and their properties formed from abstraction and comparing across interviews. The constant comparative method was used throughout by comparing incident to incident, incident to concept, all the while looking for patterns in the data (Glaser, 1992). I found at this stage that there were many smaller categories that could be collapsed into larger categories as my understanding of the caregivers' experience grew. For example, the smaller categories of 'identifying the need for help' and 'seeking help' became a part of a larger category which encompassed all of the aspects of 'help'.

The constant comparative method then revealed theoretical codes consistent with Glaser's (1978) dimension coding family; these codes uncovered the categories' relation to one another. The dimension coding family consists of properties which, in turn, define dimensions, and the dimensions are encompassed by an overall core concept or category. Sorting through theoretical memos about the emerging theory and analyzing the theoretical codes led to the core dimensions which were the main concerns that related and tied to all categories (Glaser, 1992; Stern, 1980). The core dimensions of 'maintaining control' and 'lacking control' reflected conditions present from the viewpoint of the caregivers. I found that these core dimensions were clearly evident in the data and that theoretical saturation was easily attained in this study due to the substantial number and quality of interview data available.

Viewed in terms of a core concept, I found that the phrase 'experiencing control in managing caregiving' explained the variation in the data and became the 'umbrella' for the emerging theory. The theory evolved out of the data where the patterns in the coded data defined the properties of the core dimensions and these dimensions led to the discovery of the core concept for the emerging theory. I then compared the emerging theory to existing theories for similarities and differences. The final result is an emerging theory of perceived control in caregiving which works to explain and interpret this experience as it is relevant specifically for informal, family caregivers of relatives with dementia, and may be recontextualized for caregivers in general.

Rigor

Rigor in qualitative studies is related to the trustworthiness of the research (Sandelowski, 1986). There are four issues of rigor: consistency, neutrality, truth value, and applicability (Morse & Field, 1995). Each issue is evaluated using a specific test or criteria because "meeting tests of rigor is a requisite for establishing trust in the outcomes of the inquiry" (Guba & Lincoln, 1981, p. 103). The specific criteria of rigor used to address the four issues are: auditability, which establishes consistency; confirmability, which establishes neutrality; credibility, which establishes truth value; and fittingness, which establishes applicability (Guba & Lincoln, 1981). Each of these criteria will now be discussed and then the particular ways in which they were addressed in this study will be presented.

A study is auditable when the trail that the researcher used to determine the course of the research (decision trail) is easily followed. This trail is also known as the audit trail. Essential elements of an audit trail of researcher generated data include contextual notes (fieldnotes), notes about methodological choices, notes about the procedures of data analysis and notes related to the role of the researcher as a research tool (Rodgers and Cowles, 1993).

Confirmability refers to the findings being able to be confirmed or grounded in the data (Guba & Lincoln, 1981). Findings which are grounded systematically in the data will neither be forced or have concepts which relate to no data (Glaser, 1992).

Credibility is the criterion to evaluate truth value. The question to be asked is 'are these findings true'; that is, will my findings reflect the phenomena as it is experienced by the informants rather than reflecting my previously held conceptions of the phenomena. This also relates to the criterion for evaluating applicability, which is fittingness.

Fittingness refers to the relevance of the findings and "what applies to grounded theory is its generalizability from a substantive theory of limited scope to a process of a larger scope with parsimony, based on its ability to fit, work, and be relevant" (Glaser, 1992, p. 117). If a grounded theory fits the area studied and works to explain major variations, then it will be relevant and may be modified in the future if necessary.

The principles of rigor were addressed in this study in the following ways. The audit trail was maintained through systematic and detailed recording. A personal journal was used to document personal biases, thoughts, and feelings which may influence the study, methodological memos were used to record the use of method throughout the research process, and analytic memos were used to record the development of the theory. Confirmability was enhanced by linking quotes to the explanation of the properties and dimensions found within the data. In this way, the findings were demonstrated as arising from the data itself. Periods of distance from and immersion in the text were also interspersed to maintain a fresh approach to the data (Glaser & Strauss. 1967). Credibility and fittingness were increased by having the findings validated by those persons who were able to determine if the findings 'resonated' or 'rang true' for the subject area. Validation "procedures that typically rely on further interaction with the primary data source can often be modified for those whose contact with the data is secondary" (Thorne, 1994, p. 275). In secondary analysis, it is appropriate to obtain data and interpretation validation by another person such as another student or researcher (P. A. Field, personal communication, March 26, 1996). Validation of findings was ensured by having the original researcher confirm the categories and core themes found in the data and by having a seminar with research colleagues to discuss and validate the emerging theory. In addition, a former caregiver of a family member with dementia served as a source for validation.

Ethical Considerations

The consent form from the primary research study included provision for secondary research. This provision was contingent upon the secondary study receiving approval from an ethics review committee. A letter was submitted to the Research Office in the Faculty of Nursing outlining the proposed secondary analysis study and the source of the original data. After ethical approval was received from the Faculty of Nursing (Appendix D), the study proceeded. In addition, as a secondary analyst, I was "bound by the same confidentiality and privacy restrictions as the primary analysts" (Burstein, 1978, p. 12).

A letter of agreement was also developed by the primary and secondary researchers. This letter outlined the rights, responsibilities, and obligations of the primary and secondary researchers. Included in the letter was a description of the data which was accessed (e.g., interviews, demographic data), method of access (i.e., via computer software), and provisions for reference citations in publications and presentations (Estabrooks & Romyn, 1995).

Chapter IV

FINDINGS

The findings that relate to experiencing control in caring for a relative with dementia are presented in this chapter. After introducing the informants I will provide an overview of the explanatory model of the emerging theory followed by a discussion of the dimensions and properties of the model.

The Caregivers

In this section I will introduce the caregivers who were informants in this study. I will first explain the reasons for developing individual vignettes for each caregivers. Then I will explain the groupings of the caregivers into categories of informants.

The Caregivers as Individuals

In grounded theory, the individual's experience is sacrificed in favour of the composite picture. The narratives of the experiences of the individual caregivers contribute to the emerging model but the model attempts to have relevance for the larger population of caregivers of relatives with dementia, and may even be recontextualized for caregivers in general (Glaser, 1992). The individuals' narratives were a key building block in the formation of the model. I wanted to maintain the identities of their individual narratives and to keep the context from which the data arose. To do this, I have included a summary vignette about each caregiver's narrative, assigning a fictitious name for each individual.

The vignettes introduce the narratives of each caregiver but are not meant to be considered as a thorough narrative study of each caregiver. There are no quotes given in the vignettes as these are included within the text to illustrate properties and dimensions of the model. When the caregivers are quoted within the body of the text, a brief summary of their situation and the context will be given if needed and the vignette for that individual will provide more of the background information necessary to give a complete picture of the context for the quote and individual. The summary vignettes are grouped according to whether the caregiver was a key, secondary, or minor informant (Appendix E, F, and G).

Caregiver Groupings

Although all of the caregivers contributed information about their experiences of caregiving which was useful for this study, there were those who were able to relate their experiences to the interviewer in such a way that I was able to gain a greater understanding about their caregiving situation and how they managed it. These caregivers were the key informants. The key informants were Fran, Gina, Helen, Kelly, Matt, Olivia, Sue, and Ursula. Common characteristics of the key informants were that they were able to articulate not only the facts about their caregiving experiences but they were also able to articulate clearly their feelings and reactions associated with these experiences. They were able to compare their feelings in different situations and could explain connections between past caregiving situations and their present behaviours or attitudes.

Other caregivers became secondary informants. These informants were articulate about certain aspects of their caregiving situations but were unable to express their thoughts and feelings clearly in speaking about caregiving in its entirety. This may have been simply because they did not have the background as caregivers to be able to speak to many aspects of caregiving. They may have been caregivers for only a limited time and therefore had not discussed their role and experiences as caregivers at length with anyone before the interview. The secondary informants were Betty, Carol, Eve, Jane, Patty, Pauline, and Ron.

I also found that some caregivers were minor informants. These caregivers were not able to articulate their feelings and experiences easily or they were not the primary caregiver of the person with dementia. In addition, caregivers who became minor informants may have had a short interview or their first language was not English. These factors limited the richness of the data in the interviews. The minor informants were Anna, David, Iris, Lynn, Nina, and Tom.

I did find that regardless of the type of informant, all caregivers contributed to the findings in some way. Their unique narratives of their experiences helped me understand the variations within the model and how the model fit within their specific caregiving worlds. I will now include a brief summary of the key informants: Fran, Gina, Helen, Kelly, Matt, Olivia, Sue, and Ursula. The quotes from the key informants are used to describe components of the model. The summaries of the key informants are included because a clearer understanding will be obtained about the quotes if some of the context from which they arose is known.

Fran was able to handle the daily problems and to plan to meet future needs within her caregiving situation. She spoke easily about her abilities to manage her caregiving situation and gave insight into her life as a caregiver. This insight furthered my understanding of the difficulties which caregivers face but who still manage a difficult caregiving situation. Fran spent some time in the interview explaining the family dynamics and this was valuable in understanding her experience of being and becoming a caregiver. It was obvious that Fran had thought a lot about her new role as a caregiver and was able to articulate her feelings and experiences effectively throughout the interview.

Gina s interview was unique in that it focussed on the time just prior to the placement of her mother in a long-term care facility. Gina was able to give helpful information about what it was like for her to come to the point of asking for placement and how she felt with placement being imminent.

Helen was an articulate woman who was able to clearly express her thoughts and feelings related to managing her mother s care. Helen was able to describe in detail how she felt during the time preceding her first break away from caring for her mother as well as how the break away felt and the changes that occurred upon her returning. Her description of slowly losing control followed by the suggestion from a service agency to have a break away was useful in understanding how she later learned to recognize when she was coming to a point of needing a break away from caregiving.

Kelly's narrative furthered my understanding of caregivers who are able to manage their caregiving situations. Kelly described herself as someone who was always in control but recognized the impact of caregiving on her ability to continue giving full-time care and she believed that she would not be able to care for her husband at home forever.

Matt s interviews were unique in that they captured movement from being able to manage to having difficulty managing caregiving. He was torn by his love and commitment for his wife and his increasing difficulty in caring for her.

Olivia was an articulate, informative caregiver whose description of the difficulty that new caregivers have in asking for help and not knowing how to care for their loved one was particularly moving. She illustrated what it was like for a caregiver to have difficulty managing the caregiving situation but still continue on as a caregiver.

Sue was able to give a perspective that was unique among this group of caregivers because she demonstrated the positive changes that interventions may have on managing the caregiving situation. At the time of the first interview Sue was starting counselling and then the second interview provided a look at how the counselling was progressing and its impact on her caregiving management. Listening to Sue articulate how the management of her caregiving changed with counselling was important in understanding the effect of intervention on her ability to regain control of her caregiving situation

Ursula provided a unique perspective of a caregiver who was managing her husband s care in spite of her own serious health problems. Ursula was able to articulate specific detail about her caregiving experience and how she managed it so that a rich picture was given of how she not only managed on a day to day basis but how she was also prepared for changes in the future.

The Experience of Control in Managing Caregiving

Having introduced the individuals and the context from which the model arose, I will now explain the model of experiencing control in managing caregiving. A summary of the experience of control in managing caregiving will be presented; this is the model in its entirety. This will be followed by a discussion of the specific components of the model; that is, the dimensions and their properties.

Summary of the Model

Caring for a relative with dementia is often difficult, demanding and stressful. Caregivers are usually not aware of becoming 'caregivers' and it is only in retrospect they realize that they have been a caregiver for a long period of time. The onset is insidious because of the gradual increase in the amount of care required by the person with dementia. The person who has become the caregiver seldom has had any experience in being a caregiver to an adult with a chronic, deteriorating condition. They may have cared for children or pets, but usually family caregivers have no background for their new role as caregivers of a relative with dementia. It is assumed that they will not only care for their relative and that they will be <u>able</u> to do so, but that they will also know enough to call for help when it is needed.

The reality of caregiving is that some individuals <u>are</u> able to take on the role of caregivers and to manage well. For others, it is more difficult. For all caregivers there are times when their caregiving situations are more demanding and it is at these times that caregivers are vulnerable. They may be able to weather the difficult times and return to a level of satisfactory functioning or they may need help to regain their perspective. For some, the trying aspects may accumulate and lead them to a point where they have even more difficulty managing as caregivers.

All caregivers must manage their caregiving situations; they assess their situation and evaluate their resources and from this they cope with their caregiving situation in their own unique way. As the caregiver narratives unfolded, it seemed the way the caregivers managed their caregiving situations depended on the way they experienced control in that situation. I found that all caregivers experienced control in some manner within caregiving.

The caregivers experienced control within two distinct dimensions. The dimensions became apparent when the properties were sorted and grouped and were found to define either one or the other dimension. The specific properties of each dimension will be developed later in this chapter.

The two dimensions of control identified in this study were 'maintaining control' and 'lacking control'. 'Maintaining control' is different from 'having control' or simply 'control'. If a caregiver maintained control, they had an active role in this process. It was not only that they had control but that they also worked to continue or maintain it. They preserved control by applying the information explained in the five properties within their caregiving situations. For caregivers within the dimension 'lacking control', their lack of control' was not something that they were trying actively to do; rather, it was something that they had, that was there. They thought that they had control within their caregiving, but when you listed to their language the control was lacking.

The experience of control was based on the caregivers' perception of their caregiving experience. Even if caregivers were caring for relatives with similar illnesses or had been caregivers for the same length of time they did not seem to experience control in the same way. It was the caregiver's perception of themselves as caregivers and their caregiving situation which influenced the way in which they experienced control in caregiving.

It seemed that caregivers 'declared' themselves according to either dimension; that is, it was through their speech that it became clear whether they were 'maintaining control' or 'lacking control'. There was also evidence of caregivers moving from one dimension to another.

Each dimension of control appeared to have specific properties which defined the boundaries of the dimension. Some of the caregivers were identified as being within a particular dimension because they clearly demonstrated the properties associated with that dimension. For some of the caregivers, however, it was not possible to know which dimension they were in because of a lack of data. More information was needed from these caregivers in order to clarify and fully understand their caregiving experiences. It was also possible to identify some caregivers who were in the process of moving between and within the dimensions. It is not the intent of this analysis to determine which caregivers were in each dimension or which caregivers were moving in the study. The purpose of this analysis was to determine a sense of the entire model.

The analysis of the caregivers' interviews revealed that the dimension 'maintaining control' had five properties. Briefly, the properties were: *(1) Confident language*, *(2) Positive internal resources*, *(3) Ability to recognize the need for and to ask for help*, *(4) Anticipating the future*, and *(5) Seeing impending loss of control and acting on it* Although the properties as presented here seem discrete, in reality they overlap and the information discussed under one property may also be closely related to another property.

Caregivers who maintained control had an active role in the process of sustaining the management of their situations. They used language that demonstrated their confidence in their management abilities. They were able to give examples of how they had solved problems and used language that was associated with the word 'control'. They spoke positively about themselves as caregivers and their internal resources. They had a determined, decisive outlook. Even if there were times when they did not feel positively about themselves as caregivers, they recognized that it was the circumstances which were influencing their perceptions, it was not due to something within themselves. They were not only able to assess their present situation but they were also able to anticipate the needs and changes that may occur in the future. They identified specific needs that they had and how they could change as well as the resources that would satisfy those needs. They were able to call for help when they required it.

In addition to the above properties which were evident in caregivers who maintained control, there was a final property which was crucial to these caregivers continuing on successfully with their role. These caregivers were able to recognize when they were moving toward losing control within their caregiving situations and were able to act to regain control. They recognized signals that indicated when they needed a break from caregiving and then arranged to have some time away. They may not have been able to recognize that they needed a break during their initial time of being a caregiver, but once they had been shown that these signs meant that they needed some space away from caregiving, they were then able to recognize those signs and could plan for time away.

Caregivers who demonstrated 'lacking control' seemed to just not be able to manage their caregiving situations. Briefly, the properties of the dimension 'lacking control' were: *(1) Negative internal resources*, (2) *Inability to recognize the need for or ask for help.* and *(3) No future anticipation.*

When caregivers who lacked control spoke of themselves as caregivers or their internal resources for caregiving it was with negativity. They seemed to not believe that they were able to manage as caregivers. They sometimes did recognize that they had needs which someone could help them to meet, but when they were asked directly about what help could be offered to them, they could not say what or how others may have helped them. They could not anticipate the future and seemed unwilling or unable to comprehend that the future would mean a change in their caregiving. Although they had difficulty managing their caregiving situations, it was possible to intervene with caregivers so that they could move to regain and maintain control.

It seemed that a number of factors were able to assist caregivers to be able to handle their difficult situations. For example, health care professionals were one of the factors which changed movement from 'lacking control' to 'maintaining control' within the experience of control. Health care professionals may be able to recognize when a caregiver is moving to or within the dimension 'lacking control' and to assist the caregiver to access the necessary resources to either continue on with caregiving or to seek placement for the relative with dementia in a long-term care facility. The explanatory model of experiencing control in managing caregiving will now be presented and details of the model explained further.

Model of Experiencing Control in Managing Caregiving

The findings of this study are presented as an explanatory model of the emerging theory of experiencing control in managing caregiving. I found that this model unfolded out of the data. The model first arose from the identification of patterns in the coded data, which, in turn, defined the properties of the core dimensions of the model, and these dimensions then led to the discovery of the core concept of experiencing control in managing caregiving (see Figure 1).

The dimensions represent the type of control that caregivers experienced and include: 'maintaining control' and 'lacking control'. The experience of control is based on the caregivers' perception of their caregiving experience. This is depicted within the model as circles. I found that caregivers in each dimension had particular characteristics or properties which may have influenced their inclusion into the dimension of either 'maintaining control' or 'lacking control'.

Each dimension is defined by these specific properties which provide the boundaries for that dimension. The properties of the dimensions are depicted within the model as triangles. These dimensions and their properties are discussed in detail below.

There was also evidence of movement within and between the dimensions. These movements are depicted within the model as arrows. This movement may have occurred at any time during the caregiving experience. The movement between the dimensions will also be discussed in detail below. I will expand on each of the components within the model using quotations from the caregivers to substantiate the findings.

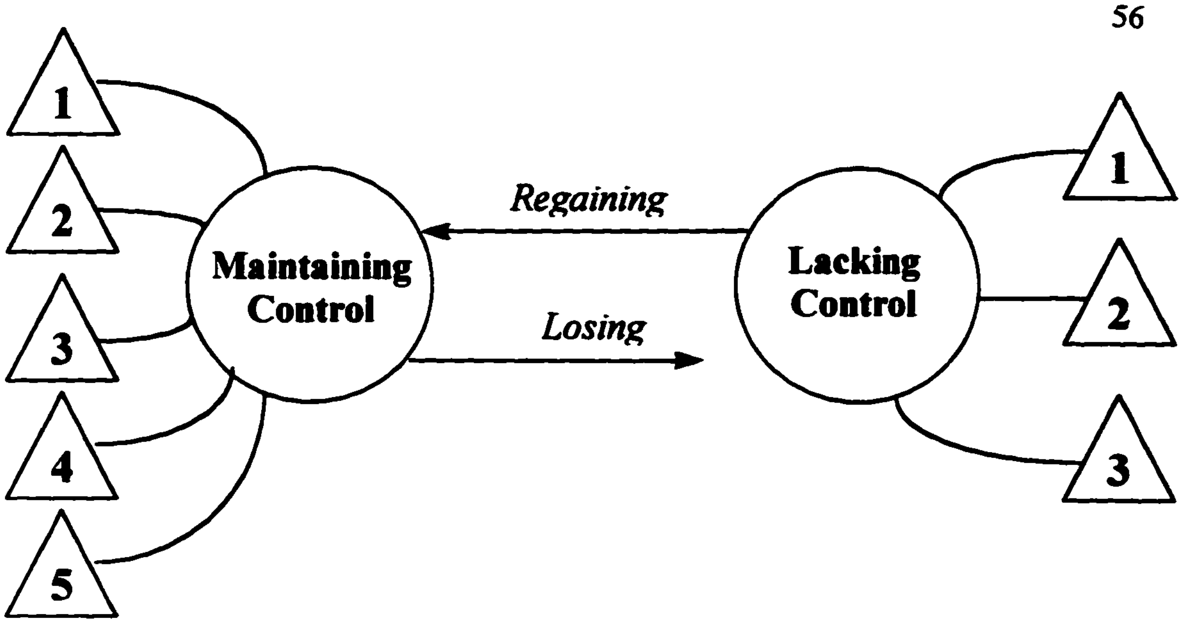

Figure Legend

Dimensions: Circles

Properties: Triangles

Maintaining Control Properties:

1. Confident language
2. Positive internal resources
3. Ability to see the need for help and to ask for it
4. Anticipating the future
5. Seeing the need for a break and acting on it

Lacking Control Properties:

1. Negative internal resources
2. Inability to see the need for help and ask for it
3. No future anticipation

Figure 1. Explanatory Model of Experiencing Control in Managing Caregiving

Explanation of the Dimensions and Properties of the Model

Dimension: Maintaining Control

The dimension 'maintaining control' was developed from sorting the properties into a larger category or dimension. There are five properties of the dimension 'maintaining control'. These properties clearly mark the boundaries of the dimension and there are numerous examples of these properties in the data. Ursula was a caregiver who typified those who maintained control. In the following quote, Ursula exemplified caregivers who maintained control:

> Ursula: So I got home care and they do the laundry for me. They're very good. That's all we've needed so far. I might need more later on, but so far we're managing. I don't think I'll be able to handle his bath, you know, if it gets too difficult.... We did sign up for a nursing home, you know, for when we needed it...you just sort of have to play it by ear.

This quote demonstrates that Ursula was able to articulate confidently her ability to solve problems and to anticipate her needs for the future. She managed the care of her husband in spite of her own very serious health problems. She showed clearly that she maintained control throughout her interview. Each of the specific properties of caregivers who maintained control will now be explained including quotes from the caregivers to demonstrate each property.

Properties of maintaining control.

Confident language

The first property of caregivers who maintained control in their caregiving situations was that they frequently used language which demonstrated their confidence in their ability to maintain control. Examples of this confident language included the following phrases and statements: "we'll make it be OK", "I can handle it", "I got it solved", "so far we're managing", "dealing with things", "I had to control it", "I'm quite capable of handling the situation right now", "it's working so far", "I did control it", "I can manage", "I could put up with it", "nothing we can't handle", "we manage somehow", "so far we're handling as best we can", and "having to deal with things". Although the language was related to control, it indicated that these caregivers had more than the ability to use 'control language'. These caregivers exuded confidence, and this confidence was evident in their language.

A key reference which reflected this ability was from Fran, a caregiver who looked after her mother at home and described her caregiving as follows:

> Fran: I did control it [her mother's care] but I had no choice. I had to look after Mom...[if my sister wants to know what I am doing]...she could talk to me more, [and] she'd find out how I manage.

Kelly also maintained control over providing care for her husband and gave examples in the following quote of her ability to problem-solve and also demonstrated language that illustrated her confidence in her ability to manage as a caregiver:

> Kelly: I have those locks done now and I feel a lot better. I know he can't get out. And he has never questioned why he can't unlock the doors and go out. He's never said anything. And I, of course, unlock them as soon as I come down and these little things are things you learn the hard way I think. I've been lucky that that's as far as it went and I got it solved. Another one was the kitchen stove...because he likes to make tea in the morning. He's always done that. And he was plugging in the kettle on the stove and then turning on burners and the wire cord from the kettle was across the burners. And it was a fire hazard. I smelled it one morning, came down and here was this cord, I grabbed it and took the kettle off and said you should only use the kettle across on the kitchen counter. Don't put it on the stove. But he puts it in on the stove and then turns on all the burners. So I had to do something about that and so the last thing at night

> I go downstairs and disconnect the stove.... So that was a worry to me and I think that's one of the things you have to do is to solve those kinds of problems so that you're not on pins and needles all the time.

The property of using confident language which caregivers who maintained control demonstrated so clearly included the ability to explain how they had solved problems. This language used by the caregivers refers to their ability to control and thus manage their caregiving situations with confidence.

Positive internal resources

The second property that caregivers who maintained control seemed to have was that their dialogue related to their internal resources was positive. A caregiver's internal resources refers to how they view themselves within the caregiving role and how they view their actions related to caregiving as contributing to this image of their caregiving role. Whenever they spoke of who they were as caregivers or what they had done as caregivers it was always with constructive language. They used phrases such as "I did it", "I decided", and "I can manage" to show that they not only had a determined outlook, but that their outlook was positive and decisive. They also characterized their specific internal resources using affirmative adjectives such as "being patient" and "understanding". They had a determined optimism, reflected in statements such as "it's gonna work" and other references to having a routine which flowed smoothly.

A key reference was from Eve, a caregiver who managed the care of her husband and very clearly demonstrated her determined, optimistic attitude. Eve believed that she would be able to manage further changes that occurred due to her husband's deteriorating dementia and said:

> Eve: It's gonna work. It's gonna work. And if it doesn't work, well then we'll have to find another way.

Eve allowed herself to make mistakes and also spoke positively when referring to herself:

> Eve: I do have a lot of patience, that's one thing to say. I sometimes lose my temper but I guess that is very natural...and it [caregiving] sometimes gets you a little bit down, you know. But then, as I said, I'm a person with a lot of patience.

Another reference was from Ursula, a caregiver who provided care for her husband in their own home. Ursula was a retired nurse who had severe emphysema, bronchitis, and congestive heart failure and was often audibly short of breath during the interview, yet reflected her ability to maintain control over her caregiving situation frequently throughout the interview. She demonstrated her positive approach in terms of having a routine in the following statement:

> Ursula: But if you can keep things cool and not too much outside interruption or too many decisions to make you can sort of sail along on a fairly even keel for awhile anyway.

It is unrealistic to expect that caregivers who maintain control will always use positive language when referring to themselves, but the majority of their speech related to themselves as caregivers was positive. When they referred to themselves negatively, they were able to indicate that it was not because of who they were or their abilities as caregivers that produced the negativity, but it was something outside of themselves which was influencing them. Helen provided an example which will clarify this aspect of caregivers who maintained control:

> Helen: I have this guilt load about how little housework I seem to accomplish. Like everywhere you look, there's a mess. And it's not because I don't try, but...you simply cannot handle everything. And I

> notice when I had her in, that I was able to accomplish a task. I got several things done from beginning to end. And I realized that it wasn't me and my lack of ability, it was the circumstances that were causing this.

Thus, this property reflects the ability of those caregivers within the dimension 'maintaining control' who referred to themselves and their abilities as caregivers with positive statements. They were optimistic and clear in their constructive statements about their ability to manage as caregivers.

Ability to recognize the need for help and to ask for help

The next property of those caregivers who were able to maintain control is that they had the ability to recognize the need for help and they were able to ask for help when the need arose. They may not have always asked immediately for help but they had the ability to ask for help when the appropriate time came for that need to be met. They made statements such as "I'll have to arrange for some help", "if this doesn't work, we'll get more help", and "so I got somebody" to demonstrate that they were able to assess the present situation and to see that more help was necessary in order for them to continue to manage the caregiving and then they could act on that assessment. Their ability to assess the present situation was evident in phrases like "so far I can handle it" and "they said if I have a problem, they will come, but for now I can manage".

They were also able to recognize where they would tap into resources for help. Examples of these resources included home care, family doctor, family, and respite services. Fran identified a doctor that she knows and demonstrated her ability to access him if needed and said "and I can phone him if I have to, at home". Ursula first recognized the resources in her seniors' building:

> Ursula: Well, we're lucky here because I don't have to worry about, if something goes wrong I know I can call for help immediately.

Then later Ursula identified the resources available to her within her family:

> Ursula: If my daughter's home there's no worry...she'd come if I needed her right off the bat.

A key reference was from Fran, a caregiver who looked after her mom at home and showed not only the ability to recognize the need for help but was also able to find the necessary resource and freely ask for help:

> Fran: If there's a problem or I don't understand, I go to my sounding board. That's F--- or J--- or someone like that. When Mom did something really erratic, I forgot what it was here last fall, I went right to Dr. R---, a psychologist, and asked him about it.
> Interviewer: That's great you have that resource there.
> Fran: Well, if I don't have it, I'll find it. Because I feel we have enough to handle, we should make use of what's there.

Fran also provided valuable insight into her thought process leading up to the first time she asked for more help:

> Fran: I was sort of trying to sort out how to figure out how to deal with all this, all these feelings I had. Like with this duty of looking after my Mom. Well someone's got to do it! And I can do it! So I will do it! Not because I just wanted to, but I knew someone had to. And I felt that I was the best person for the job. Then the feelings came to a head. And I had to sort of plan how I was going to handle them...and I was just sort of initially thinking I could just put my life on hold. But then I started seeing that well, gee, my husband felt kind of neglected, we liked to go places and we can't go.... And I just finally came to the point well, I have to have help here. I have to have a plan or she's going to make me sick! I won't be able to do my job at work, I won't be able to look after myself. What good am I going to be to anyone. I was feeling stressed out more all the time and tired. Just fatigued! And so in desperation I phoned N--- and said "how are we going to handle this". And N--- could see that I was stretched to the limit.... So N--- asked how I would feel if home care gave me four hours every Saturday...and now that I have it, if I didn't have that, it would be much more difficult for me to manage.

Kelly was not only able to know that she would need to ask for help but had also determined the type of help that would meet her need to manage her husband's bathing, based on her experiences of caring for him:

> Kelly: But that will come, that will be something that I'll have to arrange for some help...and it would have to be a man.

Thus, this property reflects the ability of caregivers who maintained control to be able to ask for help. Not only were they able to ask for help but they were also able to identify the specific needs that they had as well as the resources that they may have needed to access to meet their needs.

Anticipating the future

The fourth property of caregivers who maintained control in their caregiving situations encompasses the caregivers' ability to anticipate and plan for the future. The caregivers had realistic expectations not only of the declining course of the dementia but they were also able to anticipate their future ability to manage their situation. Phrases which illustrated this include "I know the point will come when I won't be able to" and "I think I'll have to prepare myself for something down the line".

A key reference was from Ursula, who knew her own limitations and demonstrated her ability to assess the present and reflect on the future in the following statement:

> Ursula: So I got home care and they do the laundry for me. They're very good. That's all we've needed so far. I might need more later on, but so far we're managing. I don't think I'll be able to handle his bath, you know, if it gets too difficult.... We did sign up for a nursing home, you know, for when we needed it...you just sort of have to play it by ear.

This statement also reflects the previous property of having the ability to recognize the need for and to ask for help. The combination of these two properties is important because the nature of caring for someone with dementia is that more help will be required as the disease progresses and these needs can be anticipated to some degree.

Fran cared for her mother at home and was able to recognize where she was at with her present level of help and to reflect on the future:

> Fran: The amount of care that home care is giving us now, it's fine for now, but it depends on how she deteriorates. At the day care program they have even noticed what I have noticed, that over the past month, month and a half, there's been a rapid decline.

Fran was also able to put limits to her tolerance for caregiving:

> Fran: And I would never quit my job to stay home and look after my Mom. I would put her in a facility first because without that outside interest you could crumble. Or I would crumble...well, I don't know if I would crumble but it would be easier to crumble, let me put it that way.

Eve was aware that there would come a day when she would need more help. She spoke about preparing herself for the future and the possibility that she would need more help:

> Eve: So I don't know how long I can be able to look after him...so I think I'll have to prepare myself for something maybe down the line.

It is interesting to note that caregivers who were able to anticipate what was in the future were also able to depict specific conditions that would precipitate a change in care. For example, in the quote from Ursula above, she was able to identify that when her husband was unable to bathe himself, she would then need help with this aspect of care. She also stated later, when referring to when placement may be needed, that this would occur:

> Ursula: When it gets to the stage he doesn't know me or you know gets too difficult.

Thus, this property reflects the ability of caregivers to anticipate what the future may hold for them in caring for their relative with dementia. Caregivers who maintained control were not only able to know that the future would mean a change in the type of care required but they were also able to articulate at what point that change would occur.

Seeing impending loss of control and acting on it

The final property of caregivers who maintained control is the most subtle but nevertheless was clearly evident in the interviews. These caregivers had the ability to know what 'set them off' and moved them toward the point where they would lose control. The specific phrases they used when referring to losing control include: "at my wit's end", "if I'm tired", "absolutely no energy", "getting a bit unravelled at the edges", "if I am short of breath", "when I am on the edge", "shouting", and "carrying granite".

Coupled with their ability to recognize that they were becoming out of control was their ability to use that information to avoid it or to do something about it such as planning for a break away from caregiving. One caregiver described this characteristic saying that she "has to do it" (have a break away) and then she said "and I feel better when I get back". Another caregiver even referred to this ability as "going away and regaining control".

When the caregivers did something about this impending loss of control, they then described themselves as having a "restored battery", having had "sanity time", feeling “liberated”, being able to “handle things”, and being able to maintain their own lives.

Helen described this ability to recognize the impending loss of control:

> Helen: Just before she went in for her first respite care, I was shouting and I thought, this is not good. This is not good for anybody, me, her, anybody. And then you feel like such a rotter afterwards. Imagine shouting at a poor old lady who you don’t know whether she understands or not.... But I found that my temper was getting very frayed. And the other thing was yeah...everything annoyed me. It didn’t matter what I had to do. I got to the point about the week before I went that I thought, if I get up I’ll have to put my socks on. If I put them on, I have to take them off again. I mean that’s how bad it was...and absolutely no energy. Yeah. Just couldn’t hack it.

The first time that Helen felt like this, a home care coordinator recognized that she needed a break away. Then, once Helen knew the signs which, for her, indicated impending loss of control, she was then able to recognize it sooner and plan for a break away. The interviewer later asked how one of her times away from caregiving was for Helen and how she felt when she came back:

> Helen: Oh yes, I should mention that. It was great! The first few days that she was gone, I just sort of sat like a blob. And all I did was just sort of restore my battery, I just sat and looked out at things. I didn’t even feel obligated to do anything. I barely made supper. It was wonderful! By the time she came back, I did feel a hundred percent better. My sense of humour had returned and I could handle things and I was even able to work faster and do things better. Things were not pressing in on me. It made all the difference in the world.

Ursula knew that there were physical signs which for her were a signal that she was moving toward losing control:

> Ursula: It’s when I’m really short of breath that I get owly sometimes trying to tell him to do something.

Ursula also summed up this property succinctly in the following way:

> Ursula: But I think, you know, it's good for both of you to get away from each other once in awhile.

This was emphasized again by Fran:

> Fran: And I do realize now that I do have to have time (away) from her. Because my husband and I need time with our family.

Kelly also spoke about having had to learn to recognize the impending loss of control because the stress had shown up in an angry outburst:

> Kelly: I've never thought of myself as explosive or angry and I guess all my life I have been very controlled.... So this is one thing I had decided and that is that I have to train myself to do this [have a break]. I have to make myself do this because I can't continue to carry it all the time.... I have to train myself to go and to get used to going and not worry about going. And I haven't reached that yet but I've got to do it and I know that now. I didn't know before.

Thus, this property reflects the ability of caregivers who maintained control to be able to recognize when they were reaching a point where they did not have control within their caregiving and were then able to then act to maintain or regain control. They may not have been able to do this on their own at first, but they were able to learn what the indications were that signalled to them that they were losing control and to use this information to plan for breaks in the future.

Dimension: Lacking Control

The dimension 'lacking control' was developed from sorting the properties into a larger category or dimension. There are three properties of the dimension 'lacking control'. These properties clearly mark the boundaries of the dimension and there are numerous examples of these properties in the data. An example of a caregiver in this dimension was Sue, a spouse who found it difficult to manage giving care to her husband:

> Sue: Well, I try not to react to everything that happens. Like I used to call it *getting unhooked* [italics added] but there are other words for it too, you know, like a pattern of behaviour. Like as soon as he does this I get frantic.

For caregivers who lacked control, the phrase *getting unhooked* exemplified their ability to manage their caregiving. They seemed to not be able to manage the situations which were always present in caring for a relative with dementia. They felt as if they were not handling the day-to-day reality of their lives and were distant from any sense of composure. In short, they felt as if they were *getting unhooked* in every caregiving situation they encountered. Each of the specific properties of caregivers who lacked control will now be explained including quotes from the caregivers to demonstrate each property.

Properties of lacking control.

Negative internal resources

There are three properties which define the dimension 'lacking control' and which provide clear boundaries to separate 'lacking control' from 'maintaining control'. The first property is that whenever the caregivers who lacked control spoke of their internal resources, it was with negativity. They described themselves as "feeling guilty" or "bad", "having no patience", being "a poor nurse", and being "nervous wrecks". Some of the phrases which they used included: "I find it difficult", "I can't handle it", and "I can't hack it". Gina spoke of her feelings of guilt in providing care for her mother:

> Gina: So...there's that guilt involved sometimes. I feel guilty that I'm not going to provide her with that help.

They were influenced in this respect by the stress of their situation, saying that they were "always on edge", "frantic", or that everything "really bugs/bothers me". One caregiver likened this state by saying that "it was like carrying granite", others said that the daily stress of caregiving was "very, very hard" or "very, very difficult". Gina related how she was always on edge when her mother was around:

> Gina: So I'll always hear her. And I always have my ear...because I still expect sometimes something will happen that I never expected you know...you're always on edge, I think.... So I guess...when she's not around, at least there isn't that...always expecting something.

Then later Gina remarked on how she would still feel stressed even if someone were to come in to help care for her mother:

> Gina: I knew even if there was someone else living here, and they were looking after her, I would still be doing a lot of the stuff. I would still feel that responsibility. Like if she's not out of sight, it would still be that it was my responsibility.

Gina found that the mere presence of her mom meant that she felt the heavy weight of responsibility and she was not able to manage that responsibility any longer:

> Gina: Like she stresses me out sometimes. I feel weighted down...
> And I think that a stranger even has more patience than you do 'cause you're so intertwined with the emotions and you're intertwined with the remembering of what that person was like and what they were capable of doing.

Caregivers who lacked control not only had a negative perception of their internal resources but this property is also connected to their perception of the stress that they felt.

Carol was a caregiver who was having a difficult time managing the changes that had come as a result of her husband's dementia and had tried to change her own attitude. She referred to herself as a caregiver and her internal resources negatively:

> Carol: I must say...I'm not always patient with him and I feel I can't change too much. I mean I can't change completely.

Carol then referred to the effect that the stress had on her and how she felt about herself:

> Carol: I think the stress takes as much energy...trying to think of things. And then, thinking of all the things that I want to do that I can't get at. I feel I'm not getting anything done or else I'm too tired to do them.

Carol also remarked on her husband's change in abilities due to his dementia:

> Carol: But these are things that I can't get used to. That he can only do one step at a time.

And again later when discussing how to manage a problem:

> Carol: I don't know how I can solve that one!

Pauline also spoke about the global, daily stress:

> Pauline: I understand the situation that he's in. But it's still hard day after day getting up and going through the same thing every day.

Thus, caregivers who lacked control saw themselves and their abilities as caregivers with negativity. The stress that is a part of caregiving weighed upon them and influenced their negative perceptions.

Inability to recognize the need for help or ask for help

The second property of 'lacking control' is the inability to ask for or to seek help. Others outside of the caregiving situation could easily recognize that the caregiver needed more help but the caregivers themselves could not call for help.

Ironically, the caregivers may have said throughout the course of the interview that they needed help but when asked directly if they felt that they could call for help if needed, they said that they were unable to ask for the help that they needed. This inability to ask for help or to recognize when the caregiving needs were at the point of requiring more help to deal with them was evident in the interview with Olivia, a caregiver who had difficulty caring for her husband. Olivia referred to books and other written information that she had received that she was able to access: "I've got that as a reference" but it seemed as if she was not able to use this information to identify the type of help or stage at which she might need help in her situation. The interviewer was exploring asking for help with Olivia:

> Interviewer: At what stage do you think you would see the need for some home care assistance or...
> Olivia: I don't know. I mean, I mean I know I've got a rough idea that things are maybe are going to get worse but until you experience them, and you, when you get to the point where you can't cope I guess.

Then later she elaborated on this:

> Olivia: I don't know if I would be able to ask for help you know. It's ah, I think it's inbred in us that we will go until we can't manage.

Later, Olivia spoke openly again about the difficulty that she had in asking for help:

> Olivia: It's hard. You don't like asking...and I would never have asked them.

And again later:

> Olivia: I don't know how people can help. I couldn't say.

She repeated this idea of trying to cope and not asking for help until the point where you wouldn't be able to manage:

> Olivia: I'm not going to be able to cope and I'm going to have to ask for help...I mean I know there's going to be a time when I'm going to have to ask for help and, whether it's going to be too late by the time I ask, I hope not.

Sue elaborated on this inability to ask for help even though help was desperately needed:

> Sue: I have a very difficult time asking for help too. It's very hard for me and neighbours are wonderful and everything, like that, but I find I don't know what to do with it. Like because I've never done it.

Sue was also able to articulate why she believed that she was unable to ask for help:

> Sue: I guess because if you ask for help from someone else you sort of have to be prepared to give it back. And I never really had or felt that I had the time to reciprocate...and I didn't want to be indebted to somebody all the time.

In addition, in the course of their describing a caregiving experience, caregivers may have identified specific information that would help them meet a need but again, when asked directly what type of help they would like to have more of, they were unable to identify their need or to recognize the type of help they required. One caregiver specified that she had some questions about how to stimulate her husband mentally and wanted information about this, but later when she was asked directly what help or information she needed she answered that she really didn't know.

Olivia mentioned early in the interview some specific needs for help:

> Olivia: I know that it would be nice to be able to slip into town and not have to worry...I do need the time out.

However, Olivia was unable to say what help she needed when asked about this directly:

> Olivia: I just don't know, I don't know how people can help. I couldn't say to you, well if there was this, this and this it would make it a lot easier for me. 'Cause I don't know.

Olivia later related that perhaps it was because she was unable to know how to help herself that she was subsequently unable to tell others how to help her:

> Olivia: If I knew how to say, to help myself, you know I would say well look, if you could do this and this that would be wonderful, but you know, I really don't know.

A key reference that also captures the essence of this property was also from Olivia, who described not being able to figure out what help was needed and the way that this contributed to not being able to manage her husband's care in the following way:

> Olivia: I think it's like when you go to the doctor's and he's taken all these tests cause you know there's something wrong with you and you don't know what it is. And as soon as they put a handle on it you can cope with that. Doesn't matter what it is. Okay, it's the worst you've thought of, but if you know, I think you can fight it much easier than just, you know, sort of *out on a limb and not knowing how long it's going to support you* [italics added].

Thus, caregivers who lacked control seemed to be unable to ask for or to seek out help. They may have identified in conversation that they had specific needs, but when they were asked directly how they may be helped, they were unable to articulate either their needs or the type of help that was required. They felt as if they were out on a limb, alone, and could not see any resources to help them with their situation. There was evidence, however, to indicate that caregivers were able to move toward having control within their caregiving situations. This finding will be discussed within the section of movement within and between the dimensions.

No future anticipation

The final property of 'lacking control' is that there is no anticipation of what the future holds. There was uncertainty about the caregivers' ability to manage in the future and there was also uncertainty about what their future within caregiving would have included as far as the type of care needed or the point at which they would no longer be able to manage the care of their relative at home.

An example of this property was from Matt, a caregiver who, during the time interval between interviews, had an increasingly difficult time managing the care of his wife, and could not anticipate the future:

> Matt: I still don't know when I'm going to say, well I can't look after you anymore, honey.

He was also uncertain about his ability for future caregiving management and used phrases like "I'm going to try to handle it", but there was no determination or certainty about his ability to handle future caregiving tasks.

Olivia also spoke of her uncertainty with the future and the difficulty that she had in knowing what to do:

> Olivia: It's really hard to know what to do...I find that I'm the one that's having to make most of the decisions which is really hard. 'Cause you want to do the right thing.

Carol remarked that although she had books and information on dementia, she avoided reading it and did not wish to anticipate what the future may bring:

> Carol: And I got all that and I read a certain amount of it and then it was starting to get to the icky parts so I thought well maybe he'll never reach that stage so I will not read it.

Thus, caregivers who lacked control were perhaps not able or willing to know what the future held for them. It was enough for these caregivers to try to manage their present day-to-day caregiving let alone try to anticipate what the future might bring.

The missing properties.

Caregivers who lacked control did not have two of the properties which caregivers who maintained control displayed. It was not that caregivers who lacked control had the opposite properties, rather there were two properties which were simply not evident in caregivers who lacked control. The first missing property is that caregivers who were not able to manage their caregiving situations did not use language that was associated with having control or confidence as caregivers. The property of using confident language which caregivers who maintained control demonstrate so clearly was even more striking when comparing caregivers who were lacking control but who were facing similar problems (e.g., wandering, fire hazards). For example, Jane had locks and alarms installed after her husband's first attempt to wander out of the house and Jane was able to explain how she solved this problem using language which demonstrated her confidence as a caregiver. On the other hand, Olivia had a difficult time knowing what to do when her husband would wander away repeatedly for months at a time. Caregivers who lacked control were not able to manage these problems effectively and used no language to indicate that they were in control of the situation and confident of their abilities as caregivers.

The second missing property within the dimension 'lacking control' is that these caregivers did not see when they were losing control and were therefore not able to act upon this knowledge. For example, Gina could not see that the deteriorating condition of her mother's dementia was influencing her ability to manage her mother's care. Gina was becoming fatigued and felt as if she were carrying granite but could not see that she should plan for a break away from her caregiving responsibilities. Perhaps it was because they were in the midst of not having control that they were unable to sense when they were headed into a situation where they had an even greater loss of control.

Movement Within and Between the Dimensions

There was evidence in the interviews of cognitive shifts, or movement between the control dimensions. These are the arrows depicted in the model. It was unclear whether all caregivers within a particular dimension moved in a particular direction; that is, whether all caregivers in the dimension 'maintaining control' moved toward 'lacking control' or whether those caregivers within the dimension 'lacking control' moved toward 'maintaining control'. What was clear from the data was that movement existed and that there were factors which facilitated movement toward having control. It seemed that there were factors which helped caregivers regain control. For example, health care professionals may assist caregivers to regain control by providing interventions to help them with their caregiving. A situation where a caregiver moved to regain control and the factors which influenced this movement will be discussed in the following section on movement toward 'maintaining control'. In the first section I will explain what I understand about the movement toward 'lacking control'.

Losing control: Movement toward not having control.

There was evidence in the interviews that caregivers did experience movement within their experience of control. Caregivers may have experienced movement toward not having control. I have named this arrow 'losing control'. However, it was not clear at what point the arrow of 'losing control' actually became 'lacking control'; this is the reason for the shortened arrow in the diagram.

Ron was able to express clearly two weeks after his wife was placed in a long-term care facility what it was like for him in moving toward 'lacking control' in the time right before his wife was placed in a long-term care facility:

> Ron: Well if you want to be tied down one thousand percent then you can keep her home. But if you are going to have any life at all and I'm not meaning that, mean or anything like that, I mean if you want to even go out. I couldn't even go to the car. I couldn't go out in the back, I couldn't even pull a weed without her being right, one inch away from me. I couldn't talk to the neighbour on either side. She'd get mad at me because I was not with her. She wanted to be with me, just me period and not anybody else.

Helen refers to the movement toward 'lacking control' and subsequent movement toward 'maintaining control' as "swinging":

> Helen: Well, until I actually got it [understanding that there were times that she functioned well and others when she needed a break away] I didn't think it was terribly important. There were times that I thought she was playing me for a sucker, and then I realized that that was during my bad days...so we swing, and I think perhaps she swings too.

Sue likened the movement to being on a rollercoaster:

> Sue: You see, even the part of living with this agitation is that periodically it's like being on a rollercoaster, you know. Like you're riding along and everything seems fine and then you just fly off.

Matt provided valuable insight in understanding a change in experiencing control over time. During the first interview Matt described his role as a caregiver for his wife

Nancy. He related how she had deteriorated in the last six months and how he was still managing his care for her. He demonstrated his ability to ask for help clearly by stating that "if I want to know anything I call T---" and was able to see that he might need more of their help later: "I'm probably going to have to depend on home care a lot more than I do". He used control language frequently: "I'm quite capable of handling the situation right now" and "I can handle it you know. I say that quite often...I can handle it". He was also able to anticipate what the future might hold, even though he dreaded it: "I know there is going to be that day but I hope it's not going to be for awhile yet" and again:

> Matt: I'll probably have to go to this program of having people come in and looking after her, or I'll have to get her put away, you know, not put away, that's pretty rough as far as I'm concerned. But I might have to have somebody sit with her for the day if she gets, you know, a little worse. Right now I'm sure that if she didn't get any worse I'd be living with her for a long time yet.

Matt did send his wife to an adult day program but he said that it was for her sake, because she enjoyed the people there and came home happy. He was not able to identify anything specific that he did during the time that she was at the program but he did say that he was very lonely and missed her a lot during her time there.

It was clear that at the time of the first interview that Matt was maintaining control and had been able to manage any deterioration or changes within his caregiving situation. However, at the time of the second interview Matt was having more difficulty. He said that she was "so much worse now" and that "it is really sad right now" and spoke of "having a rough time", saying "it's pretty rough", and that "this is really hard to take".

He did not speak any more of maintaining control, instead he said "I'm coping with a lot".

Matt demonstrated that he was experiencing movement toward 'lacking control' by relating his increasing difficulty in caring for his wife. He recounted one of several experiences where his wife was becoming more confused and kept asking the same question and checking the same object over and over again. After one day of this activity Matt said that the next morning: "By that time I was a nervous wreck". He made references to these times increasing in number and frequency and said: "this all builds up" and remarked about the problems: "I can't do nothing about it...you can't do nothing about it".

Although Matt still wanted to continue to care for his wife at home and said "I want to keep my wife at home as long as possible", there was now some uncertainty about how long he would keep her there and that it would be difficult for him when she did leave: "I still don't know when I'm going to say, well I can't look after you anymore, honey...and that's, that's going to be another difficult point in my life". He also admitted that he was finding that he must distance himself from the caregiving situation:

> Matt: I have to say I think you get a bit immune to the situation...you get a little harder or something like that...I think you get a little toughened up to it. It might be a sad thing to say...

Matt also remarked that he was now having a difficult time managing his wife's worsening condition:

> Matt: [She] gets on these little bit of kicks you know...which is very difficult and sometimes they go for two hours you know and you're supposed to kind of turn, steer them away from this problem.

And he revealed that he had times when it was difficult for him to manage his reactions to her confusion:

> Matt: I can handle most anything she gives but, although at times, it really bugs me you know, bothers me, I shake so much.

At this point Matt was uncertain about his role as a caregiver and he stated:

> Matt: I'm new at this too you know, I mean anything you can say I appreciate it and I'll take your word for it because I don't know.

It was clear that Matt was having a much more difficult time than in the first interview and was experiencing movement from 'maintaining control' toward 'lacking control'. His experience showed me that it was possible to recognize when movement away from 'maintaining control' and toward 'lacking control' had occurred. His narrative helped me to understand this type of movement and provided a contrast for the next case of movement within the model.

Regaining control: Movement toward maintaining control.

Caregivers may also experience movement toward having control. I have named this arrow 'regaining control'. It seemed that if caregivers did change their position within or between the dimensions that they did this using their own or outside resources for a time but that they may have come to a point where they were unable to regain control without help. There were factors which helped caregivers regain control. The factors which influenced movement toward regaining control will now be discussed and a situation of a caregiver who moved to regain control will be presented.

One of the factors which facilitated the movement toward having control was for *caregivers to have a break away* from caregiving. Some caregivers were able to use the times when home care was present with their relative to revitalize themselves and move toward maintaining or regaining control with these ‘breaks’. Fran was very clear that she was able to continue to manage caring for her mother because she not only had the breaks away but her perception of the time away was that it was very helpful for her as a caregiver. She stated:

> Fran: It’s a break and yet I don’t need to feel guilty about not being here. She’s safe, her meals are going to be on time. If she needs a bath, she’s going to get it. You know, to me...it makes my job easier.

Fran reiterated how the help that she received from home care was an outlet for her to regain control in a stressful caregiving situation:

> Fran: Now I know how the stress is. Because sometimes I feel like, “oh God, mother! You’re going to drive me nuts!” And without home care’s help you know, it would be much harder. ’Cause I wouldn’t have an outlet.

Gina also referred to the breaks away as being useful for her to feel some measure of control in a situation where she had difficulty managing the care of her mother:

> Gina: It felt really good because number one, I could do anything. I felt I had a little bit of a better sleep that night.

Sue demonstrated the movement toward ‘maintaining control’ clearly because of the advantage of having two interviews which captured the movement from ‘lacking control’ in the first interview where her resources were not adequate in helping her regain control to being able to have control with outside help in the second interview. In the first interview Sue was definitely lacking control. She was an 80-year-old caregiver who was caring for her husband with multi-infarct dementia. She found it difficult coping with the changes in her husband and so in the first interview she related how she was going to start to go to a counsellor to help her deal with the emotions of caregiving and to work through her inability to ask for help. Her husband had frequently wandered away, sometimes for months at a time and had other disturbing behaviors which Sue found difficult to manage or comprehend. She related experiences where her husband would disappear for months at a time but which she had not done something (e.g., take away his car keys, install an alarm, add locks to the doors) to prevent his disappearances from recurring:

> Sue: I was just trying to have a sleep and finally I did fall asleep, and when I got up he had gone and taken the car and he wasn't driving well. Like he was backing into the stall on his side; anyway, he didn't stay long and fortunately, he came back...but you know he was clearly trying to go without me knowing he'd gone. Not any distance, but prior to that he had disappeared for as long as four months, one time...another time two and a half months; so, it was a very real fear.

Sue also demonstrated that she was not able to manage giving care to her husband and her feelings related to not being able to manage:

> Sue: I really felt quite angry actually. Not just at him being sick but at the whole situation of helplessness over it and all the things that have happened and that you can't do anything about.

She also demonstrated her inability to ask for help as being one of the catalysts for her decision to seek counselling:

> Sue: And that's the sort of thing I want to try to work through with the counsellor. I have a very difficult time asking for help too. It's very hard for me and the neighbours are wonderful and everything like that but I find I don't know what to do with it. Like because I've never done it...and it's just, it's hard for me.

She was also able to articulate clearly her stress and lack of control in this segment:

> Sue: How can I help myself to not be so stressed all the time...and I've

> been trying to do that...
> Interviewer: Can you say a bit more about that? What would be helpful?
> Sue: Well, it's like trying to not to react to everything that happens. Like I used to call it getting unhooked but there are other words for it too, you know, like a pattern of behaviour. Like as soon as he does this I get frantic. And then I confront him which is really the worst thing I can do because then he gets panicky and then he's worse.

Sue also admitted that it was difficult for her to take time to herself ("it is quite hard for me") even though her husband's behaviors had been disturbing her ("he gets me all worked up"). So it was at this first interview that Sue demonstrated her lack of control over her caregiving situation quite clearly.

Then, the second interview two months later showed changes in her ability to manage the caregiving situation. Sue started to have more of the language of control demonstrating her confidence in her caregiving abilities present as well as now being able to recognize when she was losing control. These changes were a direct result of the counselling that had been done in the interim, and Sue related how the psychologist had helped her, in this instance, with being able to have a conversation with her husband:

> Sue: We talk about things that I've been involved with. The psychologist told me to do this and I do do it with him, but if he can't remember, I fill in for him and so when we're having a conversation I do do that a lot. I try not to do it immediately so that he can try to figure out what it is he wants to say himself...I don't punish myself for what I don't get done anymore...you have to let some things go and I phone for help when I need it.

Sue was also able to look back and to see the way that she had changed since the last interview:

> Sue: I find that I'm learning much more so since you were here last time to be more patient with myself...[she then relates an experience that would have upset her previously]...and in earlier stages, that made me kind of

> angry with him that he couldn't say "I'm just not well" or something but now it's not so important. I have certainly learned to put myself in his shoes a bit more.

Later, she reflected on these changes:

> Sue: I guess it's just learning to have a new way of life, and know that you keep on learning with it and be prepared to be flexible.

She ended the interview with this statement that summed up her new approach to managing her husband's care:

> Sue: I try to share as much as I can with him. If he's prepared to accept it and do something with it that's okay. If he's not, just talking about it is alright too. Not having any great illusions about what he might be able to add to it or anything like that. I guess that's about all I can say.

There were still times of uncertainty and situations where control was lacking but Sue recognized these situations as being stressful and reminded herself that counselling was valuable in dealing with them:

> Sue: They're very stressful, and you have to just be careful not to make something out of it and I find that the counsellor is better able to deal with that than talking it over with my family or friends because they, like sometimes I just want to talk about it.

There were factors which influenced Sue's movement toward having control. One factor was that Sue was able to have a *cognitive shift toward being more tolerant of the family member with dementia*. Sue was becoming tolerant not only of her husband's dementia but also of the resultant changes in their relationship because of his dementia.

Another factor was that she was able to become *more tolerant of herself as a caregiver*. Sue was moving toward being able to forgive herself for not being able to accomplish everything and to know that it was 'ok' to be more tolerant of what she was realistically able to accomplish. Another important factor which contributed to the movement toward having control was ***knowing that it is important to express your feelings and to find a place to do so***. Sue had recognized that she not only needed to talk about how she was feeling but she also now recognized that her family may not be able to fulfill this role for her and that she needed to continue with counselling. Sue's experience showed me that it was possible to recognize how an intervention such as counselling could change the movement away from 'lacking control' and be the start of movement toward 'maintaining control'.

Conclusion

This chapter introduced the informants and discussed the dimensions and properties of the model. The narratives of the experiences of the individual caregivers contributed to the explanatory model of the experience of control in managing caregiving. The findings were based on the interviews with twenty-one caregivers but may serve to inform practice with other caregivers. It is now important to return to the literature to compare this model with others for similarities and differences to gain insight and understanding of control and caregiving.

Chapter V

DISCUSSION AND INTERPRETATION

The purpose of this study was to explore how caregivers perceive control within their experience of caring for relatives with dementia. A qualitative approach was chosen because it was evident from a review of the literature that a clearer understanding was needed of the perception of control throughout the caregiving experience. I found that caregivers experienced control in caregiving within the dimensions of 'maintaining control' and 'lacking control' and that it was also possible to define the movement of losing and regaining control which occurred between the two dimensions. In this chapter, I will first introduce the areas from the literature which will be helpful in understanding the findings. I will then interpret the findings of this study in light of the existing literature.

Related Literature

The intent at the outset of the study was to remain conceptually open so that the theoretical direction could be determined from the findings. The literature review for this study gave an overview of the linkages between control and frameworks such as social support, coping, and personality. The experience of control was found to be related to how the caregivers managed their caregiving situations. It will be recalled that some of the caregivers like Olivia who lacked control spoke about being "out on a limb" and demonstrated that they had difficulty coping with caregiving. Other caregivers who maintained control like Ursula related how they kept difficult caregiving situations "on an even keel" and coped well with caregiving. The manner in which caregivers experienced control was directly related to how they managed their caregiving. The literature which was found to be the most helpful in understanding the findings for this study was coping literature. Lazarus and Folkman's (1984) work on coping is useful in interpreting the findings of this study, as is Pearlin and Schooler's (1978) definition of coping as including psychological resources (representing who people are) and coping responses (representing what people do, or their concrete efforts). Antonovsky's (1980) work on characteristics of the individual which impact on stressful situations will be discussed in relation to some of the properties of the dimensions. In addition, the literature on perceived control is useful in gaining a clearer picture of the various interpretations of the relationship between coping and control.

Coping and Perceived Control

In our attempts to understand behaviors, coping is a useful concept which deals with how individuals manage their situations based on a continual evaluative process (Ritchie, 1994). This orientation to coping is transactional where "coping is defined as a constantly changing cognitive and behavioral effort to manage demands that are appraised as taxing" (Lyon, 1993, p. 190). Lazarus and Folkman (1984) furthered the conceptualization of coping by conceiving of coping as a process which is constantly changing over the duration of a situation and which is dependent on the particular context and the meaning of the situation for the person.

It will be recalled that in the coping literature, Lazarus and Folkman (1984) held that the individual must first appraise the situation before dealing with it. There are two forms of appraisal: primary and secondary. Primary appraisal asks the question: "What is the significance of this situation? Is this a situation that I need to deal with?". There are three kinds of primary appraisal: irrelevant appraisal, benign-positive appraisal, and stress appraisals (Lazarus & Folkman, 1984). Secondary appraisal is the assessment of resources in relation to the situation encountered. The assessment of resources includes those resources which are internal (competence and coping strategies) and external (social support) (Lazarus & Folkman, 1984). When the demands of the situation exceed the resources assessed by the individual the discrepancy may result in potential endangerment of the individual's well-being and therefore stress is experienced by the individual (Lazarus & Folkman, 1984). The individual must then deal with the demands of the situation through cognitive and behavioral efforts so that the threat is reduced, this is known as coping (Lazarus & Folkman, 1984).

In light of the above explanation, caregiving is viewed as the demanding situation which the caregiver is faced with and which the caregiver must somehow deal with on a daily basis. Because caregiving is a demanding, difficult situation which is constantly present for the caregiver, the type of primary appraisal which occurs in caregiving is stress appraisal. Stewart (1995) also held that stressors which are chronic such as caregiving must be viewed differently in coping. In particular, caregivers experience threat (anticipated harm/loss) and challenge (anticipated gain). Both threat and challenge appraisals mobilize coping efforts (Lazarus & Folkman, 1984).

The caregivers use secondary appraisal in their daily assessment of their demanding situation (caregiving). Secondary appraisal involves assessment of external resources and internal resources. External resource assessment is related to social support. A caregiver assesses their internal resources by looking at their competence and coping repertoire. Competence can be viewed as the resources related to 'who an individual is'; that is, the resources which define them as a particular individual. Coping repertoire can be viewed as the strategies related to 'what an individual does'. The internal resources are of interest for the findings for this study.

With their caregiving situations appraised as stressful (either as a threat or challenge) and their individual resources appraised, the caregiver must then cope or deal with the demands of the situation through cognitive and behavioral efforts. Conceptually, this is where the caregivers' experience of control is situated. Perceived control is the outcome of the secondary appraisal process (Wallhagen, 1988). In this study, the caregivers' continual appraisal of their situations influenced their perceptions of control. This is congruent with the concept of appraisal as described by Koop (1994) where "appraisal refers to the meaning which individual family members attribute to the stressors (as benign, challenging or threatening, for example) and to their perceptions of their ability to manage the situation" (p. 9). It is the net appraisal which shapes the response, the thoughts, emotions and/or behavior (Lazarus & Folkman, 1984). In this study, the caregivers' experience of control was related to how they were managing or coping with their caregiving situations.

The connection between control and coping has various forms. One interpretation of the relationship between control and coping is where perceptions of control influence coping. The way in which caregivers in this study coped with their caregiving situations was determined by their experience of control. Some of the caregivers like Gina and Olivia demonstrated that they had difficulty coping with caregiving and these were the caregivers who lacked control. Other caregivers like Ursula and Fran who maintained control were also coping well with caregiving. If the caregivers were moving from 'lacking control' to 'maintaining control' there was evidence that their words and actions had become more effective in coping with their caregiving situations.

Coping is viewed as the end result of control or the "process whereby the situation is altered or managed in some way" (Koop, 1994, p. 12). Moss and Tsu (1977) linked perceptions of control with an ability to manage difficult situations in illness. Diamond and Jones (1983) also found that perceptions of control facilitated the ability to cope with distressing situations.

Another interpretation of the relationship between control and coping is an interactive one; that is, control and coping influence each other. Skinner (1995) held that when people work toward having control that this can be labelled as coping, and that, when an individual is coping they are creating competence which influences their perception of control. Thus, control and coping interact with each other.

Yet another interpretation of the relationship between control and coping is that control is a coping strategy. Bullers (1994) described the influence of control on coping by relating how perceived control acts as a coping strategy. She maintained that "those with increased perceptions of control over their lives are more likely to take active steps toward reducing or avoiding stressful circumstances. In this way perceived control acts as a coping strategy" (p. 12).

Another study which identified control as a coping strategy in caregiving was a study done by Harris (1993) on the male caregivers of spouses with Alzheimer disease. The most common themes expressed were: "commitment; social isolation/loss of companionship; coping strategies such as control...; a sense of accomplishment; the need for specialized services for men; and limited expectations of help from their children" (Harris, 1993, p. 553). In addition, "keeping control of the caregiving situation for these men had meaning beyond an extension of their work roles" (Harris, 1993, p. 553). Control enabled the male caregivers to overcome the helplessness associated with the disease process and to manage their caregiving situations. It was also evident in the present study that the caregivers who maintained control in their caregiving were active in this process and used actions and strategies to help them cope with their situations.

Skinner (1995) elaborated on actions and coping by defining coping as "action regulation [which] refers to how people mobilize, guide, manage, energize, and direct their behavior, emotion, and orientation, or how they fail to do so" (p. 82). Thus, coping deals with how individuals act to manage their thoughts and behaviors. This is in agreement with Lewis, Haberman, and Wallhagen's (1986) definition of coping as the "methods by which patients cognitively or behaviorally processed or managed their situation" (p. 33)

Coping has been referred to as the management of one's thoughts and behaviors, this idea has also been developed to include coping being based on who an individual is (psychological resources) and what that individual does (coping responses). This is clear in Pearlin and Schooler's (1978) definition of coping as including psychological resources (representing who people are) and coping responses (representing what people do, or their concrete efforts). This is also consistent with Lazarus and Folkman's (1984) idea of coping as including the cognitive and behavioral aspects used to manage a demand. Indeed, Lazarus and Folkman (1984) stated that "when control refers to cognitive or behavioral *efforts* [italics in original] to deal with a stressful encounter, we see coping and control as synonymous" (p. 170).

This is a useful framework from which to view the individual properties of the dimensions in this study. This is also congruent with Warren et al.'s (1996) definition of coping in a study of family caregivers where "coping represents the strengths and resources of the caregivers to deal with the stress of caregiving" (p. 13). The caregivers had a certain perception of control which influenced their ability to cope with their caregiving. Their coping was based on who they were as individuals (psychological resources) and what they did (coping responses).

The cognitions and perceptions of an individual are their psychological resources and their behaviors are their coping responses. Coping responses may be influenced by the psychological resources or personality characteristics that individuals draw upon to help them cope but the two are separate entities (Pearlin & Schooler, 1978). The notion of coping as including 'who an individual is' is in opposition to Lazarus and Folkman's (1984) view of control in coping as effortful. Although what an individual does to cope provides evidence of an active state, who they are would be seen by Lazarus and Folkman (1984) as that part of control which is the cognitive appraisal process.

The theoretical backdrop of viewing control and coping as including who an individual is (psychological resources) and what they do (coping responses) is useful for the interpretation and discussion of the properties of the dimensions in this study. This is one approach to interpreting the findings as they relate to the coping literature.

The properties from the dimensions 'maintaining control' and 'lacking control' will be discussed as either psychological resources or coping responses. As mentioned above, these psychological resources and coping responses are that part of control in coping known as the cognitive appraisal process. This is a part of Lazarus and Folkman's (1984) secondary appraisal where appraisal refers to what might and could be done but also includes reappraisal of completed actions. Other properties of Lazarus and Folkman's (1984) model of stress and coping are not addressed as they do not relate to the model in this study.

The properties *internal resources (positive and negative)* and *confident language* refer to psychological resources. The properties *ability to see the need and either ask or not ask for help, seeing loss of control and acting upon it,* and *future anticipation (present or not)* refer to coping responses. Each property will first be discussed in general and then compared according to each dimension.

Psychological resources.

Psychological resources include self-esteem, self-denigration and mastery, and are "the personality characteristics that people draw upon to help them withstand threats posed by events and objects in their environment" (Pearlin & Schooler, 1978, p. 5). Antonovsky (1987) has studied how individuals survive well in the face of difficult stress and has developed the concept of a sense of coherence. The characteristics of the individual which comprise the sense of coherence included manageability, challenge, and comprehensibility and Antonovsky (1987) is clear that the sense of coherence deals with *who* an individual is rather than what they *do*. An individual with a sense of coherence will have "an orientation toward one's world that sees stimuli as meaningful, comprehensible, and manageable [and the sense of coherence then] provides the motivational and cognitive basis for behavior that is more likely to resolve the problems posed by stressors than is one that sees the world as burdensome, chaotic, and overwhelming" (Antonovsky, 1987, p. 147). Therefore, the psychological resources of an individual will contribute to the way in which that individual copes with any given situation. The properties in this study that are psychological resources are *confident language* and *internal resources (positive and negative)*.

Confident language

Caregivers who maintained control used language that referred to their management abilities. They were able to give examples of how they had solved problems and used language that was associated with the word 'control'. Control language was a psychological resource used by the caregivers which demonstrated their confidence in managing their caregiving situations. This finding is consistent with Antonovsky's (1987) view of an individual who is able to manage any given situation as having a strong sense of coherence; these individuals will tend to seek to impose structure on the situation. It is also similar to Skinner's (1995) view that individuals with high perceived control have an outlook toward planning and managing problems. Wallhagen and Kagan (1993) also found that "being in charge" (p. 203) was one of the categories of perceived control which encompassed caregivers' abilities to use control language but which also included the caregivers' ability to make decisions. The caregivers' ability to use language that referred to them as having confidence in controlling or managing their situations was one of their psychological resources; it was a part of who they were that influenced how they coped with their caregiving. Those caregivers who were lacking control did not have this psychological resource.

Internal resources: Positive and Negative

Caregivers who maintained control spoke positively about themselves as caregivers and their internal resources. They had a determined, decisive outlook. Even if there were times when they did not feel positively about themselves as caregivers, they recognized that the circumstances were influencing their perceptions, it was not due to something within themselves. Skinner (1995) referred to individuals who have the ability to control any given situation as viewing the challenge as external to themselves. In this way, the individual responds to the context to make it more controllable by using a variety of behaviors and this response is "accompanied by an *optimistic attitude* [italics added] and an outlook toward planning and preventing problems from occurring in the future" (Skinner, 1995, p. 83). The caregivers who were managing their situations were able to see the challenge to manage as external to themselves and so they were able to manage the situation as the problem and not themselves as the problem. They approached their situations with a determined, optimistic attitude. Wallhagen and Kagan (1993) also found that "being OK" (p. 204) was one of the categories of perceived control which encompassed caregivers' positive affect toward themselves and their caregiving situations.

On the other hand, caregivers who lacked control spoke of themselves as caregivers or their internal resources for caregiving with negativity. They seemed to not be able to believe that they are able to manage as caregivers. Antonovsky (1987) referred to the individual with psychological resources which do not help that individual cope as having a weak sense of coherence. These individuals will have a tendency to see disorder, and to feel hopeless and burdened in any given situation. Pagel, Becker, and Copel (1985) found in a longitudinal study of spouse caregivers that a perceived loss of control was associated with depression. In addition, Morris, Morris, and Britton (1989) also found that a perceived loss of control was associated with depression and strain. The caregivers' view of their internal resources was one of their psychological resources; it was a part of who they were that influenced how they coped with their caregiving.

Coping responses.

Coping responses refer to concrete efforts on the part of the individual that influence coping (Pearlin & Schooler, 1978). The caregivers described actions that influenced their ability to manage their caregiving situations in their narratives. These actions can be viewed as coping responses.

Ability or inability to recognize the need for and to ask for help

Caregivers who maintained control were able to identify specific needs that they had as well as the resources required to satisfy those needs. They were able to call for help when they required it. The ability to use a variety of resources to manage a need that arises is described by Pearlin and Schooler (1978) as being a more effective way to cope than having a single coping response. It is the range of responses which they view as being important; it is the richness and variety which allow an individual to have protection by coping in many different situations. The caregivers who maintained control were able to identify a variety of resources with which to meet any given need. This repertoire of resources allowed them to cope with any new difficulty in their caregiving situations. This finding of 'seeing what help is needed and to ask for help when needed' is also similar to Antonovsky's (1987) component of the sense of coherence known as 'manageability'. Manageability is "the extent to which one perceives that resources are at one's disposal which are adequate to meet the demands posed by the stimuli that bombard one" (Antonovsky, 1987, p. 17). It is not only resources outside of the individual that are available to help the individual cope; Antonovsky (1987) also referred to resources within the individual that are available to help the individual cope well. The caregivers who maintained control in this study were able to recognize when they had a need that was beyond the scope of their own resources. They were then able to recognize that an external resource was required to meet that need and to ask for it.

On the other hand, caregivers who lacked control were unable to call for help when it was needed. They sometimes did recognize that they had needs which someone could help them meet, but when they were asked directly about what help could be offered to them they could not say what or how others may help them. Skinner (1995) described individuals who were threatened and did not perceive that they had control as being full of self-doubt with their general orientation being confusion. The caregivers who lacked control did not have the self-confidence to say what help they required in spite of often being able to recognize within the course of conversation that they had certain needs. In addition, Warren, et al. (1996) found that caregivers did not access resources and they reasoned that this was because some caregivers may be reluctant to access services or may have difficulty asking for help.

Future: Anticipation or no anticipation

Caregivers who maintained control were not only able to assess their present situation but they were also able to anticipate the needs and changes that may occur in the future. This is an aspect of Lewis et al.'s (1986) cognitive control, which is achieved by managing information and includes the tasks of monitoring, describing, and evaluating. The caregivers who maintained control and anticipated future needs were able to take in an assessment of their present situation and to evaluate where they were at and what would be needed in the future. Skinner (1995) also referred to individuals who seek to control situations as seeking information and planning in order to prevent problems in the future. Wallhagen and Kagan (1993) also found that "being on top of" (p. 202) was one of the categories of perceived control which encompassed caregivers' abilities to monitor, anticipate, and plan for the future.

On the other hand, caregivers who lacked control were unable to anticipate the future and seemed unwilling or unable to comprehend that the future may mean a change in their caregiving. This is similar to Skinner's (1995) description of individuals who feel threatened as feeling hopeless and who react to difficulties in the future by putting off the threatening activity or decisions as long as possible. These individuals, as mentioned previously, also have confusion and self-doubt. Antonovsky's (1987) description of individuals who do not manage well and have a weak sense of coherence also includes feelings of hopelessness and burden. The caregivers who lacked control and who were not able to anticipate the future seemed to be putting off making any decisions about changes in their caregiving and seemed to be unable to say with confidence that changes would occur with the deteriorating condition of their relative with dementia.

Seeing impending loss of control and acting on it

Caregivers who maintained control demonstrated a concrete coping effort by recognizing when they were moving toward losing control within their caregiving situations and then acting to regain control. They were able to recognize signals that indicated when they needed a break from caregiving and then arranged to have time away. Caregivers who maintained control were able to recognize a change from having control to not having control. In losing control, these caregivers knew that something had changed. This finding is similar to Langer's (1975) idea that a temporary loss of control is anxiety arousing. If the loss of control continues, then the anxiety is replaced by a chronic feeling of no control and is characterized by "passivity and giving up in the face of failure" (Langer, 1975, p. 323). The caregivers were able to recognize that they felt uneasy in their caregiving and were able to do something to avoid burnout or what Langer (1975) referred to as passivity.

On the other hand, caregivers who lacked control were not able to see that they lacked control and were therefore not able to act upon this knowledge. Perhaps this was because they were in the midst of not having control that they were unable to sense when they were headed into a situation where they would have had an even greater loss of control.

Movement.

There was evidence of movement between the dimensions 'maintaining control' and 'lacking control'. Some caregivers in this study did not appear to move from within their dimension. However, there were caregivers who did appear to move. Caregivers who were maintaining control but moving toward 'lacking control' were 'losing control'. For caregivers losing control, it was found that elements which had previously been present which helped then to maintain control were not longer present. These elements included: caregivers no longer using confident language, not being able to see when they needed help or to be able to call for it, and also not being able to recognize that a break away from caregiving was needed. Caregivers who moved from ‘lacking control’ toward ‘maintaining control’ were ‘regaining control’. For caregivers regaining control, it was found that certain factors could assist them in moving to regain control. These factors included: being able to have a break away from caregiving, having a cognitive shift toward being more tolerant of the family member with dementia, being more tolerant of themselves as a caregiver, and knowing that it is important to express their feelings and finding a place to do so.

It is clear from reading the literature on control and coping that there is no magic formula for managing difficult situations such as caregiving. As Skinner (1995) so aptly stated: “many elements must be in place for people to experience themselves as effective. However, if any one element is absent, then so too may be the experience of control” (p. 64). The caregivers who moved from ‘maintaining control’ to ‘lacking control’ could have had some element missing which moved them into a situation where they had no control. It seems possible for caregivers to weather many of these situations where control is lacking for quite some time and to find new ways of managing. However, there may come a point where caregivers are not able to manage any longer in a situation where there is no control. Indeed, Wallhagen and Kagan (1993) found that control could become temporarily lost and that “maintaining some sense of control, no matter how achieved, seemed necessary to continuing in the caregiving role” (p. 201).

Willoughby and Keating (1991) also found that losing control was an important aspect related to a caregiver’s decision to institutionalize a relative with dementia. The process of gaining and relinquishing control within caregiving was found to encompass five stages: emerging recognition, taking control: making my own decisions, losing control: accepting the decisions of others, adjusting to the psychiatric institution, and moving on. There was a point within the second stage where a cognitive shift occurred on the part of the caregiver with the acknowledgment that more help was needed to provide adequate care for the dementia person. This resulted in Stage 3 which was a period of crisis where the caregiver experienced being out of control and had to make the cognitive shift to acknowledge the appropriateness of the decision to institutionalize their relative. This finding in the Willoughby and Keating (1991) study where caregivers experience a loss of control and then institutionalize their relative is congruent with the findings of this study.

It is interesting to speculate on the influence of multiple experiences of losing control in caregiving on the decision to admit a relative with dementia to a long-term care facility. It could be that caregivers experience a 'back and forth' movement where they lose control, somehow find a way to regain control, then lose it again. This back and forth movement may continue for some time but perhaps there comes a point where the caregiver moves all of the way over to 'lacking control' and they are then unable to regain control anymore. The caregiver would then be at the point where a decision to institutionalize their relative would be imminent.

Attempts have been made to determine specific aspects of caregiving which lead caregivers to seek placement for their relative with dementia. Warren, et al. (1996) held that "the level of impairment in the Alzheimer relative seems to affect this decision [to admit their Alzheimer relative into a long-term care facility] more than family involvement" (p. 32). However, from the caregiver quotations used to support this statement it seems to me that there was an element having to do with the caregivers themselves and their ability to manage their caregiving which was overlooked. The first quotation used to support Warren et al.'s (1996) conclusion is from a wife caregiver who said she had to admit her ill husband into a long-term care facility "'because I'm getting to the point where I can't handle it any more. I'm burnt out'" (p. 32). In light of the findings of the present study, this caregiver may be at the point where she has no control over her caregiving and is now lacking control. Perhaps the only way she could regain control was to seek placement for her husband.

The second quotation used by Warren, et al. (1996) is from an adult daughter caregiver who explained that "'when mother came to live here, I had in the back of my mind that, when night-time was disturbed and when she became incontinent, either or...well both happened pretty much at the same time...and it was primarily me saying well, I can't do this anymore'" (p. 32). This caregiver seems to be saying that there was a point that she, as a caregiver, reached where she could not handle caregiving anymore. It could be that the level of impairment of the relative with dementia influenced the decision for placement. However, in light of the findings of this study these caregivers need to be listened to with a new perspective. The caregivers seem to be saying that they reach a point where the movement toward 'lacking control' is not able to be tolerated and the only way they see to turn it around is to seek placement. I contend that it is the caregivers' perception of their caregiving situation and how they perceive that they are managing it rather than the level of impairment of the relative with dementia that would seem to influence placement decisions. This is congruent with Strang's (1995) finding that it was the stage of caregiving as perceived by the caregiver rather than their relative's stage of dementia that determined whether the caregiver sought respite or not.

The factors which may influence movement from 'lacking control' to 'maintaining control' are also rarely identified in the literature. What is evident in the literature is that perceived control and coping can be altered, but again there is no magic formula available to do so. Skinner (1995) referred to perceived control and the possibility for change:

> perceived control is usually considered a flexible set of interrelated beliefs that are organized around interpretations of prior interactions in specific domains. In contrast to personality traits, these belief sets are viewed as constructed by individuals; hence, they are open to new experiences and can be altered. (p. 4)

Wallhagen and Kagan (1993) found that even if caregivers could not change their situation they could change their responses to it. This is similar to the factor which influenced Sue's regaining control by having a cognitive shift toward being more tolerant of the family member with dementia after she realized that she would be unable to change her husband or his condition. The other factor found in this study which is mentioned in the literature is being more tolerant of yourself as a caregiver. Wallhagen and Kagan (1993) found that being patient helped to maintain the perception of control, however, they did not specify whether the patience was with oneself or with the relative with dementia. The final factors that Wallhagen and Kagan (1993) found which influenced the perception of control for caregivers were being organized and having a routine.

The notion of movement in managing caregiving is a finding which does not seem to be present in the literature. This may be due to the specific focus of this study on the day-to-day experience of caregiving. Other research to date on caregivers and control has studied the experience of caregiving in its entirety. For example, Willoughby and Keating (1991) found that when caregivers reflected on the caregiving after institutionalizing their relative that caregiving could be depicted as stages over time. These stages were large chunks of caregiving situations whereas this study looked at caregivers who were in any number of the larger stages and examined what the specific experience was for them, at that point in that stage on a daily basis.

This area related to movement within the explanatory model is a new finding which has important implications for practice and research. The overall findings from this study will add to our understanding of control but it is the findings concerned with caregivers who regain and lose control which can inform our practice in new ways. The impact of this study on practice and research will be discussed further in the next chapter.

Conclusion

This chapter interpreted the findings of the explanatory model of managing caregiving in light of the literature on perceived control and coping. Coping is a "rich and fertile construct about which we know so little in spite of how much it has been studied" (Jaloweic, 1993, p. 70). This study found that control was related to coping, thus serving to further clarify this aspect of coping. The properties of the control dimensions were interpreted as internal resources of individuals; that is, as either psychological resources or coping strategies which enabled caregivers to cope with their caregiving situations. The area of movement within the explanatory model was presented as a new finding in the literature.

CHAPTER VI

IMPLICATIONS

In this chapter I will provide a substantive summary of the study findings. I will then relate the insights gained from the research methods used and conclude with the implications of the findings for nursing practice and future research.

Substantive Summary

The purpose of this study was to explore the experience of control as perceived by family caregivers of relatives with dementia. The intent was to describe and explain, from the viewpoint of family caregivers, what the significance of control was for them in their caregiving situations. Caregiving is a difficult role which is taken on insidiously by family members of relatives with dementia. This role is associated with stress and burden. Despite the difficulties associated with caregiving, some caregivers adapt well to their caregiving situations. Factors which have been related to caregivers' adaptation included the role of social support, coping and personality. Another factor which was found in studies on caregiver adaptation was control (Harris, 1993; Wallhagen & Kagan, 1993; Willoughby & Keating, 1991). Perceived control has also been linked with social support, coping, and personality frameworks. However, there has been confusion as to the specific meaning and role of control in caregiving. There have been limited studies done specifically on control and caregiving (Harris, 1993; Miller, 1987; Wallhagen, 1993; Wallhagen & Kagan, 1993; Willoughby & Keating, 1991; Wuest et al., 1994). Therefore, it was timely to study control and caregiving so that a clearer understanding of the experience of control as perceived by caregivers could be obtained. The intent at the beginning of this study was to remain conceptually open to the direction which the findings may lead. This was congruent with the choice of a qualitative method for this study.

The experience of control was related to how the caregivers managed their caregiving situations. The manner in which caregivers experienced control related to how they managed their caregiving. Thus, the most appropriate literature from which to view the findings was within the coping literature.

I found that all caregivers experienced control in some manner within caregiving. The experience of control was the outcome of the secondary appraisal process as described by Lazarus and Folkman (1984) where the caregivers used secondary appraisal in their daily assessment of their demanding caregiving situations. Secondary appraisal involves the assessment of external resources and internal resources. External resource assessment includes factors such as social support. The findings of this study related to the internal resources of caregivers' secondary appraisal. Caregivers assessed their internal resources by looking at their competence and coping repertoire. Competence can be viewed as the resources related to 'who an individual is'; that is, the *psychological resources* which define them as a particular individual. Coping repertoire can be viewed as the *coping strategies* related to 'what an individual does'. The properties within each dimension of control found in this study related to either the psychological resources or the coping strategies which then enabled the caregivers to cope with their demanding situations.

In this study, the dimensions of control were characterized as being either 'maintaining control' or 'lacking control'. Each dimension of control was determined to have specific properties which defined the boundaries of the dimension. The dimension 'maintaining control' had five properties. Briefly, the properties were: *(1) Confident language*, *(2) Positive internal resources*, *(3) Ability to recognize the need for and to ask for help*, *(4) Anticipating the future*, and *(5) Seeing impending loss of control and acting on it*

Caregivers who maintained control had an active role in the process of sustaining the management of their situations. Their *psychological resources* included their use of language that referred to their management abilities. They were able to give examples of how they had solved problems and used language that was associated with the word 'control'. In addition, another psychological resource they presented was that they spoke positively about themselves as caregivers and their internal resources. They had a determined, decisive outlook. Even if there were times when they did not feel positively about themselves as caregivers, they recognized that it was the circumstances which were influencing their perceptions, it was not due to something within themselves.

The *coping strategies* that caregivers who maintained control presented included their ability to not only able to assess their present situation but to also anticipate the needs and changes that may occur in the future. They identified specific needs that they had and how they might have changed as well as the resources that would satisfy those needs. They were able to call for help when they required it.

In addition, another coping strategy which was evident in caregivers who maintained control was that these caregivers were able to recognize when they were moving toward losing control within their caregiving situations and were then able to act to regain control. They recognized signals that indicated when they needed a break from caregiving and then arranged to have time away. They may not have been able to recognize that they needed a break during their initial time of being a caregiver, but once they were shown that these signs meant that they needed a some space they were then able to recognize those signs in the future and to plan for time away.

Caregivers who were in the dimension 'lacking control' were not seeking to mismanage their caregiving situations, rather, they seemed to just not be able to manage them. Briefly, the properties of the dimension 'lacking control' were: *(1) Negative internal resources*, (2) *Inability to recognize the need for or ask for help*. and *(3) No future anticipation*.

The *psychological resources* for caregivers who lacked control included the finding that when caregivers who lacked control spoke of themselves as caregivers or their internal resources for caregiving it was with negativity. They seemed to not believe that they were able to manage as caregivers. They sometimes did recognize that they had needs which someone could help them to meet, but when they were asked directly about what help could be offered to them, they could not say what or how others may have helped them.

The *coping strategies* which were evident in caregivers who lacked control included the finding that they could not anticipate the future and seemed unwilling or unable to comprehend that the future may mean a change in their caregiving. Although they had difficulty managing their caregiving situations, it was possible to intervene with caregivers so that they could move to regain and maintain control.

A new finding which has not received attention in the literature was that there was movement noted between the two dimensions. Caregivers could move toward lacking control; this movement was identified as 'losing control'. Caregivers could also move toward maintaining control; this movement was identified as 'regaining control'. For caregivers losing control, it was found that elements which has previously been present which helped then to maintain control were not longer present. For caregivers regaining control, it was found that certain factors could assist them in moving to regain control. These factors included: being able to have a break away from caregiving, having a cognitive shift toward being more tolerant of the family member with dementia, being more tolerant of yourself as a caregiver, and knowing that it is important to express your feelings and to find a place to do so. These factors have important implications for nursing practice which will be discussed later in this chapter.

Insights Gained from the Study

An interpretivist orientation, using grounded theory as the methodological approach to the data, was employed to identify, describe, and propose a beginning theory of the process of perceived control and informal, family caregivers. This approach allowed me to study the experience of control within the context of family caregiving in order to begin to address the lack of clarity concerning control in the literature. Using this method, I was confident that the findings would reflect the viewpoint of the caregivers. Because the interviews were analyzed as secondary data, it was not possible for me to 'massage' the direction (and therefore findings) of the interview. It was evident from the interviews that the caregivers were expressing their concerns about caregiving as they saw them, and when I analyzed their words, I knew that the findings would reflect their reality of caregiving. I was allowed to be a facilitator; that is, to be able to look at their experiences and explain what I understood from them. I was fortunate in having excellent sources for validation of these findings. These sources ranged from my supervisor, an expert in community care and caregivers; my committee members who gave thoughtful direction; a thesis seminar of research colleagues who helped me clarify the structure of the findings; and a former caregiver of a relative with dementia who gave me insight in understanding the nature of being a 'caregiver'.

In addition, an insight I gained during this study has had an immediate impact on my practice as a nurse. I was struck in one interview by the way in which several health care professionals tried to influence a caregiver to change the management of her caregiving. The caregiver was able to handle her caregiving situation but it was different than the way that the health care professionals would have done it. By listening to this dialogue of differing ways of managing care, I was challenged to consider the ways in which I manage care for individuals that may be different, but not necessarily better, than the care given to them by a family member.

Limitations of the Study

An insight I gained about a weakness inherent in doing secondary analysis is that I was unable to ask questions that were in my mind during the interview. It was frustrating at times to listen to interviews and say aloud "ask them about this...", "what do they mean by that phrase...", and "how long do they perceive themselves to have been a caregiver...and what does that perception mean in terms of the example they are relating now". I also felt that it would have been advantageous to have had a second or third interview with some of the caregivers so that more background information would have been obtained to explore whether the individuals' experience of control was related only to their caregiving role or to other areas of their lives. In addition, I was unable to go back to the caregivers themselves to clarify ideas and to satisfy a natural curiosity to find out what happened next in the lives of these fascinating individuals. This is a potential limitation related to the rigor of secondary analysis which can be overcome by modifying the procedures for validation (Thorne, 1994).

Implications for Practice

The findings of this study suggest several implications for nursing practice. The explanatory model of experiencing control in managing caregiving may be a useful tool to educate health care professionals involved with family caregivers so that they will have a better understanding of family caregivers of relatives with dementia. Nurses and other health care professionals need to be aware of how caregivers are managing their caregiving situations. The findings of this study show that there are recognizable properties which will help nurses to know whether a caregiver is managing or whether they are moving into an area where they will not be able to cope with the caregiving situation. Nurses need to encourage caregivers to relate their experiences of caregiving and to explore with them about their caregiving management.

For caregivers who are maintaining control, nurses need to support these caregivers' effort in managing their caregiving. Nurses can provide information about dementia and resources available to the caregiver so that caregivers are aware of these resources and have the information necessary to access them at the appropriate time. Nurses can also plan with caregivers for the future management of caregiving including breaks away for the caregiver.

For caregivers who lack control, nurses may be able to recognize that these caregivers need support and possibly assistance from service agencies. Such caregivers may not be able to recognize that they are not managing, but may speak of their situations as being 'difficult' or 'hard'. Nurses need to be attuned to these caregivers as they relate their caregiving experiences for clues that intervention is needed.

In addition, it is important for nurses to be aware that caregivers who lack control do not anticipate the future. In this study, they did not plan for changes in caregiving or see the need for breaks away from their relative to re-energize themselves. Nurses are in a position to recognize that caregivers who lack control may need help to plan ahead. In this way, nurses may facilitate a positive caregiving experience and perhaps prevent a crisis by anticipating future caregiving needs and arranging additional resources to support the caregiver.

Nurses need to actively listen to caregivers with whom they are in contact over a period of time for signs that they are not managing their caregiving situation. Health care professionals may be able to recognize when a caregiver is moving to or within the dimension 'lacking control' and to assist the caregiver to access the necessary resources to continue on with caregiving. Caregivers may need help from nurses to access resources so that they are supported and continue on in their caregiving roles. If necessary, nurses may also facilitate the placement of the relative in a long-term care facility. This is a critical time for caregivers and I agree with Wallhagen and Kagan (1993) that "we need to be ready to help ease caregivers through such transitions, to be available with resources, and to support caregiver decisions in a way that promotes their feeling at peace with themselves rather than feeling guilty" (p. 210).

Nurses can also intervene to assist the caregiver to maintain control by putting into place some of the factors found in this study that influence the movement from 'lacking control' toward 'maintaining control'. These factors included: being able to have a break away from caregiving, having a cognitive shift toward being more tolerant of the family member with dementia, being more tolerant of yourself as a caregiver, and knowing that it is important to express your feelings and to find a place to do so. Some suggestions for nurses to implement these factors include: recognizing when a caregiver needs a break and teaching them the signs which indicate that time away is needed; assisting caregiver in having a break away by providing information on respite services; and encouraging caregivers to talk openly about their caregiving experiences.

Finally, nurses need to evaluate the effects of their actions on caregivers. All too often, caregivers are offered services which the nurse feels are 'essential' but which in reality the caregiver sees as 'detrimental'. It is important to be reminded that the way which family members manage the care of their relative may be different than the 'professional' way, but it is certainly not 'wrong'. Nurses need to work with caregivers to find the best possible solutions to their caregiving management problems and to evaluate the effects of these solutions in an open, consultative manner.

Implications for Future Research

Several aspects of the findings of this study merit further research. It is important for more studies to be done within the context of caregiving so that it will become clearer what the experience of control is like for family caregivers of relatives with other conditions. Most research on control has been done in an experimental setting which contributes "little information about (1) how individuals experience personal control, (2) how patients deal with personal control in natural settings, or (3) how patients use personal control and under what conditions during long-term uncontrollable or life-threatening situations" (Lewis, et al., 1986, pp. 27-8). Control is not only dynamic but it is also context-bound (Wallhagen & Kagan, 1993). In addition, control, as it relates to coping must be studied in a particular context because "different experiences may elicit different coping efforts" (Browne, Byrne, Roberts, & Sword, 1994, p. 91). It is important to continue the study of control in a natural setting with family caregivers of relatives with dementia.

An important area for further research is to examine how caregivers ask or do not ask for help. The caregivers in this study who were lacking control had difficulty asking for help. Warren et al. (1996) also found that caregivers have difficulty asking for help. This area merits further study to determine why caregivers have difficulty asking for help, what types of caregivers have difficulty asking for help, and how health care professionals can assist caregivers to seek help when it is needed. Social support is also another area connected to caregivers asking for help that is relevant for future studies.

Research into the role of personality and caregivers is warranted because the nature of the findings of this study indicate that it is characteristics within the caregiver that are important in their caregiving management. The link between the dynamic characteristics related to control, coping, and personality needs more scrutiny.

It is also important to plan for research which follows caregivers longitudinally throughout the course of their caregiving in order to gain a better understanding of how caregivers manage over time. In this way, the 'back and forth' movement of caregivers who function well for a time, lose control, regain control, and perhaps end up lacking control and institutionalizing their relative could be clarified. The nature of the movement from 'maintaining control' towards 'lacking control' could be confirmed; that is, the point where caregivers who are losing control actually become those who lack control would be better understood. In addition, more light might be shed on the timing for this movement, to determine if this movement is linked to a particular stage of caregiving. It would also be useful to develop ways of assessing the management abilities of caregivers over time so that nurses would be able to intervene more effectively and in a timely manner when situations arise which have an adverse effect on the caregivers' ability to control and thus manage their caregiving situations.

Conclusion

There has been much research on the concept of control and many attempts to develop theories about the perception of control. These theories "have in common that they try to explain how control experiences contribute to the construction of beliefs, and how these beliefs in turn promote or undermine effective interactions. The theories differ in the specific part of that process on which they focus" (Skinner, 1995, p. 20). The emerging theory of the experience of control in managing caregiving described in this study provides an explanatory model as a starting point for further research and the model also provides direction for nursing practice.

On a personal level, the research process stimulated my thinking in ways that I had not thought possible. It was exciting to gain understanding of an experience, moving from the words of individuals to greater levels of abstraction. It was also fascinating to create a model that helps to explain a complex idea such as perceived control and a valuable experience to explain the model to others, in written and oral forms.

Finally, I was challenged to work with family caregivers in a new way that includes more open communication and fewer assumptions about what I think they need or where they are at in their caregiving. This work has also started a rethinking of who I am as a professional caregiver and the ways that I perceive that I manage caregiving situations.

REFERENCES

Abel, E., & Sherman, J. J. (1991). Use of national data sets to teach graduate students research skills. Western Journal of Nursing Research, 13(6), 794-797.

Anthony-Bergstone, C. R., Zarit, S. H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. Psychology and Aging, 3(3), 245-248.

Antonovsky, A. (1987). Unraveling the mystery of health. How people manage stress and stay well. San Francisco: Jossey-Bass Publishers.

Antonovsky, A. (1992). Janforum: Locus of control theory. Journal of Advanced Nursing, 17, 1014-1015.

Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. Research in Nursing and Health, 13, 375-384.

Averill, J. R. (1973). Personal control over aversive stimuli and its relationship to stress. Psychological Bulletin, 80(4), 286-303.

Baker, C., Wuest, J., & Stern, P. N. (1992). Method slurring: The grounded theory/phenomenology example. Journal of Advanced Nursing, 17, 1355-1360.

Barusch, A. S. (1988). Problems and coping strategies of elderly spouse caregivers. The Gerontologist, 28(5), 677-685.

Baumgarten, M. (1989). The health of persons giving care to the demented elderly: a critical review of the literature. Journal of Clinical Epidemiology, 42(12), 1137-1148.

Baumgarten, M., Battista, R. N., Infante-Rivard, C., Hanley, J. A., Becker, R., & Gauthier, S. (1992). The psychological and physical health of family members caring for an elderly person with dementia. Journal of Clinical Epidemiology, 45, 61-70.

Bergmark, A., & Oscarsson, L. (1987). The concept of control and alcoholism. British Journal of Addiction, 82, 1203-1212.

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

Browne, G. B., Byrne, C., Roberts, J., & Sword, W. (1994). Methodological challenges in coping and adaptation research. Canadian Journal of Nursing Research, 26(3), 89-96.

Bullers, S. (1994). Women's roles and health: The mediating effect of perceived control. Women and Health, 22(2), 11-30.

Burstein, L. (1978). Secondary analysis: An important resource for educational research and evaluation. Educational Researcher, 7(5), 9-12.

Canadian Study of Health and Aging. (1994). Patterns of caring for people with dementia in Canada. Canadian Journal on Aging, 13(4),470-487.

Cohen, D., & Eisdorfer, C. (1988). Depression in family members caring for a relative with Alzheimer's Disease. Journal of the American Geriatrics Society, 36, 885-889.

Collins, C. E., Given, B. A., & Given, C. W. (1994). Interventions with family caregivers of persons with Alzheimer's Disease. Nursing Clinics of North America, 29(1), 195-207.

Diamond, M., & Jones, S. L. (1983). Chronic illness across the life span. Norwalk, CT: Appleton-Century Crofts.

Estabrooks, C. A., Field, P. A., & Morse, J. M. (1994). Aggregating qualitative findings: An approach to theory development. Qualitative Health Research, 4(4), 503-511.

Estabrooks, C. A., & Romyn, D. M. (1995). Data sharing in nursing research: Advantages and challenges. Canadian Journal of Nursing Research, 27(1), 77-88.

Fitting, M., Rabins, P., Lucas, M. J., & Eastham, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. The Gerontologist, 26(3), 248-252.

Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. Journal of Personality and Social Psychology, 46(4), 839-852.

George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26(3), 253-259.

Given, C. W., Collins, C. E., & Given, B. A. (1988). Sources of stress among families caring for relatives with Alzheimer s Disease. Nursing Clinics of North America, 23(1), 69-82.

Glaser, B. G. (1963). Retreading research materials: The use of secondary analysis by the independent researcher. The American Behavioral Scientist, 6(10), 11-14.

Glaser, B. G. (1978). Theoretical sensitivity: Advances in the methodology of grounded theory. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1992). Basics of grounded theory analysis. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine.

Glass, G. V. (1976). Primary, secondary and meta-analysis of research. Educational Researcher, 5(11), 3-8.

Gleit, C., & Graham, B. (1989). Secondary data analysis: A valuable resource. Nursing Research, 38(6), 380-381.

Guba, E.G., & Lincoln, Y. S. (1981). Effective evaluation. Improving the usefulness of evaluation results through responsive and naturalistic approaches. San Francisco: Jossey-Bass.

Harris, P. B. (1993). The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer s Disease victims. The Gerontologist, 33(4), 551-556.

Herron, D. G. (1989). Secondary data analysis: Research method for the clinical nurse specialist. Clinical Nurse Specialist, 3(2), 66-69.

Hershberger, W. A. (1990). Control theory and learning theory. American Behavioral Scientist, 34(1), 55-66.

Hickson, J., Housley, W. F., & Boyle, C. (1988). The relationship of locus of control, age, and sex to life satisfaction and death anxiety in older persons. International Journal of Aging and Human Development, 26(3), 191-199.

Holstein, J. A., & Gubrium, J. F. (1995). The active interview. Thousand Oaks, CA: Sage Publications.

Jacobson, A. F., Hamilton, P., & Galloway, J. (1993). Obtaining and evaluating data sets for secondary analysis in nursing research. Western Journal of Nursing Research, 15(4), 483-494.

Jalowiec, A. (1993). Coping with illness: Synthesis and critique of the nursing coping literature from 1980-1990. In J. S. Barnfather & B. L. Lyon (Eds.), Stress and coping: State of the science and implications for nursing theory, research and practice, (pp. 65-83). Indianapolis: Sigma Theta Tau.

Jones, P. S., & Martinson, I. M. (1992). The experience of bereavement in caregivers of family members with Alzheimer's Disease. Image: Journal of Nursing Scholarship, 24(3), 172-176.

Koop, P. M. (1994). Stress, appraisal and coping with cancer. Unpublished PhD Dissertation, University of Alberta, Edmonton, AB.

Krause, N., & Stryker, S. (1984). Stress and well-being: The buffering role of locus of control beliefs. Social Science and Medicine, 18(9), 783-790.

Kuhlman, G. J., Wilson, H. S., Hutchinson, S. A., & Wallhagen, M. (1991). Alzheimer's Disease and family caregiving: Critical synthesis of the literature and research agenda. Nursing Research, 40(6), 331-337.

Kvale, S. (1984). The qualitative research interview: A phenomenological and a hermeneutical mode of understanding. Journal of Phenomenological Psychology, 14(2), 171-196.

Langer, E. J. (1975). The illusion of control. Journal of Personality and Social Psychology, 32(2), 311-328.

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

Lefcourt, H. M. (1976). Locus of control: Current trends in theory and research. Hillsdale, New Jersey: Lawrence Erlbaum Associates Publishers.

Lewis, F. M., Haberman, M. R., & Wallhagen, M. I. (1986). How adults with late-stage cancer experience personal control. Journal of Psychosocial Oncology, 4(4), 27-42.

Lobo, M. L. (1986). Secondary analysis as a strategy for nursing research. In P. L. Chinn (Ed.), Nursing research methodology. Issues and implementation, (pp. 295-304). Rockville: Aspen Publishers, Inc.

Lyon, B. L. (1993). Summary and preliminary synthesis. In J. S. Barnfather & B. L. Lyon (Eds.), Stress and coping: State of the science and implications for nursing theory, research and practice, (pp. 185-192). Indianapolis: Sigma Theta Tau.

Maas, M. L., & Buckwalter, K. C. (1991). Alzheimers Disease. In Fitzpatrick, J. J., Taunton, R. L., Jacox, A. K. (Eds.), Annual review of nursing research, 9, (pp. 19-56). New York: Springer.

Mace, N. L. & Rabins, P.V. (1981). The 36-hour day. Baltimore: Johns Hopkins University Press.

Marshall, V. (1987). Aging in Canada: Social perspectives. Ontario: Fitzhenrey and Whiteside.

McArt, E. W., & McDougal, L. W. (1985). Secondary data analyses: A new approach to nursing research. Image: Journal of Nursing Scholarship, 17(2), 54-57.

Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: A sourcebook of new methods. (2nd ed.). Thousand Oaks, CA: Sage.

Miller, B. (1987). Gender and control among spouses of the cognitively impaired: A research note. The Gerontologist, 27(4), 447-453.

Miller, J. D. (1982). Secondary analysis and science education research. Journal of Research in Science Teaching, 19(9), 719-725.

Miller, S. M. (1979). Controllability and human stress: Method, evidence, and theory. Behavior Research and Therapy, 17, 287-304.

Miller, S. M. (1980). Why having control reduces stress: If I can stop the roller coaster I dont want to get off. In J. Garber & M. E. P. Seligman (Eds.), Human helplessness: Theory and application, (pp. 71-95). New York: Academic Press.

Montbriand, M. J., & Laing, G. P. (1991). Alternative health care as a control strategy. Journal of Advanced Nursing, 16, 325-332.

Moos, R. H., & Tsu, V. D. (1977). The crisis of physical illness: An overview. In R. H. Moos (Ed.), Coping with physical illness, (pp. 3-21). New York, NY: Plenum Medical Book Company.

Morris, L. W., Morris, R. G., & Britton, P. G. (1989). Cognitive style and perceived control in spouse caregivers of dementia sufferers. British Journal of Medical Psychology, 62, 173-179.

Morse, J. M., & Field, P. A. (1995). Qualitative research methods for health professions. (2nd ed.). Thousand Oaks, CA: Sage.

Motenko, A. (1989). The frustrations, gratifications, and well-being of dementia caregivers. The Gerontologist, 29, 166-172.

Murrell, S., & Norris, F. (1983). Resources, life events, and changes in psychological states: A prospective framework. American Journal of Community Psychology, 11, 473-491.

National Advisory Council on Aging (1994). The social contract and seniors: Preparing for the 21st century. Ottawa: Minister of Supply and Services Canada.

National Advisory Council on Aging (1995). The NACA position on community services in health care for seniors: Progress and challenges. Ottawa: Minister of Supply and Services Canada.

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

Oberle, K. (1991). A decade of research in locus of control: What have we learned? Journal of Advanced Nursing, 16, 800-806.

Pagel, M. D., Becker, J., & Coppel, D. B. (1985). Loss of control, self-blame, and depression: An investigation of spouse caregivers of Alzheimer's Disease patients. Journal of Abnormal Psychology, 94(2), 169-182.

Parks, S. H., & Pilisuk, M. (1991). Caregiver burden: Gender and the psychological costs of caregiving. American Journal of Orthopsychiatry, 61(4), 501-509.

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

Reed, J. (1992). Secondary data in nursing research. Journal of Advanced Nursing, 17(7), 877-883.

Richards, T. J., & Richards, L. (1994). Using computers in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research (pp. 445-462). Thousand Oaks, CA: Sage.

Ritchie, J. A. (1994). Coping with what, when, where, how-and so what? Canadian Journal of Nursing Research, 26(3), 7-10.

Rodgers, B. L., & Cowles, K. V. (1993). The qualitative research audit trail: A complex collection of documentation. *Research in Nursing and Health, 16,* 219-226.

Rothbaum, F., Weisz, J. R., & Snyder, S. S. (1982). Changing the world and changing the self: A two-process model of perceived control. *Journal of Personality and Social Psychology, 42*(1), 5-37.

Rotter, J. B. (1966). Generalized expectancies for internal and external control of reinforcement. *Psychological Monographs, 80*(1), 1-28.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Sandelowski, M., Davis, D.H., & Harris, B.G. (1989). Artful design: Writing the proposal for research in the naturalist paradigm. *Research in Nursing and Health, 12,* 77-84.

Schorr, D., & Rodin, J. (1982). The role of perceived control in practitioner-patient relationships. In T. A. Wills (Ed.), *Basic processes in helping relationships,* (pp. 155-186). New York: Academic Press.

Skinner, E. A. (1995). *Perceived control, motivation & coping*. Thousand Oaks, CA: Sage Publications.

Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. . *Image: Journal of Nursing Scholarship, XII*(1), 20-23.

Stewart, M. J. (1995). Social support, coping, and self-care. In M. J. Stewart (Ed.), *Community nursing. Promoting Canadians' health,* (pp. 89-124). Toronto: W. B. Saunders.

Strang, V. R. (1995). *The experience of respite for caregivers of dementia persons*. Unpublished PhD Dissertation, University of Alberta, Edmonton, AB.

Syme, S. L. (1991). Control and health: A personal perspective. *Advances, The Journal of Mind-Body Health, 7*(2), 16-27.

Taft, L. B. (1993). Computer-assisted qualitative analysis. *Research in Nursing and Health, 16,* 379-383.

Taylor, S. E. (1983). Adjustment to threatening events. A theory of cognitive adaptation. *American Psychologist,* (November), 1161-1173.

Thompson, S. C. (1981). Will it hurt less if I can control it? A complex answer to a simple question. Psychological Bulletin, 90(1), 84-101.

Thorne, S. (1994). Secondary analysis in qualitative research: Issues and implications. In J. M. Morse (Ed.), Critical issues in qualitative research methods, (pp. 263-279). Thousand Oaks: Sage Publications.

Vitaliano, P. P., Russo, J., Young, H. M., Teri, L., & Maiuro, R. D. (1991). Predictors of burden in spouse caregivers of individuals with Alzheimer's Disease. Psychology and Aging, 6, (3), 392-402.

Wallhagen, M. I. (1988). Perceived control and adaptation in elderly caregivers. Unpublished PhD Dissertation, University of Washington, Seattle, WA.

Wallhagen, M. I. (1993). Perceived control and adaptation in elder caregivers: Development of an explanatory model. International Journal of Aging and Human Development, 36(3), 219-237.

Wallhagen, M. I., Kagan, S. H. (1993). Staying within bounds: Perceived control and the experience of elderly caregivers. Journal of Aging Studies, 7(2), 197-213.

Warren, S., Keating, N., Janzen, W., & Wertenberger, D. (1996). Caring for a Relative with Alzheimer Disease: How Extended Family Members Help the Primary Caregiver . Edmonton: University of Alberta.

Weber, S. J. (1986). The Nature of Interviewing. Phenomenology & Pedagogy, 4(2), 65-72.

Willoughby, J., & Keating, N. (1991). Being in control: The process of caring for a relative with Alzheimer's Disease. Qualitative Health Research, 1(1), 27-50.

Wuest, J., Ericson, P. K., & Stern, P. N. (1994). Becoming strangers: the changing family caregiving relationship in Alzheimer's Disease. Journal of Advanced Nursing, 20, 437-443.

Zarit, S. H. (1989). Do we need another "Stress and caregiving" study? The Gerontologist, 29(2), 147-148.

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist, 26(3), 260-266.

Zarit, S. L., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20(6), 649-655.

APPENDIX A

Consent Form: Primary Study

(Strang, 1995, p. 202-203)

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:_______________________________

APPENDIX B

Interview Guide: Primary Study

(Strang, 1995, p. 199-200)

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: Primary Study

(Strang, 1995, p. 204-205)

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

APPENDIX D

Ethical Approval of Secondary Study

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): Vivian Szabo, MN Candidate

TITLE OF PROJECT: "The Family Caregivers' Perception of Control in Their Experience of Caring for Dementia Persons"

The members of the review committee, having examined the application for the above named project, consider the procedures, as outlined by the applicants, to be acceptable on ethical grounds for research involving human subjects.

June 3 1996
Date

Lander
Janice Lander, PhD
Chair, Ethics Review Committee

ERC 96-089
5005-02-089

APPENDIX E

CAREGIVER VIGNETTES

Key Informants

Fran

Fran is the eldest daughter in a family of five children and she is the primary caregiver for her mother Grace. Grace had been deteriorating mentally for quite some time before the family realized that something had changed. Grace's husband cared for her and covered up much of the change but when he died suddenly and Grace came to live with Fran they realized that Grace was not the mother that they had known previously. Fran became the primary caregiver despite another suggestion from her siblings because she felt she was the one who was able to manage the caregiving. She describes herself as choosing to control the caregiving because she felt that it had to be done and that the other suggestion (e.g., for Grace to live with the widow of one of the brothers) was not appropriate.

Fran spends some time in the interview explaining the family dynamics and this was valuable information in understanding her experience of being and becoming a caregiver. It is obvious that Fran has thought a lot about her new role as a caregiver and is able to articulate her feelings and experiences throughout the interview.

Fran is able to use the resources around her to arrange for a break if needed and sees the value in being able to ask for more help if needed. Grace does visit her other children but this is not a regular occurrence and Fran believes it is because they do not understand how to be with Grace when she is with them. Fran is quite clear that she is willing to explain how she manages her mother's care if the other siblings wanted to know the details but the friction between the siblings seems to prevent an open flow of ideas and communication.

Gina

Gina is the primary caregiver for her mother Hilary. Within the first few minutes of the interview Gina explains that she has been suffering from depression due to a divorce and is now in the process of placing her mother in a long-term care facility. Hilary is still able to feed and clothe herself and to be left alone for part of the day. Hilary also attends an Adult Day Program every weekday.

Gina believes that she is not able to care for her mother because she and her mother are very different people. Gina doesn't like to cook and prefers to stay at home with a book whereas she sees her mother as someone who likes to socialize and cook. Gina feels that she must cook for her mother and serve something different to her every day. Gina feels that it will be in her mother's best interests to be placed rather than have extra help around the home.

The overarching feeling in this interview is that Gina is tired and stressed and not able to carry on with her mother at home. The mere presence of her mother makes her feel uneasy. Gina is unable to distinguish in any situation whether Hilary is unable to do a certain task or whether she simply doesn't want to do it. Gina is frustrated by this and can't understand the impact of the dementia on her mother. Gina is wrapped up in the feelings and stress of the situation.

The whole tone of the interview changes when Gina relates to the interviewer about her time away from her mother. She speaks happily about being able to do whatever she wants. Her tone changes immediately when she speaks about coming back to be with her mother and she articulates clearly that her stress is very much related to her mother's presence and the fact that she is not able to know what might happen. It is enough for Gina to control her own fragile existence without having the added responsibility of caring for Hilary.

Gina was determined to find a long-term placement for her mother and explains this process in detail. Her tone and manner in explaining how she finally received word of her impending placement are determined and it sounds as though this is something that is a desperate need for her. Even when she is told that her mom's symptoms of dementia are not that severe and that she could perhaps manage with help from home care Gina relates that it is her ultimate goal to have her mom placed even if she has to use 'connections' to make it happen. When Gina received word that Hilary is to be placed in the near future there is obvious relief in her voice. Gina's final thoughts on caregiving are that it will make you sick before your time and that it puts a person under unnecessary stress.

Helen

Helen is the primary caregiver for her mother Julie. Helen used to have a full-time caregiver living with them to care for Julie but when Helen was laid off she became the primary caregiver. The person who used to be the full-time caregiver still lives with them and she helps out with the laundry. Helen is an articulate woman who used to have an interesting and responsible job. She finds the change to being a caregiver difficult but finds ways to mange to still have a life by having breaks away from Julie. Helen did have children from a previous marriage but they have since died and her second husband's children are not connected strongly to Helen as she and her second husband have only been married for two years.

Helen is able to manage caring for Julie without difficulty because she is aware of the resources around her and has no difficulty asking for help. She also relates how she learned that she needed to have time away from her caregiving responsibilities. Helen is able to describe in detail how she felt during the time preceding her first break away from caring for Julie as well as how the break away felt and the changes that occurred upon her returning. Her description of slowly losing control followed by the suggestion from Home Care to have a break away is useful in understanding how she later learned to recognize when she was coming to a point of needing a break away from Julie. These times away are also valuable for Helen to spend time with her husband; she related that this is something that she values and has felt that they have not had enough time together.

Kelly

Kelly is the primary caregiver for her husband, Martin who now has Alzheimer disease. Kelly describes herself as someone who was always in control but now recognizes the impact of caregiving on her ability to continue giving full-time care and she believes that she will not be able to care for Martin at home forever.

Kelly and Martin have four children who are very supportive and Kelly is able to phone them for help whenever she needs to have some time alone or is unable to manage a specific situation and needs a third person to help manage Martin's confusion. Kelly has a difficult time being away however, as she always feels that she is still responsible and managing the caregiving even though she is not physically there.

Kelly is methodical in her management of Martin's care and uses the resources around her to meet her needs within the caregiving situation. She plans and organizes all of the aspects of caregiving and if she is not able to handle something she arranges help to have it done. She has difficulty only when she takes his comments personally; if she can keep these in perspective then she has no difficulty in managing to continue to care for him.

Matt

Matt is the primary caregiver for his wife Nancy, who suffers from dementia. Nancy is Matt's second wife and it is Nancy's third marriage. They both have children from their previous marriages but Nancy's children are both mentally handicapped and do not know about their mother's illness. Matt's children are supportive but do not live in the same vicinity as Matt and Nancy.

Matt is very close to Nancy and prefers to have her with him at all times but he does send her to an Adult Day Program because she enjoys socializing there and comes home happy at the end of the day. Matt talks about receiving more help and placing Nancy eventually but believes that, for now, the best place for her to be is with him at home. There was some reference made to Matt's first wife dying of cancer but it was unclear if he cared for her at home.

During the first interview it is obvious that Matt is managing to care for his wife without too much difficulty. He is able to take changes in stride and find the necessary resources to manage the changes. He is able to ask for help when it is needed.

During the second interview it is obvious that Nancy's condition has deteriorated significantly. Matt has started to use a respite bed to have breaks away even though at first it was very difficult emotionally for him to be away from her. He makes references to his not being able to manage her care as well as before and says that he has had to become immune to the situation. He now uses others to manage changes in her behaviour. Instead of his previous confidence and frank statements about being able to handle his wife's care he now makes references to things building up and having to cope with a lot.

Even though Nancy's stage of dementia is an early one, Matt is finding that the times when she is confused and restless for two hours are difficult. He is now unsure of his caregiving and says that he is having a rough time. Although no specific questions were asked about placement Matt does say that the time when she is placed will be a difficult one for him. He seems torn by his love and commitment to her and his increasing difficulty in managing her care.

Olivia

Olivia is the primary caregiver for her husband, Patrick, who has multi-infarct dementia. Olivia describes herself as a new caregiver and is having a difficult time managing Patrick's care. Patrick is still able drive to play a game of golf and to do daily activities such as dressing and bathing.

Olivia says that her friends and family have been supportive and caring. She and Patrick recently went on a cruise with their son and since that time their son has been in contact regularly with Olivia. She finds these contacts helpful. She has difficulty asking for help and believes that this is because she just doesn't like asking and does not know how others may be of help to her. She wonders if she will ask for help when she is at the point where she cannot manage at all and wonders if she has these beliefs because she is a woman.

Olivia is continually looking for someone to guide her and to let her know what she should be doing to care for Patrick in the best way possible. She is unsure of herself and frequently wonders aloud what she should do in any given situation. She wants to know the future to be forewarned about what things can happen but also hopes that he will stay at his present level of functioning for a long time.

Sue

Sue is the primary caregiver for her second husband, Terry, who has multi-infarct dementia. Sue's first husband died when she was young, leaving her with a six-year old and pregnant. When she delivered, the baby was handicapped and she believes that this experience brought on a pattern of behaviour that is influencing her present caregiving situation. She finds it difficult asking for help and also has trouble dealing with her emotions related to being a caregiver. Because of this, she has sought the help of a psychologist and during the first interview she had made an appointment to begin counselling.

Sue does have some help from home care but finds that it is not enough help. Her son is helpful but all of the children from both Sue and Terry do not live close to them.

Sue tries to have Terry understand his memory loss and tries to teach him to remember details about his day. Terry is unsuccessful in any attempts at improving or understanding his memory loss and becomes difficult or aggressive if criticized.

Sue finds it difficult to change any aspects of the caregiving situation. Terry has wandered away many times, frequently for months on end but she is reluctant to take away his car keys or have special locks or alarms installed in their home. She frequently mentions the stress that she feels and the overwhelming emotions associated with caring for Terry.

During the second interview Sue relates how the counselling sessions have been helping her to have perspective about caring for Terry. She has learned that she needs to have a break away from caregiving even though she never realized this need before. She has also learned that she can still care for her husband but that she must accept his level of functioning and work within that level. She articulates the changes in her caregiving since talking with the psychologist and relates how she reacts to situations differently since counselling. She admits that she is still learning and has plans to continue with the counselling because she sees that it fulfills a need that family cannot fill for her.

Ursula

Ursula is the primary caregiver for her husband Warren who has Alzheimer

Disease. Ursula is a former nurse who is retired and has many health problems. She was frequently and audibly short of breath during the interview.

Ursula has a supportive and helpful daughter that she is able to call upon if extra help is needed. Warren goes to an Adult Day Program during the week and Home Care also comes in to help with laundry.

Ursula is very much aware of her limitations and is able to manage Warren's care by having a routine and anticipating the help that will be needed in the future. She is able to recognize the point at which more help would be needed and is able to ask for help without difficulty.

Ursula recognizes when she needs a break away from caring for Warren and appreciates the time that she has for herself while he is at the Adult Day Program. She is able to assess her present situation and know that for now she is able to manage his care at home but has also made arrangements for nursing home placement if it is needed in the future.

APPENDIX F

CAREGIVER VIGNETTES

Secondary Informants

Betty

Betty is the primary caregiver for her husband Charles. Her deep love and commitment to caring for Charles are evident throughout the interview. Their past relationship has been close, full of travelling and they also have children that they are close to. Betty has recently turned down an opportunity to place her husband in an institution, preferring to keep him at home with her. She manages her husband's care with help with bathing and she did try sending her husband to an Adult Day Program but withdrew him from it when she saw that he just sat all alone and never interacted with anyone.

When Betty frequently refers to qualities within herself that help her to manage her caregiving situation. She relates experiences to show that it is her influence which leads to positive outcomes in caring for Charles. She is also quick to state how she helped others to care for Charles (e.g., when he was in the hospital). It is interesting to note that her perception of how others see her and what others say about her is always positive; that is, she sees others as always commenting on her exceptional ability as a caregiver.

Betty is in full control of managing care for Charles but she does allow herself a break away and when she speaks of these breaks her tone changes and brightens. This same tone is in her voice when she speaks about her daughter asking for more home care hours for another break in the future.

Betty fits meeting her needs into the routine of caring for Charles and she is willing to have her children help out but does not expect them to help her. Her life philosophy seems to be that she has always maintained control and she and Charles have managed without help and that others should do the same.

Carol

Carol is the primary caregiver for her second husband Darcy. They both have children from previous marriages who have contact with them but are not involved in caring for Darcy. Although Carol is an only child, Darcy comes from a family of ten children and Carol is close to all of the sisters-in-law and finds them to be a valuable support.

Carol has a difficult time coping with the changes that have come since the onset of the dementia. Her former responses do not work and because she is unable to control the situation she tries to change her attitude about it instead. She is willing to accept ideas and suggestions on how to care for Darcy from others but is unable to think about how to manage the details of his care beyond a very basic level. She is unable to think about the future and what it might bring.

In speaking of his care and her concerns to others she believes that they do not want to know about her situation and if they do listen to her that they question the truth of what she tells them. She finds it difficult to manage his care, feeling that she doesn't get anything done. She complains of being tired and speaks of being stressed. She wants to go away or out to have some time for herself and hopes that she will be able to do this but is unable to make the arrangements to ensure that it will happen.

Carol doesn't seek out support but if it is offered to her then she readily accepts. She concludes the interview by saying that she is able to talk to her daughter about caring for Darcy only because she doesn't keep her on the phone too long and she doesn't talk so much as to burden her with the problems she has caring for Darcy.

Eve

Eve cares for her husband Frank at home after taking him out of a nursing home because she didn't like the care he was receiving there. She still uses a respite bed if she needs to go away for a break and Frank attends an Adult Day Program one day a week so that Eve can do errands.

A good portion of the first interview was spent in Eve explaining the details of the recent death of her son-in-law who used to help her out and which has obviously had a big impact on the family. Eve relates how she believes that it is the young ones who are dying while the old ones keep living. This idea was not explored further even though it would have been interesting to see if that belief related to her thoughts on caring for Frank. It would also have been interesting to know how Frank felt or if he realized that his son had died.

Eve describes herself as a patient woman and believes that being patient helps her in caring for Frank. She does lose her temper with Frank at times but thinks that it is natural to do this. I wonder if she gets her identity from being a caregiver because there were many times in the interview where she seemed connected strongly to caring for Frank not for his sake, but for her own.

Jane

Jane is the primary caregiver for her husband Larry, who suffers from Alzheimer disease. Jane and Larry moved to Canada from Europe and have recently moved from a home to an apartment closer to their children to have extra help to care for him. Their daughter-in-law is a nurse who is supportive and helpful but it is clear throughout the interview that it is Jane who manages all aspects of her husband's care.

Larry does attend an Adult Day Program and Home Care will soon be coming in to help Jane at home. Jane goes along with whatever Larry says as her way of managing his confusion so that she does not upset him. This way of managing has worked for her in many situations and if is doesn't work then she devises another method of accomplishing what she need to get done.

The love that Larry and Jane share is evident throughout the interview. They also have close relationships with their two children and Jane is willing to share the management of Larry's care with them, especially if there is a decision to be made that she thinks that they will be able to have input that will help in making the decision.

Patty

Patty is the primary caregiver for her dad Randy, who has Alzheimer disease. Patty has cared for Randy in her home for quite a long time and has only recently used the respite program. Randy attends an Adult Day Program and Patty finds the time that he is away helpful for her to complete her errands and have some time to herself.

Patty does have a sister who has offered to help with Randy's care but Patty does not believe that her offer is a sincere one and so has never acted upon it. Patty finds it difficult to have to share her home with Randy and feels that there have been changes in family relationship because of his presence. Despite this feeling, Patty is grateful that Randy is alive because he is one of her few remaining relatives. Her concluding thought is that it is not necessarily the best idea to care for an aging parent in one's home.

Pauline

Pauline is the primary caregiver for her uncle Sandy who has senile dementia. Pauline has many health problems and took on Sandy's care after her mother died because there was no other family member available to care for him. She tried to place him in a senior's apartment but relented and kept him with her when he cried at the suggestion of leaving her home. Sandy is still able to go out on his own even though Pauline says that he does become lost at times but has thus far always been able to find his way home.

Pauline believes that any help for either of them would be beneficial, especially as she is scheduled to have surgery soon. She prefers to manage any extra help that is needed by using family resources because she has had a bad experience using home care. She also relates all caregiving questions not to herself as the primary caregiver, but with reference to the family. She sees the 'family' as being responsible for Sandy's care rather than his care being solely her responsibility.

Ron

Ron was recently the primary caregiver for his wife Tina, who has dementia. Tina was recently admitted to a long-term care facility because it was not possible for Ron to continue caring for her at home. Ron relates how Tina would follow him around and he was unable to do anything without her being a few inches away from him. He was unable to speak on the phone without her becoming very angry at him and interrupting the conversation so that he could be with her again. Although Ron finds that he is lonely now he realizes that he was not able to care for Tina any longer at home.

Now that Tina has been placed Ron is able to manage the outbursts which occur every time he leaves her after a visit. She will come to the door of the facility with him and then start swearing and become aggressive. Ron brings a nurse along with him when he leaves and when he relates these experiences during the interview he says that he is able to place this behaviour in perspective because he knows that it is happening to other people as well.

APPENDIX G

CAREGIVER VIGNETTES

Minor Informants

Anna

Anna is the primary caregiver to her mother, Barbara, who has dementia. Barbara has ten children and most of them live in the same geographical area as Anna. Anna has been the primary caregiver for Barbara since she was diagnosed with dementia, with the exception of a brief period of time while she was attending school. Anna has two of her own children, one who is 7 and one who is 18. Her older son does help out with Barbara's care and was present during the interview to act as a translator due to a language barrier. Anna's husband is mentioned but does not take a direct role in the caregiving. There are plans to move to a bigger house because Barbara moved into the room that was the youngest son's and more room is needed for the family to function because of caring for Barbara in their home.

In the interview, Anna relates that much of her motivation for caregiving comes from her cultural belief system. It is this cultural obligation to care for elderly parents that influences every aspect of caregiving. Anna does not feel that she can tell her mother what to do or to change her behaviour, even if it is disruptive. She feels that she must care for her mother by providing for her physical needs but out of respect for and mixed in with the cultural obligation to her she does not feel that she can even try to change her behaviour.

Anna works two jobs and has a schedule that is demanding and exhausting.

She does have some help from Home Care and is also on Self-Managed Care but is reluctant to ask for more help to care for Barbara. When asked about what would lead her to ask for more help she replied that she would need help only if her mother was sicker or is she (Anna) was not able to get her rest. The need to have adequate rest is repeated often in this interview as something that is important to Anna, but she never feels that she has enough time to feel completely rested.

Barbara has a strong role in the family and the other siblings feel that they have an obligation to visit her often. When the siblings are visiting, Anna feels obligated to serve them food or tea. The motivation for this is also related to culture. Barbara will never tell the other children not to come or to leave once they are there. Anna understands this to mean that Barbara does not care for her or her feelings.

Anna believes that because their mother raised them and invested her time into their lives that they must respect her for that and care for her now that she is elderly. Even with the help of home care they feel they must physically be at home with her as a part of this cultural obligation to care for one's parents.

The concept of cultural obligation was not fully explored in this interview and there were definite language difficulties and barriers. However, it is clear that Anna is determined to care for her mother because her mother has raised and cared for her and has given her everything and now she must do the same for her.

David

David is not the usual caregiver for his mother, Evelyn. The usual caregivers are his brother and sister-in-law. At the time of the interview they were away on holidays and David was the primary caregiver for this period of time. David usually cares for Evelyn two days a week and various odd times to cover the times that home care is not able to fill in until his brother and sister-in-law return home.

This interview was shorter than most of the others due to the fact that David was not the usual caregiver and because of this was less articulate about the experience of caring for Evelyn. However, the interview is a good example of collaborative control with the care shared and managed well between siblings. David related that they are able to solve problems together and feels that if there were only one of them to care for Evelyn then it would be very difficult to manage the situation.

Iris

Iris is the primary caregiver for her mother Krista. Krista uses a respite bed three days a week and spends the remainder of each week at home with Iris. Iris would like to increase the amount of time that Krista is using the respite bed but financial concerns limit this desire. Iris has a difficult time in knowing how to care for her mother. She complains that her mother smokes a lot and Iris is unable to do anything about this but does use cigarettes to encourage her mother to do activities. Iris has no control over what Krista does unless she moves her cigarettes and then Krista will follow. Iris also has a difficult time with Krista's incontinence and with the fact that when Krista does use the washroom that she uses a lot of toilet paper.

Iris distrusts her mom and believes that her mom uses her dementia to control what Iris does. Iris wonders at times if her mom is really demented or just doing things to bother her deliberately. Iris doesn't know how to handle Krista except to use her cigarettes as a motivator.

The time that Krista is in the respite bed is when Iris finds that she enjoys not having to listen for her mom. Iris also does not visit her during that time and waits as long as possible to pick her up from the institution. Iris says that by the time the respite days come she has had it and under the present circumstances it is not difficult to imagine that Iris will soon need to seek permanent placement for Krista.

Lynn

Lynn is the primary caregiver for Nick, who has dementia. Lynn has many medical problems and did have Nick placed in a long-term care facility at one point but brought him home because she didn't like the care that he was receiving there.

Nick also has emphysema and has stopped walking. There appeared to be no physical reason for Nick to stop walking but it is interesting to note that he chose the day of a huge wedding anniversary celebration for Lynn and Nick to stop walking. Lynn finds it easiest to care for Nick when he goes to bed and falls asleep. She makes frequent references to the difficulty that she has in caring for Nick on a daily basis and it is unclear from the interview whether she receives help from Home Care. Their children are supportive and help out a lot but there is also no references to Lynn being able to call them for extra help.

Nina

Nina is the primary caregiver for her husband Paul, who has Alzheimer disease. Paul and Nina came to Canada from Europe and have lived a life full of overcoming the difficulties associated with moving to a new country. Nina's voice is full of emotion as she describes how difficult it is for them to now cope with the changes in Paul's ability to function. Nina has no trouble relating specific experiences, feelings and background information but she is often crying during the interview and says that she has had a difficult time coping emotionally with Paul's dementia.

Nina is very connected to her family, community and church and relies on them for support and encouragement. She is also very close to her family doctor and waits for his advice before making any decision concerning Paul's care.

Nina speaks often about the stressful nature of her caregiving experience and how grateful she is for the advice given to her by health care professionals. Nina is able to recognize her need for more help to care for Paul but has a difficult time asking for help, despite being surrounded by friends, neighbours and church family who have said that they would help her at any time. Even if help is given to her she feels that it must be paid back at some future time.

At the time of the interview, Paul is in a long-term care facility for a two-week assessment. Nina is unsure whether this assessment will mean that Paul will be placed but she would still like to care for him at home as long as possible if the doctors think that this is an appropriate option.

Tom

Tom was recently the primary caregiver for his second wife, Vera, who has Alzheimer disease. Vera has recently been placed in a long-term care facility. At the beginning of the interview it was difficult to know whether he had admitted her to a long-term care facility or whether she had died because he always referred to her in the past tense. Then later in the interview it is clear that she has been recently admitted but that he says that it feels it is as if she has died and he has lost something.

Tom and Vera both have children from previous marriages and Vera's children visit her often. Tom finds it difficult to visit Vera because he says that they are unable to have a conversation because Vera's speech is incoherent.

Tom relates that he believes that he has been able to manage Vera's caregiving and subsequent admission to a facility because of his education and training. He is a retired physician and throughout the interview he gives concise descriptions of his wife's symptoms and his method for managing them.