

**THE EXPERIENCE OF ADULT SONS AND DAUGHTERS OF  
HOSPITALIZED FRAIL ELDERLY PARENTS:  
A QUALITATIVE STUDY**

by

**ANN L. LEMIEUX**

**A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba  
in partial fulfillment of the requirement for the degree of**

**MASTER OF NURSING**

© 1996

Permission has been granted to the LIBRARY OF THE UNIVERSITY OF MANITOBA to lend or sell copies of this thesis, to the NATIONAL LIBRARY OF CANADA to microfilm this thesis and to lend or sell copies of the film, and UNIVERSITY MICROFILMS to publish an abstract of this thesis.

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's permission.



National Library  
of Canada

Bibliothèque nationale  
du Canada

Acquisitions and  
Bibliographic Services

Acquisitions et  
services bibliographiques

395 Wellington Street  
Ottawa ON K1A 0N4  
Canada

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 this thesis in microform, paper or electronic formats.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

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

0-612-23378-2

THE UNIVERSITY OF MANITOBA  
FACULTY OF GRADUATE STUDIES  
COPYRIGHT PERMISSION

THE EXPERIENCE OF ADULT SONS AND DAUGHTERS OF  
HOSPITALIZED FRAIL ELDERLY PARENTS:  
A QUALITATIVE STUDY

BY

ANN L. LEMIEUX

A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of

MASTER OF NURSING

Ann L. Lemieux © 1996

Permission has been granted to the LIBRARY OF THE UNIVERSITY OF MANITOBA to lend or sell copies of this thesis/practicum, to the NATIONAL LIBRARY OF CANADA to microfilm this thesis/practicum and to lend or sell copies of the film, and to UNIVERSITY MICROFILMS INC. to publish an abstract of this thesis/practicum..

This reproduction or copy of this thesis has been made available by authority of the copyright owner solely for the purpose of private study and research, and may only be reproduced and copied as permitted by copyright laws or with express written authorization from the copyright owner.

I hereby declare that I am the sole author of this thesis.

I authorize the University of Manitoba to lend this thesis to other institutions or individuals for the purpose of scholarly research.

Ann L. Lemieux

I further authorize the University of Manitoba to reproduce this thesis by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

Ann L. Lemieux

## ABSTRACT

Change in the health and functional status of elderly adults may emerge gradually or suddenly and creates stress and the need for change in the roles of adult offspring. Demographic projections on the aging population, combined with pressures on the health care system have significant implications for family caregivers. The purpose of this study was to examine the subjective experience of adult offspring of frail elderly patients on geriatric medicine wards in a Canadian teaching hospital.

Guided by a conceptual model of the caregiving stress process, the qualitative design incorporated tenets from ethnography. Twelve informants were purposively selected to obtain substantive data on their perception of change in their parents' health, their caregiving role, and their interaction with siblings and health care professionals. Data were gathered through face-to-face interviews and analysed using Leininger's (1985) phases of pattern and theme analysis. The "Ethnograph" computerized software program assisted data coding and sorting processes.

Patterns revealed the changing nature of health crises, complications, and frailty, worries for the future, frustration and friction with siblings, the challenges of monitoring care, relentlessly seeking information, encouraging parents' resilience, attending to self, and the meaning embodied in caregiving. Thematic analysis led to the metaphor of the *Caregiving Labyrinth* as a conceptual scheme for understanding parental caregiving in the hospital context. The themes were: (a) caregiving as symbolic journey, (b) weaving through complexities, and (c) the centre of meaning.

Implications for nursing practice and education suggest that it is important that geriatric models of care ensure continuity, communication, and consideration of

family members' needs from the time of admission and throughout the hospitalization. Studies on interventions to promote healthy transitions along the caregiving trajectory and research on family units involved in caregiving are recommended for further research.

## DEDICATION

For my parents, Kathleen and Stan, whose love and encouragement have been a source of inspiration.

*The pattern of entering,  
getting to the center,  
and coming out of  
a labyrinth experience,  
is a map of the psychological process:  
shedding, finding, and integrating.  
We find what really matters to us  
and can reach the core or center  
of meaning in ourselves,  
which is the center of the labyrinth,  
and then we have the task  
of integrating this  
into what we do with our lives  
when we emerge.*

Jean Shinoda Bolen, *Crossing to Avalon*

## ACKNOWLEDGEMENTS

My sincere thanks and gratitude to all the people who helped me along the journey of completing this thesis and especially to:

Dr. Cynthia Cameron, my thesis chairperson, whose care, wisdom, and experience were a great source of guidance and strength and helped me to emerge successfully from this labyrinthine experience.

Dr. Lorna Guse, my thesis advisor, for her advise and constructive comments that helped to bring clarity to my thinking and writing.

Dr. Carol Harvey, my external advisor, for her support and encouragement to celebrate and enjoy the research process.

The "labyrinth walkers", the adult sons and daughters, who so generously shared their stories.

Heather Hay, Linda Rigaux and Janet Ringer, faithful friends who kept me from being swallowed by the *Minotaur*.

Dr. Colin Powell and Dr. Lynne Mitchell-Pederson, for reading and commenting on drafts of the thesis, I am especially thankful for their helpful suggestions.

Pat Hosang and all my colleagues at St. Boniface General Hospital for their ongoing support and encouragement.

Finally for the financial support received during my graduate studies from: the University of Manitoba for two Graduate Fellowships, the St. Boniface General Hospital for the Gerontological Nursing Practicum Fellowship, and the Canadian Nurses Foundation for the Extencicare Scholarship in Gerontology.



## TABLE OF CONTENTS

	Page
Abstract . . . . .	i
Dedication . . . . .	iii
Acknowledgements . . . . .	iv
<b>CHAPTER I: OVERVIEW OF THE STUDY</b>	
Introduction . . . . .	1
Statement of the Problem . . . . .	1
The Research Questions . . . . .	5
Significance of the Study to Nursing . . . . .	6
Conceptual Framework . . . . .	8
Definition of Terms . . . . .	12
Conclusion . . . . .	12
<b>CHAPTER II: REVIEW OF THE LITERATURE</b>	
Introduction . . . . .	14
The Frail Elderly - Impact on the Family . . . . .	14
Role Reversal - Transition to Parent Care . . . . .	18
Stress & Coping Models . . . . .	22
Impact of Caregiving . . . . .	25
Family Dynamics . . . . .	28
Conclusion . . . . .	31

<b>CHAPTER III: RESEARCH METHODOLOGY AND PROCEDURES</b>	<b>Page</b>
The Research Design . . . . .	32
Study Context . . . . .	33
Sample Selection . . . . .	34
Ethical Considerations . . . . .	37
Data Collection Methods . . . . .	38
Data Analysis . . . . .	41
Establishing Trustworthiness . . . . .	43
Conclusion . . . . .	47

**CHAPTER IV: FINDINGS**

Introduction . . . . .	49
Demographic Characteristic . . . . .	49
Components and Patterns . . . . .	49
Table 1: Demographic Profile . . . . .	51
Table 2: Components and Patterns . . . . .	52
The Parents' Health . . . . .	53
The Adult Sons'/Daughters' Role . . . . .	57
Interaction with Health Professionals . . . . .	63
Coping Behaviors . . . . .	68
Response of Siblings . . . . .	71
Meaning of Caregiving . . . . .	75
Conclusion . . . . .	81

<b>CHAPTER V: DISCUSSION</b>	<b>Page</b>
Introduction . . . . .	83
The Caregiving Labyrinth . . . . .	83
Figure 1: Conceptual Scheme . . . . .	85
Theme 1: Caregiving as Symbolic Journey . . . . .	86
Theme 2: Weaving Through Complexities . . . . .	91
Theme 3: Center of Meaning . . . . .	96
Conceptual Framework . . . . .	99
Limitations . . . . .	101
Implications for Nursing Practice & Education . . . . .	102
Implications for Nursing Research . . . . .	104
Conclusion . . . . .	105
<b>REFERENCES . . . . .</b>	<b>107</b>
<b>APPENDICES</b>	
A. Verbal Request . . . . .	124
B. Explanation of the Study . . . . .	125
C. Consent Form for Informants . . . . .	127
D. Explanation of the Study for Patients . . . . .	130
E. Demographic Data . . . . .	132
F. Checklist: Functional Status . . . . .	138
G. Checklist: Caregiving Role . . . . .	141
H. Interview Guide . . . . .	142
I. Field Notes . . . . .	145

# CHAPTER I

## OVERVIEW OF THE STUDY

### Introduction

This chapter identifies the purpose and the research questions addressed in the study. The clinical and theoretical underpinnings that gave direction to the study are provided. Rationale supporting the need for this study, as well as the conceptual framework and major concepts that guided the study, are also identified.

### Statement of the Problem

Change in the health and functional status of an elderly adult may emerge gradually or suddenly. Not only may the life of the older adult be affected, but also the lives of family members may change. A significant decline in the health condition of elderly parents may create substantial stress and a need for change in the role of adult sons and daughters.

Several factors influence the degree of stress, the extent of change in adult offsprings' roles, and the process of adapting to these changes. How adult sons and daughters perceive, interpret and ascribe meaning to the change in their parents' health condition and to the change in their caregiving role forms the central question of the thesis.

It is both essential and timely to understand the subjective appraisal of sons and daughters who are instrumental in providing and coordinating resources to meet their parents' needs. The perceptions of adult offspring have a bearing on whether or not an

elderly patient can successfully return to community-based living.

Canadian demographic projections of the elderly population indicate that by the year 2006, 15% of the population will be aged 65 or over (Statistics Canada, 1990). The population segment of individuals aged 75 and over is increasing the most rapidly; this group is also the most frail and require higher levels of support (Statistics Canada, 1990). This projection combined with the cost containment trend in health care of shifting hospital based care for the elderly to community based programs has considerable implications for the role of family members (Bull, 1990; Nolan & Grant, 1992; Oktay & Volland, 1990; O'Neill & Sorensen, 1991).

The impact of hospitalization on frail elderly people has been well documented in the literature. Elderly patients frequently have characteristics that place them at greater risk for developing additional health and functional impairments (Davis, Shapiro, & Kane, 1984; Palmer, Landefeld, Kresevic, & Kowal, 1994; Rockwood, Fox, Stolee, Robertson, & Beattie, 1994; Tappen & Beckerman, 1993). They may be dealing with a number of chronic diseases, multisystem problems, numerous hospital admissions, and recent losses in their social network, all of which make more complicated their recovery and return to independent living (Blumenfield, Morris & Sherman, 1982; Rockwood et al., 1994).

Hospital stays are generally longer for elderly patients and the incidence of complications tends to increase with age (Gillick, Serrell & Gillick, 1982; Palmer et al., 1994). Complications commonly include adverse drug reactions, incontinence, falls, infection, and confusional states that may result in a loss of functional ability in the areas

of mobility, activities of daily living, bowel and bladder functioning, and cognitive competence (Davis et al., 1984; Lipowski, 1983; Rosen, 1994).

Kuypers and Bengtson (1983) stress that older persons confronting illness may be particularly vulnerable to losing their capacity to adapt, to perform roles adequately, and to have a sense of mastery. They are vulnerable to losing previous self-care abilities and believing that they are helpless. The experience of being hospitalized for some older persons leads to their feeling increasingly dependent and incompetent.

Family members are also vulnerable to having a difficult time responding to the problems of the older person (Beckingham & Bauman, 1990; Kuypers & Bengtson, 1983). An important dimension of elderly patients' hospital experience is the impact of their changing needs on their adult offspring. The roles of sons and daughters are frequently in a state of flux and transition as parents require either additional or different types of assistance than prior to their admission to hospital. Adult sons and daughters may view patients' need for helping or caregiving assistance as something that will be ongoing and continue to increase once the parent is discharged.

Presently, there is scarce documentation of the experience of adult sons and daughters of hospitalized elderly parents going through an acute health care crisis (Bull, 1990; Bull, Jervis, & Her, 1995; Laitinen, 1994; Nolan & Grant, 1992). Little attention has focused on the impact on families of caring for elderly persons who have sustained a hip fracture or a stroke (Silliman & Sternberg, 1988). Some interest has been shown in the experience of family members of hospitalized elderly patients awaiting placement in a long term care facility (Hall, 1989; Rosenthal, Sulman, & Marshall, 1992).

Health professionals, by involving themselves early on with adult offspring, may help to ease their anxiety and thus prevent their interpreting the situation as a crisis. The sense that their parents' needs create a crisis may negatively affect the adult sons' or daughters' perception of their capacity to help in caregiving activities. Cicirelli (1988) examined the filial anxiety that adult offspring experience regarding the anticipated care needs of elderly parents. He suggests that moderate levels of filial anxiety may promote adult sons' and daughters' motivation for caregiving, whereas high levels of anxiety may lead to avoidance of caregiving activities.

The significance of family members' subjective appraisal of the caregiving experience, particularly in relation to stress and burden, has been addressed in the literature on older families (Montgomery, Gonyea, & Hooyman, 1985; Novak & Guest, 1989; Zarit, Todd, & Zarit, 1986). Most studies, however, have drawn their samples from community based populations and/or have studied the experience of caregivers of elderly family members with dementia. Research on the meaning of caregiving to cognitively aware but physically disabled elderly family members has been neglected (O'Neill & Sorensen, 1991).

There is a need for research on the experience of adult offspring with hospitalized frail elderly parents who are cognitively aware but do require the support and help of their family if they are to return successfully to community-based living. Knowledge of such experience may help health care professionals identify the needs of these family members. Health care professionals' quick response may enable adult sons and daughters to engage effectively in caregiving activities and thus facilitate the successful discharge

of hospitalized elderly patients back to the community. Moos and Schaefer (1986) indicate that during periods of change or transition, individuals are open to the suggestions and advice of others. Nurses and other health care professionals who are aware of the issues related to parental caregiving are in a position to prepare adult offspring for what they may encounter and to help them mobilize their coping resources.

The purpose of this study was, therefore, to examine the subjective appraisal of adult sons and daughters as they adapted to change in their hospitalized parents' health, their caregiving role, and their interaction with siblings and health care professionals. A qualitative design was utilized to describe, understand, analyze, and interpret the characteristics of this phenomenon.

### **The Research Questions**

The following research questions were examined in this study:

1. How do adult sons and daughters understand the changes in the health of hospitalized frail elderly parents?
2. What are adult sons' and daughters' interpretations of what the changes in parents' health will imply for their caregiving role?
3. How do adult sons and daughters perceive their interaction with health care professionals?
4. How are adult sons and daughters coping with the changes and demands of the situation?



5. What are adult sons' and daughters' understanding of their siblings' perception, interpretation, and appraisal of the situation?
6. How do adult sons and daughters ascribe meaning to caring for their parents?

### Significance of the Study to Nursing

In hospitals, the complex issues facing sons and daughters pose many challenges for practising nurses. The downsizing of health care institutions and the trend to providing care and treatment in the community requires nurses to be knowledgeable in communicating and problem solving with families (Bull, 1990; Grandine, 1995; Nolan & Grant, 1992). Grandine (1995) has suggested that a family focus has the potential to "reduce morbidity, recidivism, and health care costs" (p. 31).

Adult offspring frequently voice anxieties to the nurse about their parents' well-being as well as worries about their own capacity to respond to their parents' needs. Systems theory suggest that change in one family member affect all family members (Wright & Leahey, 1984), a phenomenon clearly evident to nurses who work with elderly patients. Although individual adult sons and daughters were the informants in this study, O'Neill and Sprensen (1991) highlight the importance for nurses to understand that an individual's perception is grounded in the family context. Therefore, relationship dynamics of how siblings respond to change in their elderly parents must be addressed.

Responding to the concerns and worries expressed by the sons and daughters of elderly patients in a sensitive, relevant, and effectual manner is an important dimension of clinical nursing practice. The "helping" and "teaching-coaching" domains of nursing

described by Benner (1984) indicate the therapeutic role nurses may play with elderly patients and their sons and daughters. Benner (1984) has described a number of competencies or components to these two domains. These include (a) providing emotional and informational support to patients' families, (b) guiding individuals through emotional and developmental change, (c) assisting patients (and families) to integrate the implications of illness and recovery into their lifestyles, (d) opening ways of "being" and coping for the patient and family.

Burnside (1990) proposed that sensitivity, expertise, and caring are three fundamental components of gerontological nursing. Caring is described as the essential and central value guiding the practice of nursing (Benner & Wrubel, 1989; Roach, 1987). A vital starting point from which to build nursing knowledge and enable nurses to work in a caring and effective manner with the adult sons and daughters of elderly patients, is to begin by understanding the reality of those central to the lived experience: their perceptions, understandings, interpretations, and meaning of the changes they are facing.

This study attempted to:

1. Expand understanding of how elderly parents' hospitalization is subjectively experienced by their adult sons and daughters.
2. Help delineate ways for nurses to assess adult sons' and daughters' appraisal and interpretation of the situation.
3. Add to our knowledge of what nursing interventions are supportive to adult sons and daughters.
4. Help strengthen a family-oriented approach to caring for hospitalized frail elderly

patients.

5. Add to our understanding of the relationship dynamics among siblings in families with frail elderly parents.

### **Conceptual Framework**

The study was guided by the conceptual model developed by Pearlin, Mullan, Semple, and Skaff (1990) from their research on the stress process and specifically from exploratory research among spouses and adult offspring caring for relatives with Alzheimer's disease. Their aim was to clarify the stress process as it pertains to caregiving, and to offer the model as a guideline for future caregiving research. Although the model stemmed from research on caregiving related to Alzheimer's disease, application to caregiving related to other chronic health conditions appeared feasible. The conceptual components of the model were useful as a sensitizing framework for this study. The potential for caregiving to be stressful is a reality that has been well documented in the literature on adult offspring caring for older frail parents (Brody, 1981, 1985; Brody, Kleban, Johnsen, Hoffman, & Schoonover, 1987; Montgomery et al., 1985; Neugarten & Hagestad, 1976; Young & Kahana, 1989). Pearlin et al. (1990) described caregiver stress as a process encompassing contextual features, psychological, intra-familial, and social components.

### **Conceptual Components of the Model**

The caregiving stress process is comprised of four domains: "the background and

context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress" (Pearlin et al., 1990, p. 586).

First, the background and contexts of the stress process were described by Pearlin et al. (1990) as including four interactive components. These are: (a) the characteristics of the caregiver, such as age, gender, and economic status, (b) the characteristics of the caregiving history, that is, the nature of the caregiver's relationship with the care-receiver, and the length of time care has been required, (c) the existing family network and social support resources, and (d) the access to, and linkages with, community programs.

The second domain describes the primary and secondary stressors embodied in the caregiving stress process. Pearlin et al. (1990) proposed that the primary stressors of the situation influence the secondary stressors. In their work with family caregivers of individuals with Alzheimer's disease, they found that the primary stressors were associated with both objective and subjective indicators. Objective indicators are defined as those directly connected to the needs and demands of the care-receiver. Subjective indicators relate to the changing relationship between the caregiver and care-receiver. Indicators of objective stressors include the cognitive status of the care-receiver, behavioral manifestations related to Alzheimer's disease, and the amount of help needed with instrumental and personal activities of daily living. Subjective stressors are the caregivers' sense of personal hardship and the loss of the former relationship with the care-receiver due to the nature of the chronic disease.

Secondary stressors appear to be influenced by and flow from the demands of the

caregiving situation, particularly if the caregiving trajectory is progressively demanding and longstanding (Pearlin et al., 1990). The secondary stressors include: (a) role strains, and (b) intrapsychic strains. Pearlin et al. (1990) indicated that in addition to role strains involving occupational, economic, and social pressures, the impact on family roles is keenly felt. The potential for family conflict emerges predominantly in relationship to the appraisal of the care-receiver's condition and needs, the amount of involvement with the care-receiver, and the recognition (or lack of recognition) of the primary caregiver's efforts.

Intrapsychic strains are described as involving individuals' global perception of self-esteem and self-efficacy, and elements of these constructs pertinent to the caregiving situation. According to Pearlin et al. (1990, p. 589), four dimensions pertaining to the latter are embodied in the context of caregiving for family members with Alzheimer's disease: (a) role captivity or the sense of being trapped, (b) loss of self-identity, (c) a sense of competence, and (d) a feeling of inner growth.

The third domain of the model describe the mediators, that is, coping and social support, which may assist with decreasing the impact of stressors along the course of the stress process. Coping is defined by Pearlin et al. (1990, p. 590) as those behaviors initiated by the individual: (a) to manage the caregiving situation causing the stress, (b) to manage the meaning of the situation, and (c) to manage the effects of the stress being experienced. Social support is defined as a buffer in the stress process which encompasses both instrumental components, such as, assistance with caregiving tasks, and expressive components, for example, having a concerned confidant (Pearlin et al.,

1990).

The fourth domain of the model, the outcomes, refers to the efficacy of the mediators in terms of the caregiver's physical and mental health and ability to continue in the role over the course of time. Pearlin et al. (1990) suggest that "different types and levels of outcomes are interrelated" (p. 590) and that unresolved emotional distress may eventually lead to compromised physical well-being.

In summary the underlying premise is that caregiver stress is "a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers and that, consequently, vary in their impact on caregivers' health and behavior" (Pearlin et al., 1990, p. 591). The model emphasizes that caregiver stress is not a discrete event but rather a dynamic changing process comprised of many interrelated components (Pearlin et al., 1990).

The model sensitized the researcher to the relevant concepts, while remaining faithful to the qualitative design of the study. The goal of this research was to describe and understand the experience of parental caregiving from the perspective of adult offspring with an eye to developing an explanatory scheme. The narrative data revealed that caring for parents in hospital is a consuming, changing, and complex process. Thematic analysis of the components and patterns derived from the data led to the metaphor of a *Labyrinth* as a conceptual scheme for understanding the study participants' experience.

### Definition of Terms

For the purpose of this study, the concepts relating to the research questions are:

1. **Stressors:** A stressor is an event that has the potential to bring about change in the family system. Stressors in this study involve change in the parent's health and change in the adult offspring's role. Stressors include the demands which may arise from the initial situation, as well as, role strains and intrapsychic strains which may evolve over the course of time.
2. **Caregiver:** The caregiver is the adult son or daughter identified by the head nurse on the geriatric ward, as the one principally responsible for providing and coordinating the resources to meet the patient's needs.
3. **Mediators:** Mediators are the coping (cognitive, emotional, and behavioral) and social support buffers used to manage the demands on the situation.
4. **Subjective Appraisal:** Subjective appraisal includes the caregiver's perception; understanding; feelings; interpretation; and meaning of the stressors being experienced, their interactions with health care professionals and siblings, and the mediating factors which may have bearing on the situation.

### Conclusion

The experience of adult sons and daughters of hospitalized frail elderly parents was identified as a significant problem requiring further research. The conceptual model guided the research process and a qualitative design was used to examine the perceptions,

interpretations and meanings experienced by the study's participants. The next chapter presents a review of the literature.



## CHAPTER II

### REVIEW OF THE LITERATURE

#### Introduction

The literature on the caregiving role of families with aging members is extensive. The normative and motivational aspects of adult offsprings' caring for older parents have been explored. Expansive attention has been paid to the types of caregiving behaviors and the consequences associated with family caregiving, particularly caregiver burden. The range of resources, such as social support, that help family members cope with caregiving, has also been examined. The majority of studies on family caregiving have concentrated on the care provided to elderly demented persons who reside in the community or in nursing homes.

These studies have been helpful in identifying the impact of change in the health of an older family member on the family system. Germane to the focus of this study was literature on: the implications of the needs of the frail elderly, caring for elderly parents, factors influencing stress and burden, family dynamics, and the role of appraisal in coping with change. Salient literature on these topics is reviewed in subsequent sections.

#### The Frail Elderly - Impact on the Family

The risk of chronic health problems affecting the functional ability of elderly people increases as they age, particularly past age 75 (National Advisory Council on Aging, 1989). When health problems causing frailty occur in old age, it is particularly

to family members that older adults turn in times of need (Chappell, 1989). Family members are the primary caregivers providing emotional and instrumental support as the older person becomes increasingly dependent (Brody, 1985). It has been estimated that approximately 80% of care provided to older persons comes from family and friends (Brody, 1985; Chappell, 1989). After spouses, children, particularly daughters, are the secondary source of help to the elderly, providing support, assistance, and link with bureaucratic institutions for various supportive services (Shanas, 1980; Sussman, 1976; Tobin, 1987). The family role in providing this support, care, and advocacy for older family members continues even when hospitalization and/or institutionalization occurs (Bowers, 1987, 1988; Hall, 1989; Wolfson, Handfield-Jones, Glass, McClaren, & Keyserlingk, 1993).

Wolfson et al. (1993) examined how adult offspring of hospitalized parents perceived their sense of responsibility for their parents' care. The study was conducted in a Canadian teaching hospital. The criteria for inclusion were patients for whom discharge was pending and who would likely require care from their families. Data were collected from adult sons and daughters (N=170) on their attitude toward caring for elderly parents. The design of the study utilized vignettes which described clinical and social situations commonly encountered by the elderly. The researchers sought to determine what the participants felt "should" be provided in the hypothetical context of the vignettes compared to what the participants felt they "could" provide when asked to envision themselves in the vignettes.

First, participants were asked what levels of emotional support, physical

assistance, and financial help "should" be provided to the parents described in the vignettes. Then the participants responded to what they felt they "could" do if the vignettes described their own parents' situation. A limitation of the study design is the potential for response bias, such as, social desirability regarding attitudes to family caregiving. However despite this limitation, the findings provide useful insights on (a) the ordering of the types of assistance that should be provided, and (b) the practical issues of what assistance could be provided (Wolfson et al., 1993).

These data suggest that adult offspring feel a strong moral obligation to provide emotional, physical, and financial support in a hierarchical order. Providing emotional support was consistent between the "should" and "could" contexts. However, the data reveal differences in the subjects perceived capacity to provide actual physical or financial support, that is, differences existed between the "should" and the "could". The researchers questioned whether Canadian families feel that physical and financial support for older members are the responsibility of government. Whereas the Wolfson et al. (1993) study addressed abstract issues of filial responsibility, Hall's (1989) study at a Canadian general hospital examined the actual helping behaviors of adult sons and daughters (N=27) performed for chronically ill parents who were patients on acute care medical units. Hall (1989) found that, in spite of their parents being inpatients, adult offspring provided help with meeting specific needs. The predominant types of help sons and daughters perceived as being their role to perform included psychological support, bureaucratic mediation, and personal care.

Responding to their parents' needs had required sons and daughters to make

changes in their lifestyle. Hall's study also addressed the extent of stress experienced by the adult offspring as a result of providing help. Participants reported feeling emotionally exhausted, tied down, and physically worn out (Hall, 1989). Hall (1989, 1990) urged health care professionals to view the adult sons and daughters of hospitalized chronically ill elderly people as important resources who also have needs to be addressed.

According to Nolan and Grant (1992), the expectations put on families to assume caregiving responsibilities following an episode of acute hospital care may not always be appropriate. They cited a number of factors that should be weighed by health care professionals before assuming that available family members can be expected to provide care upon discharge of the elderly patient. Family members' degree of perceived and informed choice with assuming caregiving responsibilities, involvement in discharge planning, and the quality and nature of their relationship with the patient are mediating factors which should be taken into consideration, particularly if the role of caregiver is being adopted reluctantly. Nolan and Grant (1992) strongly recommended that nurses in acute care settings assume a pivotal role in discharge planning with family members that gives attention to their position and needs in concert with those of the patient. To ignore family needs can lead to strained or destructive family interactions.

The growing literature on comprehensive discharge planning for the hospitalized elderly is instructive on strategies that promote positive outcomes for both elderly patients and their caregivers (Bull 1994a, 1994b, 1994c; Coulton, Dunkle, Chow, Haug, & Vielhaber, 1988; Kennedy, Neidlinger, & Scroggins, 1987; Naylor, 1990; Naylor & Shaid, 1991; Naylor et al., 1994). The potential benefits identified in patient and family

related outcomes include shortened hospital stays, smoother transition from hospital to home, and lower rehospitalization rates. A summary of the key directives from these researchers' studies were the necessity for: (a) ongoing patient and caregiver involvement in discharge planning commencing early in the hospital stay, (b) assessing the family's perspectives, expectations, preferences, and availability of assistance, (c) promoting effective two-way communication between health care professionals and patients and families (i.e. encouraging questions, seeking clarification), (d) providing information on managing the parents' health problems and the availability of community resources, and (e) follow-up (eg. by telephone) in the first two to three weeks after discharge.

Given the demographic trends, the changes in health care, and the reliance on informal caregivers, consideration of families' expectations and needs is timely.

### **Role Reversal - The Transition to Parent Care**

The changing needs of the elderly parent may call for significant transition in the roles of adult sons and daughters and family patterns of interaction. Brody (1985) suggested that care of aging parents is a normative but stressful experience. The transition may evoke a "dialectic tension of dependence/independence" (Brody, 1985, p. 23) as the inner meaning of parent care is assimilated. "Being depended on by one's elderly parent and being depended on by one's young child have different inner meanings" captures the essence of this tension (Brody, 1985, p. 23). Brody (1985) concluded that, whereas some adult offspring adapt well to this life cycle transition, others experience a great deal of stress in response to their role change with frailer

highly dependent parents. In fact according to Carter and McGoldrick (1984), family stress was often greatest at normative transitional stages in the family life cycle. This was particularly true if the change in role was viewed as an interruption in family member development.

Three studies confirmed the complexities involved with assuming a caregiving role with parents: the degree of filial anxiety (Cicirelli, 1988), the sequence of involvement (Hansson et al., 1990), and the purpose of caregiving (Bowers, 1987). Cicirelli (1988) designed a study to develop an instrument to measure filial anxiety. The random sample consisted of 71 adult offspring who had a parent living in the community. Filial anxiety was defined as "a state of worry or concern about the anticipated decline and death of an aging parent, as well as, worry or concern about the ability to meet anticipated caregiving needs, either prior to any caregiving or during the provision of care and in anticipation of further parental decline and additional needs for care" (Cicirelli, 1988, p. 478).

Cicirelli constructed two dimensions of filial anxiety. The first reflected adult offsprings' anxiety over their ability to assume the caregiving role. The second addressed adult offsprings' anxiety concerning the well-being of parents. Validity of the instrument was addressed with a second sample (N=53) using the filial anxiety scale and a number of other instruments that measured attachment, health indicators, and death anxiety. The instrument's ability to predict the adult offsprings' anxiety about parents' welfare was greater when the offsprings' attachment to the parent was greater and the indications of parental decline were stronger. The findings also identified that the adult

offsprings' anxiety about their ability to take on a caregiving role were directly associated with the imminent and difficult nature of parents' needs (Cicirelli, 1988). Cicirelli (1988) suggested that this instrument was useful to study adult offsprings' caregiving behavior across the caregiving trajectory. Although the sample for this study consisted of adult offspring who were only engaged in providing instrumental care, such as grocery shopping, Cicirelli hypothesized that filial anxiety would also likely occur when personal care was provided.

Hansson et al. (1990) suggested that the involvement of adult offspring in helping activities with aging parents follows a caregiving trajectory, progressing from least to increased involvement. In a survey study with 242 adult children of community based elderly parents, they sought to identify normative patterns of parent care and to explore the connection of caregiving with the subjects' perception of their elderly parents' overall health and functioning. They suggested that involvement followed a sequence whereby adult offspring first begin (a) to think about their parents' age-related changes, then (b) to learn about issues related to aging, and finally (c) to monitor their parents' health and functional status. Sons and daughters' view of their parents' ability to manage determined their awareness of aging issues and involvement in parent care. Perceptions related to changes in parents' health, as well as parents' personality, adjustment and support factors, were the predominant indicators for increased awareness and involvement. Adult offspring saw the need to balance their intervention and involvement with respect for and maintenance of parents' independence. This study sheds light on how sons and daughters begin the process of appraising their parents' situation and the

need to modify their role with parents.

Bowers (1987) used a theory-generating research design to study the experience of middle-aged women caring for community-based elderly parents with dementia. Analysis of the data revealed that the process of caregiving is more accurately understood when the purpose of caregiving activities, as opposed to the types of caregiving tasks, is elucidated. Bowers (1987) defined caregiving by the meaning a caregiver ascribed to both observable behaviors and mental activities. Five categories of caregiving emerged from the interview data; including (a) anticipatory (anticipating and preparing for what might happen to the parent), (b) preventive (preventing physical harm), (c) supervisory (coordinating and supervising the care provided by other people), (d) instrumental (performing direct care), and (e) protective care (preserving the parent's self-concept).

These three studies, Cicirelli (1988), Hansson et al. (1990), and Bowers (1987), have shed light on some of the processes adult offspring face. Caution must be applied in generalizing the findings as each has design limitations. In the first two studies, the elderly parents were fairly independent with personal activities of daily living. As well, the implications of a sudden crisis in the health condition of elderly parents on the stages and phases of parental caregiving were overlooked. A limitation of Bower's (1987) model is that it was developed to study caregiving of family members with dementia so it may have some limited generalizability where parents are cognitively aware. The cross-sectional perspective of the studies is another shortcoming, limiting the relationship between variables as "association" rather than "causal". To track the transitions and changes along the caregiving trajectory over time with longitudinal studies would expand



our knowledge.

### Stress & Coping Models

The literature on stress offers models of individual response to stressful situations that can be fruitfully applied to adult sons and daughters caring for elderly parents. Reviewing the processes of coping and adapting to change, stress, or crisis helps in understanding the response of adult offspring as they encounter health related changes in their aging parents.

According to Moos and Schaefer's (1986) model, a number of adaptive tasks and coping skills facilitate the management of life transitions and crises. Moos and Schaefer (1986, p.14) have categorized the three domains of coping skills: (a) appraisal-focused, (b) problem-solving focused, and (c) emotion-focused. The individual's process of appraisal and reappraisal occurs over time and involves finding meaning or a sense of purpose in the event. In addition to the influence of how an individual perceives and interprets the situation, other behaviors that promote adaptation include the individual finding out relevant information and seeking support from family and friends (Moos & Schaefer, 1986).

Lazarus and Folkman (1984) proposed a cognitive-phenomenologic stress model to understand coping with change. In this transactional, process-oriented approach they defined coping as "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 behaviors are

determined by the individual's continuous appraisal and reappraisal of events and the inherent meaning of events. Individual characteristics and situational factors influence cognitive appraisal processes, and, in turn, the problem-focused and emotion-focused efforts to manage the problem. Lazarus and Folkman (1984) emphasize the contextual nature of stressful events and coping styles. In other words, what is helpful to a person from one situation to another or over the course of time may vary considerably.

Knowledge of how change in the health of older members is appraised by the family system has also been conceptualized. Kuypers and Bengtson (1984) use a phenomenological perspective to shed light on understanding the family with older members. They propose that, "family members are interpreters of family life: they continuously construct analyses of what family interactions mean, how these are consistent or inconsistent with previously constructed meanings, and what they imply by way of expectation, duty, loyalty, and individual rights" (Kuypers & Bengtson, 1984, p. 7).

The process of constructed meaning influences how the family responds and adapts to stressful events involving an elderly parent. Kuypers and Bengtson (1984) highlighted three features of constructed meaning that affect the transition to a caregiving role with elderly parents. First, the interpretation that individuals ascribe to a situation may be very different from the facts of the situation. As well, individuals may not recognize the subjectivity of their view. Meaning exists in the individual, not necessarily in the situation. Second, individuals have a tendency to hold on to interpretations and meanings that may no longer fit the situation or the people involved

or help with the adjustment to change. One of the challenges facing families is that the required change may be incompatible with how they have perceived their roles and obligations in the past. Third, each individual in the family system may hold different meanings and interpretations of the situation. This can lead to conflict and confusion between members as the family attempts to respond to the changes occurring in the family system.

Kuypers and Bengtson (1983), in their work with older families who are experiencing crisis and are having difficulty coping with their situation, suggested that a number of issues affect families when they face changes related to aging. Socio-cultural perceptions and stereotypes that view problems of aging as progressive and helpless influence the appraisal of the situation. In Western culture, the bonds to one's family of origin change throughout the lifespan. Involvement is transferred to new commitments such as career and one's family of procreation. This diversification of loyalty may make drawing together difficult and may trigger tensions concerning obligations and commitments. The situation may also cause to surface old family conflicts and may create difficulties in working together as a problem solving unit.

Pearlin et al.'s (1990, p. 590) conceptual model, which guided this study, regards "management of the meaning of the situation" as an element of coping, one of the mediators of the stress process. Three factors were identified in the development of a measure to examine "management of meaning": (a) reduction of expectations of the care-receiver, (b) making positive comparisons, and (c) a larger sense of the meaning of the illness. The authors caution that reliability of the measures have not yet been

established. Caregiving appraisal was the subject of a paper by Lawton, Kleban, Moss, Rovine, and Glicksman (1989). Their work, based on two research projects with caregivers of community based and institutionalized cognitively impaired elders, revealed that appraisal is a multifaceted and subjective phenomenon. Dimensions of caregiving appraisal included subjective caregiving burden, caregiving satisfaction, and perceived caregiving impact.

### **Impact of Caregiving**

Although many of the changes associated with aging are anticipated and taken in stride by individuals and families, the literature on older families indicates that health-related changes may be viewed as stressful and sometimes crisis events. Neugarten and Hagestad (1976) state that family stress in later life is predominantly related to the impact of illness and disability on elderly family members. In view of the trend toward earlier discharge of frail elderly hospitalized patients and the pivotal role of adult offspring in providing assistance to older parents, attention to the experience of filial caregivers is clearly indicated (Archbold, Stewart, Greenlick & Harvath, 1990; Bull, 1990; Robinson & Thurnher, 1979; Silliman, 1993).

Caring for frail elderly parents may create opportunity for individual and interpersonal growth for adult children; it may also lead to family disruption. Adult offspring frequently experience role strain, stress, and sometimes a sense of crisis as they struggle with family and social roles, their own developmental tasks, and concurrent stressors (Barnes, Given, & Given, 1992; Kirscher, 1979; Kuypers & Bengtson, 1983;

Springer & Brubaker, 1984). Parent care has the potential to stimulate intense emotions. An individual may be attempting to resolve a number of concerns. Issues arising from experiences in one's family of origin, anticipating final separation from a parent, and thoughts about one's own aging process are common themes.

Robinson and Thurnher (1979) found that adult offspring viewed parental caregiving as being stressful particularly when it meant changing their lifestyle and goals for the future. Their findings, based on a longitudinal study, illustrated that adult sons' and daughters' appraisal of their parents became more negative over the span of time as parents' mental condition declined and care demands increased. This study followed the son and daughter subjects over the course of five years. The crucial indicator of adult offsprings' negative perceptions was their experience of being confined, not the actual care requirements of the parent. One of the limitations of the study is that the actual health of the parents was not clearly defined. The study did not explore how the offsprings' negative appraisals of their parents affected their coping behavior nor how other family members influenced their responses to caregiving.

There is scant literature on caregiver stress and burden that explicitly addresses how subjective appraisal and the meaning of parent care influences coping behavior. Montgomery et al. (1985) conducted a study with 80 family caregivers of community based elderly people to clarify the relationship between caring for a family elder and the caregiver's experience of burden. Adult offspring accounted for 71 percent of the sample. Subjects were interviewed to measure subjective and objective burden, caregiving tasks, and to identify demographic variables. Subjective burden was defined as the

caregivers' attitudes toward or emotional reaction to the caregiving experience. Objective burden was defined as the extent of disruptions or changes in various aspects of the caregiver's life and household. Montgomery et al. (1985) demonstrated that different factors predicted each type of burden. Subjective burden was associated with characteristics of the caregiver such as age and income. Objective burden was related to the types of tasks such as bathing, dressing, and transportation but not the sum of tasks or the time spent.

Montgomery et al. (1985) underlined the importance of distinguishing between the type of burden when planning interventions with family caregivers. Subjective burden appears to be related to characteristics of the caregiver and may help health care professionals identify who is at risk for burden. However, this was a small, non-representative sample. Clearly, more research is needed on the subjective experience of caregivers and how subjective appraisal influences coping.

The subjective perception of caregiving was studied to some extent in a cross-sectional study Novak and Guest (1989) conducted with 30 caregivers of spouses with Alzheimer's disease. The study addressed the relationship between caregiver burden and care-receivers' level of dementia, the length of time the caregiver has been caring for the spouse, and the caregivers' subjective perception of caregiving. Quantitative instruments assessed the care receivers' condition and severity of dementia, the extent of caregiver burden, and the caregivers' perceived happiness and satisfaction. Novak and Guest (1989) suggested that neither the condition of the care-receiver nor the length of time involved in caregiving can account for the experience of burden. They proposed that

caregivers do not necessarily go through stages linked to care-receivers' condition. A strong desire to perform caregiving activities had a positive correlation with burden. Novak and Guest (1989) concluded that research is needed to understand more thoroughly the subjective perceptions of caregivers.

A number of methodological issues limit the ability to compare and contrast the findings of caregiving studies. Disparity exists in the numerous definitions of caregiver, the kinds of assistance being rendered, the needs of the care-receiver, and who has been included in the samples (Barer & Johnson, 1990).

### **Family Dynamics**

Although most research has focused on the primary caregiver and the elderly person, it is recognized that parent care often involves more than one adult son or daughter. Brody (1985) cautions that parent care situations occur in the context of individual and family histories and personalities. Both individual and family dimensions influence adaptation to change in family structure, roles, and interaction. Zarit, Reever, & Bach-Peterson (1980) reported that the experience of primary family caregivers is influenced by their perception of how other family members are interpreting and responding to the situation. Primary caregivers who received support from other family members experienced less stress or less of a sense of burden than caregivers whose family members did not perceive or acknowledge the implications of the situation (Zarit et al., 1980).

Barer and Johnson (1990) indicated, in their five year review of the literature on

caregiving, that little reference is made to the larger family network. Studies on the primary caregiver have concentrated on measuring aspects of the caregiving role and have largely ignored family dynamics and the family as a functioning unit. Matthews (1987) stated that research on older families has tended to be the study of dyadic intergenerational relationships between a parent and one adult offspring. She stresses that the primary adult son or daughter caregiver must be thought of within the structure and the dynamics of the family in order to understand how the adult son/daughter responds to the caregiving situation. Matthews and Rosner (1988) conducted an exploratory study to learn how adult siblings respond as a family unit to the perceived needs of elderly parents. The purpose of the study was to describe two groups of factors. First, it explored the factors that lead to mobilization of the family unit. Second, it described the factors that influence the participation styles of siblings in providing parent care. Matthews and Rosner (1988) interviewed pairs of sisters, representing sibling groups from fifty families who had a parent over 75 years living in the community. The data were analyzed qualitatively.

The findings illustrated that, when changes in parents' health or when widowhood occurred, adult offspring communicated with each other to validate their perceptions of their parents' needs and to discuss what action was necessary. As in the Hannson et al. (1990) study, the pattern of caregiving followed the least involvement required in order to preserve parents' independence. Matthews and Rosner (1988) inductively identified five styles of sibling participation in parent care. The range of styles included: (a) routine - "the core of regular assistance", (b) backup - "not regularly involved but can



be counted on to help", (c) circumscribed - "carefully bounded participation, for example, 'calls once a week'", (d) sporadic - "provides help at own convenience", and (e) dissociated - "cannot be counted on for help" (Matthews & Rosner, 1988, p. 188-189).

Family structure, family history, and extrafamilial ties affected the siblings' style of participation (Matthews & Rosner, 1988). Variables such as the number, composition, sex, and personality characteristics of siblings influenced who provided what kinds of care. Conflict was reported in half of the families and in most cases it had been evident prior to providing care to parents. The effect of having had conflict varied across families. Some siblings were able to maintain a working relationship in order to manage the care needs of parents, while, for others, conflict resulted in withdrawing from the family unit. Matthews (1993) recommended a qualitative approach to study older families and interdependence of family members.

Several researchers have recommended the need to study the primary caregiver as part of the caregiving network in order to study the family as a functioning unit. Brubaker (1990) and Mancini & Blieszner (1989) identify the need for research that: (a) is guided by theoretical frameworks, (b) addresses issues related to the impact of changes in health on family relationships, and (c) utilizes qualitative designs to capture the dynamics of family interpretations and relationships. The methodological issue of identifying the unit of analysis in family research still remains and more research is needed on family life cycle processes (Blenkner, 1965; Brody, 1985; Carter & McGoldrick, 1984; Robinson & Thurnher, 1979). Gilliss (1983) highlighted the

difficulty of studying families based on the perceptions and interpretations of individual family members. She identified the threat to reliability and validity of the data when one individual is the primary source of data collection and cautioned that the story of the informant cannot be generalized to other members in the family (Gilliss, 1983).

However, Gilliss (1983) has suggested that data collection from one family member is valid when the family is treated as context. Research that seeks information on the impact of health of an individual on the family system is an example of when such an approach is appropriate. Interviewing one family member can provide a view of family process and interdependence (Gilliss, 1983).

### Conclusion

In conclusion, the literature review supports the need for this study. It has identified: (a) the need to address the implications and expectations of parental caregiving on family members, (b) the complexity of adult offspring's transition to a caregiving role, (c) a concern for how adult sons and daughters appraise and cope with the changes they are facing, (d) the need for more understanding of the subjective experience and perceptions of family caregivers, and (e) the fact that there is a lack of research on the experience of family units mobilizing to help cognitively aware frail elderly parents experiencing an acute health care episode.

A qualitative design was proposed to achieve a deeper understanding of the experience of adult offspring of hospitalized elderly parents. The following chapter describes the research design.

## CHAPTER III

### RESEARCH METHODOLOGY AND PROCEDURES

#### The Research Design

The design of this study is qualitative and draws on the tenets of the ethnographic research method. The goal of qualitative research is to generate rich and meaningful data from the "emic" or subjective perspective of the study participants (Lincoln & Guba, 1985). The researcher strives to learn about particular phenomena from the participants' own words, experiences, and interpretations (Field & Morse, 1985; Leininger, 1985; Mancini & Blieszner, 1989). Individuals who are the subject of the research are "informants" from whom the researcher will gain knowledge and understanding. The informants of this study were adult offspring who were experiencing change in their family system, specifically change in their parent's health and change in their family roles.

Ethnography is a way of gathering, reporting, and analyzing the ways in which informants sort out the meaning of their world (Aamodt, 1991). Leininger (1985) has identified "mini ethnography" as a type of ethnography useful for nursing research. She has defined a mini ethnography as, "a small scale ethnography focused on a specific or a narrow area of inquiry" (Leininger, 1985, p. 35). Leininger (1985) stated that the ethnographic approach is beneficial for nursing research when the intention of the researcher is (a) to learn about an experience that has not been adequately studied, (b) to capture the entirety of a human experience, and (c) to clarify and expand knowledge

about a subject or situation that has been primarily gained through the use of "etic" or objective methods (Leininger, 1985).

The subjective experience of adult offspring of hospitalized frail elderly parents has not received adequate attention. The purpose of the study was to attempt to understand their reality from their perspective. A qualitative, ethnographic approach was an appropriate means to discover the feelings, views, patterns of action, and interpretations of adult sons and daughters as they adjusted to change in their family system.

### Study Context

Three forty-bed geriatric wards of a Canadian teaching hospital were chosen as a source for participants. The in-patient beds served as part of a comprehensive geriatric service which included acute geriatric care, general geriatric rehabilitation, specialized geriatric orthopedic/amputee and stroke rehabilitation, and interim care for patients awaiting nursing home placement. Other components of the service included a Day Hospital program, geriatric and gero-psychiatry consultation, and home visiting in collaboration with community services and resources. The clinical programs were supported by interdisciplinary teams whose members included nurses, geriatricians, physiotherapists, occupational therapists, family medicine physicians, pastoral care workers, social workers, pharmacists, dieticians, speech therapists, and recreation therapists.

Patients on these wards were acutely ill people aged 65 and older with physical

illness. Included were some patients with concomitant psychiatric illness or where psychiatric features were secondary to physical illness. "Acute illness" included recognized disease entities and unexplained ill-defined symptoms of recent onset, such as falls, incontinence, confusion, immobility, which were radically interfering with independence. As well, patients had sometimes been transferred to the geriatric service from within the hospital for assessment, rehabilitation, and comprehensive discharge planning. Patients customarily suffered from multiple pathology, were frail, and were socially isolated (Department of Geriatric Medicine, 1994-95).

The origin of admissions and the destination of discharges reflected the acute care and rehabilitative nature of the geriatric service and patient population. Over the course of the data collection time period, 47% of patients were admitted from the Emergency/Observation Units. When combined with those patient admitted directly from home, usually from precrisis situations, the figure rose to 52% of admissions. Patients transferred from the hospital's medical, surgical, or psychiatric units comprised 42% of admissions. Sixty-seven percent of patients were discharged home, 16% were transferred to nursing homes, 5% to other facilities, 5% were transferred to the hospital's medical, surgical, or psychiatric units, and 7% of patients died.

### **Sample Selection**

The adult sons and daughters of patients who had been living in the community prior to their hospitalization were the target population of the study. Individual sons or daughters as opposed to whole family units were recruited. The geographic proximity

of adult offspring varied and recruitment of all adult siblings was not feasible. Within the hospital context, one of the adult offspring was usually identified as the family spokesperson. However, the intent of the study was to explore informants' view of family dynamics.

The study sample was selected through theoretical, purposeful sampling technique. The goal of a purposeful sample is to recruit informants with knowledge of the lived experience so that the range and breadth of the phenomena can be comprehended (Morse, 1991). This involves selecting informants according to the needs of the study. The changes adult offspring face may emerge gradually over the trajectory of a chronic disease process or as a result of a sudden event such as a stroke. The determining criterion for establishing sample size in qualitative research is to achieve adequacy of sufficient, complete, and relevant data (Morse, 1991). Saturation of data has been achieved when the researcher is not hearing anything new and is the test for sample size (Lincoln & Guba, 1985; Morse, 1991). In order to obtain data on the entire scope of the phenomena, both adult sons and daughters experiencing sudden change and those experiencing progressive change in their family system were recruited. Informants who were immersed in the process of adapting to these changes and were willing to describe and examine their experience were chosen.

Leininger (1985) suggests that depending on the area of interest, about 10 to 15 key informants constitute a desired sample number. A sample of 12 adult offspring had been proposed and proved to be more than adequate in achieving saturation of the data. The inclusion criteria consisted of informants who were the adult sons or daughters:

1. of a cognitively aware elderly patient on one of three geriatric wards at a Canadian teaching hospital.
2. of an elderly patient who had been living in the community prior to admission, and had experienced a sudden or progressive change in health requiring hospitalization, and had developed needs for additional help from the adult son or daughter upon anticipating future return to the community.
3. identified by the head nurse on the geriatric ward, as the family member principally responsible for providing and coordinating the resources to meet the needs of the elderly parent.
4. who had siblings (regardless of geographic location).
5. and who were able to understand English verbally and were willing to answer open-ended questions and contemplate their experiences.

Potential study informants were identified by the head nurses on the geriatric wards. The patient's hospital record and the nursing kardex were reviewed to determine patients and adult offspring who met the study inclusion criteria. Potential informants were approached by the head nurses to request whether the researcher could contact them to discuss the study (Appendix A). Appointments were scheduled with sons or daughters who indicated a willingness to discuss the project, the study was explained (Appendix B), and for those who agreed to participate in the study, written, informed consent was obtained at the time of the data collection interview (Appendix C). With respect to the informants' parents (i.e. the patients) an explanation of the purpose of the study and permission to obtain information about their health condition from their hospital chart

was requested and obtained (Appendix D).

Informant recruitment and data collection occurred over an eleven month period. Sixteen potential informants were interviewed to explain the project in order to obtain the sample size of twelve. All sixteen adult offspring had agreed to participate in the study. However, four individuals ended up not participating when two of the patients were discharged before the interviews could be arranged. Two individuals changed their minds about participating.

### **Ethical Considerations**

A fundamental requirement and responsibility of the researcher is to safeguard the rights of individuals participating in a research project. The principles of research ethics are "voluntary participation, freedom from physical or psychological harm and distress, and anonymity or confidentiality of information" (Polit & Hungler, 1987, p. 25). In order to respect the informants' basic rights, the researcher employed several strategies.

First and foremost, as previously discussed, the informants and patients were provided with a verbal and written explanation of the thesis study. Information included a description of: the nature, purpose, and duration of the study, the data collection method, how the data would be used, and the potential risks and benefits of participation. Throughout the selection process and subsequent interviews with informants it was reinforced that participation was strictly voluntary and refusal would in no way affect their parent's care. Informants had the option to withdraw from the study at anytime. However, no such requests were made.



Although the study informants were not expected to suffer any ill effects as a result of their involvement in the study, the content of the area of interest had the potential to evoke personal feelings and possible discomfort. Therefore, thoughtful attention was paid to the comfort of informants and the researcher was mindful of a number of strategies to employ should an informant experience difficulty. The researcher was prepared to offer to stop the discussion and reschedule the interview at another time. If there were issues that required attention, the researcher would, with the informant's consent, refer the adult son/daughter to an appropriate health care professional. As well, informants were assured that they could choose not to have the interview tape-recorded, could refuse to answer any question, and could choose to stop the interview at any time.

Interestingly, all informants viewed their participation in the study as a positive experience that was useful in putting events and feelings into perspective. There were no questions that any of the informants refused to answer. The interview data was held in the strictest confidence. Tape recordings and transcripts were identified by code number only and the list of informants was kept entirely separate from the data. Only the researcher had access to the list of informants. Only the researcher and her thesis chair had access to the transcripts.

### **Data Collection Methods**

Data collection methods included demographic data on the parents and adult sons and daughters (Appendix E), checklists to identify informants' appraisal of changes in

their parents' functional ability (Appendix F) and their caregiving role (Appendix G), semi-structured in-depth interview (Appendix H), and field note recording (Appendix I).

Checklists to identify the functional status of parents and the types of helping or caregiving behaviors of the adult offspring were drawn from geriatric and caregiving literature (Hansson et al. 1990; Katz et al., 1963; Lawton & Brody, 1969). The purpose of the checklists was to provide baseline information from the informants' viewpoint of the extent of changes that had occurred from the time prior to hospitalization to the time of the interviews. The checklists were used in a semi-structured format that did not limit informants' ability to give the most accurate and complete answer.

Because the goal of the study was to gain "thick description" (Lincoln & Guba, 1985, p. 125) about sensitive, personal, and complex phenomena, the interviews with informants were semi-structured and were held face-to-face. Face-to-face interviews are recommended in gathering data that are sensitive and personal (Polit & Hungler, 1985; Wilson, 1989). Face-to-face interviews also allow the researcher to observe non-verbal communication and to clarify informant's responses.

The structure of the interviews moved from open-ended structured questions to increasing structure as the analysis of informants' experience evolved. May (1991) emphasizes the importance of the researcher remaining flexible during the interview process in order to obtain information that is not preconceived and allows for discovery of the informant's viewpoint. At the same time, the researcher is seeking to gather consistent information that has enough coherence to allow for comparison between and among informants (May, 1991).

The interview questions (Appendix H) asked informants to describe their experience and their perception of: (a) the change in their parent's health, (b) their caregiving role with the parent, (c) their interaction with health professionals, (d) how they were coping, (e) how they thought their siblings were responding to the situation, and (f) the meaning caregiving had for them. The guide was pilot-tested for clarity, comprehensiveness, and feasibility with two adult offspring of older parents who had undergone health-related and role changes in their own family system, prior to its use with informants. The language of some of the questions was criticized as sounding too clinical and was adjusted accordingly.

The twelve interviews took place at a time and location mutually agreed upon, with ten taking place at the hospital, one occurring at the informant's place of employment, and one being conducted at the informant's home. The time period from the initial introduction of the study to the interviews ranged from five to eleven days. The interviews lasted from 90 to 120 minutes and were tape recorded to permit accurate retention of data obtained and to facilitate the researcher's attention to the interview process. The tapes were transcribed verbatim and reviewed for accuracy.

Field note recording of observational, personal, and methodological notes as described by Wilson (1989) was done as close to the time of interviews as possible. Observational notes are the descriptions of events, for example, where the interview was held, who was present, what happened. Personal notes contain the researcher's feelings, reactions, and interpretations of events, for example, my personal feelings evoked as informants tell their story. Methodological notes chronicle and critique how the study

is being conducted, for example, refining how questions are being posed to informants.

A system for recording the field notes enabled the researcher to retrieve and analyze their content. The pages of a notebook were divided into three columns, one for each type of field note (Appendix I). The field notes were written as soon after the interview as possible to allow the author to analyze the progress of the study, to recognize personal bias, and to refine the tactics being used for data collection.

### Data Analysis

The mechanical task of organizing the qualitative interview data was facilitated by using the computer data management system "Ethnograph" (Seidel & Clark, 1984).

Thematic analysis of the qualitative data was used as the method of interpretive analysis. Leininger (1985) describes thematic and pattern analysis as a method that "focuses on the analysis of different cognitive and identifiable themes and patterns of living or of behavior" (p. 60).

The "Ethnograph" computer program has the capacity to store, catalogue, and retrieve large amounts of data. It facilitates the researcher's interpretive task of making theoretical sense of the data (Seidel & Clark, 1984). Sequential steps developed by Leininger (1985) were used to interpret the interview data. The following description of the data analysis incorporates the mechanical tasks associated with the "Ethnograph" and the analytical tasks as outlined by Leininger (1985).

The first mechanical task was to transcribe the raw interview data directly into formatted files on a word processor computer program. The data file contained

identifiers such as file name and file notes. Line numbers were added to facilitate identifying segments of the data. The data were stored leaving a wide right margin to allow for writing codes and notes.

The first analytical step was to identify and describe components or fragments of ideas or experiences in the data (Leininger, 1985, p. 61). In accord with Seidel's and Clark's (1984) recommendation, a printed copy of the numbered data file was used to mark out important passages in pencil along the right margin. In this initial step, the author identified examples of changes in parents' health and the informants' caregiving role, the informants' interpretations of the changes, the ascribed meaning of their caregiving, their interaction with health professionals, their coping behaviors and their siblings' response to the situation.

The second step of the analysis process was to combine related data into meaningful categories and patterns (Leininger, 1985, p. 61). These passages were collated using the ethnograph word processing software. The "Ethnograph" program allows a maximum of three codes for each line of text. Codes were sorted, organized, and reorganized until a coherent category system emerged that accounted for the separate experiences of the informants. Finally, comparisons were made across categories, and across subjects, to identify the similarities and differences in descriptions of their experiences.

This process generated important insights into the complex experiences of these sons and daughters as they attempted to cope with the changes associated with the hospitalization of their frail elderly parents. The third step of analysis focused on the

identification of abstract themes formulated from the analysis and synthesis of the categories and patterns. Leininger (1985) describes themes as, "large units of analysis derived from patterns which can explain multiple aspects of human behavior" (p. 61).

In summary the "Ethnograph" program eased the mechanical task of handling large quantities of data and facilitated the researcher's conceptualization process. However, analysis of qualitative data is complex and, "much creative and analytic thinking is required to 'put the pieces' together" (Leininger, 1985, p. 60). Segments of coded data were independently reviewed by the thesis chair to establish consensual validation with the researcher.

### Establishing Trustworthiness

Establishing confidence in the study's findings and analysis is essential to the integrity of the qualitative research process. Leininger (1985) maintains that validity in qualitative research "refers to gaining knowledge and understanding of the true nature, essence, meanings, attributes, and characteristics of a particular phenomenon under study" (p. 68). The criteria of trustworthiness must be established in qualitative research, just as reliability and validity must be demonstrated in quantitative research. The criteria for establishing the trustworthiness of the data in this qualitative study were based on the work of Lincoln and Guba (1985) and Guba and Lincoln (1989). These relevant criteria included:

1. Truth Value: Credibility

The credibility of an inquiry is achieved if the research presents a faithful

description or interpretation of the experience (Lincoln and Guba, 1985; Sandelowski, 1986). In qualitative research, the researcher is the primary data collection tool. In order to ensure the quality of the study, it is important for the researcher, not only, to establish rapport with informants, but to identify personal bias and subjectivity (LeCompte, 1987). Koch (1994) states that "self-awareness of the researcher is essential" (p. 977). Acknowledging the potential affect of my personal bias and feelings was achieved through ongoing reflection of the recorded personal field notes.

One special problem that I needed to be attentive to was recognizing the role conflict I experienced between the roles of research nurse, geriatric nurse, and nurse administrator. Balancing clinical and research obligations is a common ethical dilemma encountered by clinical researchers. Koch's (1994) experience of encountering neglect and inadequate care to elderly patients during a research project highlights the poignant ethical predicaments and merging of roles that may occur.

During the course of the first few interviews I found myself responding from a clinical perspective to the situations being described. I was not being an impartial listener but was instead jumping in with suggestions and advice on how they might manage the situation. I believed I had a professional responsibility to help ease the difficulties the informants were encountering with the health care system and their personal struggles with providing parent care. I was able to relieve the tension between my roles as researcher and as clinician by waiting until the interview was completed before discussing problem solving strategies they might employ. In this way, I was able to validate their concerns and provide guidance on such things as whom they should talk

should talk to, how to advocate for a family conference, and what kinds of resources were available to them, yet not interfere with the research process.

I also found myself thinking of ways to heighten the awareness of the patient care teams to the needs, especially communication needs, of family members. I realized I had to delay acting from an administrative perspective on what I was learning from the informants. I had to separate issues related to the functioning of the patient care teams from this project in order to protect the integrity of the research. Justification for this decision was based on my concern to clearly understand the situation with a view to contributing to improved family care in the future. Discussions with my thesis chair and colleagues helped me to define and debrief the role conflicts I experienced during the interviews.

Establishing trust and rapport with informants are important to promote their sharing of rich and meaningful data. In this study, rapport was achieved by respecting the rights of informants, as previously discussed, and being sensitive to the multiple demands on their time. The initial meeting to describe the study helped establish a comfort level and openness to describing their experience. This first meeting began on the ward where they were visiting their parents. This allowed me to observe them, albeit briefly, in the context of their experience. Interestingly, the informants seemed initially surprised but, very appreciative that someone wanted to learn how their parents' hospitalization was affecting them.

I had anticipated that I might require at least two interviews with informants to obtain the data. However, possibly because the ice had been broken during the first



meeting, all the questions related to the study were fully discussed during the subsequent interview. Informants were given the option to stop mid-way through the interview but their preference was to continue, largely because they were "immersed" in telling their story and partly because it was burdensome to fit another interview into their busy schedules.

## 2. Consistency: Confirmability

This criterion refers to dependability that the findings are representative of the informants' narratives. That is, that the patterns and themes are grounded in the data base. During the course of the data collection, the researcher clarified findings and interpretations with the informants by determining accuracy of understanding as well as comparisons with other informant responses.

Being faithful to what was most important to the informants was assisted by analysis of the methodological field notes as the study progressed. In this way, listening to the informants' stories was in the foreground of the process with the interview guide providing the background. The study's progress, process, and preliminary patterns were periodically discussed with the thesis committee chair. Recurrent patterns in the narratives and not hearing anything new from informants confirmed that saturation of the data had occurred.

## 3. Applicability: Transferability

Transferability refers to the ability of research findings to "fit" into contexts

outside the study situation (Lincoln & Guba, 1985). "Fittingness" as a criterion for evaluating qualitative research is determined by the extent of similarity between two contexts (Guba & Lincoln, 1989).

This is achieved by providing sufficient contextual information and describing the rationale for the coding of data into patterns and themes. It involves displaying the descriptive data to allow readers of the study to determine if they agree with the "fit" between the data and the identification of patterns and themes. The display of the data permits the reader to decide if the experience described in the study provides understanding of adult offspring in similar contexts.

This was addressed by asking two expert geriatric nurses to review drafts of the findings, as well as, the emerging patterns and themes, to determine how well the analysis fit with their previous experiences. They confirmed that the description and interpretation was consistent with their work with families and elderly hospitalized patients. They encouraged me to increase the number of quotes from the original data as the rich and meaningful stories told in the informants' own words added value and vigour to the interpretation.

### **Conclusion**

In summary, this qualitative study was designed to investigate the subjective experience of adult offspring of hospitalized frail elderly parents. Twelve key informants were purposively selected in order to obtain substantive data. Data were gathered through interviews and analyzed using Leininger's (1985) phases of analysis. The

Ethnograph computerized software program assisted data coding and sorting processes.

Lincoln and Guba's (1985) criteria were used for establishing trustworthiness of the data.

## CHAPTER IV

### FINDINGS

#### Introduction

The findings presented in this chapter, concentrate on the components and patterns identified in the first two steps of the analysis process. The themes which emerge from the synthesis and analysis of the findings are conceptualized as a consuming, changing, and complex *Caregiving Labyrinth*. The thematic analysis is presented in the discussion chapter.

#### Demographic Characteristics

The twelve elderly patients, ten women and two men, ranged in age from 69 to 85 years, with a mean of 76 years. The twelve informants in this study, ten adult daughters and two adult sons, ranged in age from 33 to 58 years, with a mean of 45 years. The majority of them were employed outside the home and had children of their own. All of the informants lived within geographic proximity to their parents and two single daughters actually resided in the same home with their mothers.

In describing the patients and informants, a summary of their major characteristics is provided in Table 1.

#### Components and Patterns

The six components identified in the study refer to the major topics addressed

with informants, that is, parents' health, caregiving role, interaction with health professionals, coping, response of siblings, and the meaning of parental caregiving. Each component contributes to a number of patterns emerging from the data that categorize the experience of the informants. Table 2 summarizes the components and patterns.

Table 1: Demographic Profile of Patients &amp; Informants

Characteristics	n	n
	PATIENTS	INFORMANTS
Number:	12	12
Familial relationship:		
mother	9	-
father	3	-
daughter	-	10
son	-	2
Age:		
mean	76	45
range	69-85	33-58
Marital Status:		
single	-	3
married	2	5
widowed	8	-
divorced	2	4
Education:		
grade 8 or less	4	-
some high school	4	2
high school diploma	2	5
some college	1	4
college degree	1	1
Living Arrangement:		
Lives with:		
alone	7	2
spouse &/or dep.ch.	2	8
adult ch./eld.parent	2	2
siblings	1	-
Type of housing:		
apartment	2	1
house	7	11
senior housing	3	-
Informants' Siblings (n):		
mean	-	2.6
range	-	1-4

Table 2:

COMPONENTSPATTERNSThe Parents' Health*Pre-Admission Health**Crisis, Complications, and Frailty**Worries For The Future*The Adult Sons'/  
Daughters' Caregiving  
Role*Expanding Role**Anticipating/Wait and See**Monitoring/Tacit Knowing**Supporting and Encouraging Resilience*Interaction with  
Health Professionals*Relentlessly Seeking Information  
Hitting a Wall**Confidence Undermined**Pursing Involvement/Receiving  
Guidance*Coping Behaviors*Expressing Emotions**Attending to Self**Asking for Help*Response of Siblings*Frustration and Friction**Sorting It Out*Meaning of Caregiving*Life on Hold**Completing the Circle/  
Give and Take**Feeling Imprisoned*

### The Parents' Health

The first component is the parents' health. Three patterns emerged from the data in relationship to this component: preadmission health, crisis, complications and frailty, and worries for the future.

#### *Pre-Admission Health*

In terms of their health prior to this hospitalization, the patients as a whole had experienced minimal functional disability, that is, minimal difficulty performing basic activities of daily living (such as eating, washing, dressing). Assistance had been required for instrumental activities of daily living (such as, housekeeping and grocery shopping). Mobility problems such as climbing stairs were present for a number of the patients as a consequence of arthritis and previous hip fractures.

#### *Crisis, Complications, and Frailty*

The second pattern emerging from the data was related to the critical condition of their parents' health. Admission to the hospital had in most cases been precipitated by emergent and urgent conditions, presenting problems included fractured hips, congestive heart failure, urinary tract infections, vein thrombosis leading to emergency surgery, and cancer surgery. Recognition that something was wrong is illustrated by the following informants' reflections on the days leading up to taking their mothers to the emergency department:

*She had told me over a week that she wasn't feeling too good with that*



*right side, she didn't eat very much. She would eat and I would take her over salads, jelly, puddings, and she still couldn't eat, she was getting bloated on that side. So I knew something was wrong if she's only eating light foods.*

*They (emergency staff) checked her out and did urine samples and blood work and blood pressure. And they came to the consensus that it was just a small infection, that they would send her home with medication. And I said to the doctor 'pardon me, she's going to be released'? I says this is the second time in a couple of weeks that she's been in to emergency, the last time was the Z. And I says she was in there for a kidney infection and she wasn't feeling good even when she come out.*

*She had a few little falls, or she would be starting to get unsteady on her feet...she lost a lot of weight and it knocked out her sugar balance and all of that...and she's slipping into much of a depression and the whole thing was feeding off each other...that's sort of when things started to go downhill.*

Patients' course in hospital had been alarmingly circuitous, that is, just when they would think they were on the way to recovery, a new crisis would develop. Several of the patients had serious and potentially life-threatening complications during the course of their hospitalization. Complications included the development of pneumonia, kidney failure, delirium, septic shock, stroke and neurogenic bladder.

Constantly shifting directions and uncertainty of survival were distinctive elements of the parents' hospital experience. As parents fought for life, their sons and daughters

stood vigil. The following statements by two informants express how they experienced their parents' fluctuating condition:

*We were told that my dad would only be in the hospital like two, maximum three weeks which has turned into three months. He had complications with the surgery. His kidneys failed, he got pneumonia, he was in ICU for 18 days so we just kind of lived day by day not knowing if he was going to pull through even.*

*He went from a functioning person to a shadow at this point. You can't really look for tomorrow because you don't know what tomorrow's going to bring.*

*I just see her losing the ability to be independent, I think that more and more things will be unfortunately taken away from her. And I think that's what's the sad part.*

*My mother was a dynamo lady who did, she just did everything and she was an incredible woman.*

*You know, you get very sad too when you think that this is your only parent left. And you know how long are they going to be here and considering their age and all the things that are really medically unstable with them, you know it's pretty scary.*

During their hospital stay, these patients had been relocated from the Emergency and Observation Units, back and forth between the Intensive Care Unit, surgical and medical units, and were on geriatric units when their sons and daughters were

interviewed. The length of hospital stay at the time of the interview ranged from four weeks to five months.

The frailty caused by chronic diseases and acute illness were affecting the elderly patients' functional and emotional capabilities and what would eventually happen for them was still ambiguous. Each patient had a number of co-morbidities in addition to their presenting problem. Diagnoses included conditions such as diabetes, heart disease, osteoarthritis, chronic obstructive lung disease, and hypertension. Changes associated with aging, such as decreased vision and hearing, were also contributing to their heightened vulnerability.

#### *Worries For The Future*

The focus of the third pattern was related to what the future held. Informants were worried and fearful about their parents' future health. Worries about what lay ahead for their parents centered around the prognosis and trajectory of health problems and their parents' ability to continue living in the community. As one daughter stated, "I'm really getting stressed worrying how my mom's going to cope when she comes home". Fear that parents would be dependent had surfaced and anxiety about their will to recover was evident. One informant commented, "Well, I'm worried that he doesn't want to get stronger where I think he could. I'm worried that he's just going to give up".

In some cases the hospitalized parents had been providing care to their spouses prior to their own illness. Therefore, not only were informants worried about what the

health outcome would mean for the hospitalized parent, but also what the consequences would be for the other parent and the informant's expanding role. The fear of falls and whether a parent could continue to drive stood out on the list of concerns raised.

In addition to uneasiness about the prognosis of their parents' chronic health problems, the specter of mental impairment had raised its head. Some of the parents had experienced cognitive disturbances, such as memory loss and absent-mindedness through the course of their hospitalization. The possibility of future mental problems was weighing on informants' minds as this comment illustrates:

*More than anything, the biggest worry would be if her mind goes and she gets forgetful and then she can't live on her own...plug in the kettle and then forget about it or something or have the stove going and put her hand in it or stuff like that is what concerns me.*

### **The Adult Sons'/Daughters' Caregiving Role**

The second component arising from the study is the adult sons' and daughters' caregiving role before and during the hospital experience. Four patterns were important to the informants' caregiving process: their expanding role, anticipating needs/wait and see, monitoring care/tacit knowledge, and encouraging resilience.

#### ***Expanding Role***

The first pattern relates to the expansion of their role. Some of the informants had been caregiving for quite a long time (up to 7 years) whereas others were relative

newcomers to this role. Prior to their parents' hospitalization, most informants had primarily been required to help with with instrumental activities of daily living, such as housekeeping, grocery shopping, and transportation, as well as with emotional-social support.

Informants described the process of becoming involved in caregiving as something that occurs naturally. One informant remarked, "it kind of just happens, like you don't really almost notice it happening it just seems to start, I guess because they're sick. You have to do what you have to do". Three informants reported having previous caregiving experience with a parent who had died. Two daughters were presently caring for both parents. The demands on these informants were great as they ran from one parent in the hospital to the other in the community, and then to their own families.

Previous hospitalizations had resulted in changes in their role. One informant described how her role had expanded over the previous six months following her mother's hip surgery:

*I think since last summer, since her hip surgery the responsibility of me has increased, you know. I had to do her laundry, she couldn't go down the stairs. She had to go down twelve stairs in the old apartment before she moved into the seniors home...And she's found it harder making meals because of bending over, because of her back.*

All informants indicated that their role had expanded dramatically as a consequence of parents' medical crises. Throughout the crisis stage and during the

recovery and rehabilitation phases, they were actively involved in interacting with health professionals (physicians, nurses, social workers, rehabilitation therapists), visiting almost every day, monitoring their parents' condition and care, supporting and encouraging their frail parents.

### *Anticipating/Wait and See*

The second pattern to emerge throughout the hospital experience was preparing for their expanded caregiving role. Informants knew their parents would be relying on them more. As they looked to the future, they were anticipating and thinking about their parents' needs. Their first goal was to promote recovery and discharge from hospital. Because the medical and functional outcomes were still not clear, a number of the informants were in a "wait and see" pattern. However, contingency plans were forming in their minds, although generally these had not been discussed with their parents. One daughter, when asked if she thought her mother might need more personal care, such as help with bathing and dressing responded:

*Oh definitely. She was able to do all of that before. Today we just discussed that and she was very apprehensive. She told her therapist that she didn't want any help, that she was perfectly capable of showering or whatever, but today when I insisted that they do a home visit they'll realize that she cannot do that. So I think she's feeling pretty lousy right now, like she's upstairs in her room, she's feeling pretty lousy because she had to consent to have someone come in a couple of times a week to bathe her, I think she's not happy with that.*

There was intense sensitivity about choosing the right time and manner of bringing up difficult matters with their mothers or fathers. Informants wanted to make decisions collaboratively with their parents and to prevent premature decisions. As one son remarked, he did not want to cast doubts in his mother's mind about her ability to regain independence:

*I wouldn't mention it (i.e. tentative plan for supporting her in the community), I don't want her to think, because she's so positive that everything's fine, so we'll just leave it at that and see what happens. Unless it's downright obvious that she can't cope and then I would certainly say something. But, you know, if she feels she can do something, until she sort of proves otherwise...*

One topic that was particularly difficult for offspring to contemplate, let alone broach with parents, was the possibility that they might not be able to continue living in the community and/or in their own homes. The thought of introducing the idea that their parents should move from their homes or that they might need ongoing nursing care produced considerable distress. For one informant, the worry that she might have to take her mother into her home was something she couldn't bear thinking about and wanted to postpone considering for as long as possible.

Part of the dilemma was a fear of hurting their parents:

*You don't want to insult them. You don't want to say this is filthy, it's got to be cleaned, because nobody wants that. I don't know if we can ever get him out of there. Maybe if he's really feeling sick he might be a little more*

*cooperative, but I don't know, we'll have to wait and see."*

Another informant, whose mother and aunt lived together, was concerned for the potential conflict that might unfold:

*I think she (the aunt) really wants her (the informant's mother) to come home, you know. And today I suggested to her that they may have to sell the house and I think she's worried because certainly my brother and I have talked about it and if my mom has to sell and move into an apartment I mean we'd like her closer in our end of the city. My aunt doesn't feel very comfortable in that end of the city. So there'll be major, I mean there's going to be lots of conflict.*

### ***Monitoring/Tacit Knowing***

The third pattern related to the caregiving role that unfolded during the course of their experience was that of monitoring their parents' condition and care. This became a way of life during the hospital experience. Throughout the interviews, informants described the vigilance they maintained in keeping track of such things as their parents' nutrition, bowel movements, strength, and mood. They experienced tremendous guilt when they failed to observe significant changes in their parents.

On other occasions, heart-wrenching anger would ensue when their tacit knowledge that something was terribly wrong was either ignored or minimized by the doctors and nurses. The following are two comments made by informants:

*And then he was in step-down, he got sick again and couldn't breathe, and*



*here's another thing too that I think to myself, 'where was I that I couldn't see this happening'. He lost so much weight, he was so sick he wasn't eating. They eventually came to the conclusion that he didn't have enough calories to work his lung...they put him back into intensive care to feed him through a feeding tube. And I kick myself for not thinking to myself he's getting skinnier and skinnier and couldn't I think they should be feeding him.*

*And I called Dr. C. and I said you know I think my dad's getting sick. And he said no there's no reason to keep him in hospital. And they said that my dad was capable of looking after himself, which he wasn't even before he went in hospital the first time. Twenty-four hours after he was discharged we had to rush him to emergency. They put him in Intensive Care, he needed three blood transfusions.*

### ***Supporting and Encouraging Resilience***

The fourth pattern of caregiving that emerged throughout the study was that adult sons and daughters were supportive to their parents. They provided emotional succor, especially in relation to the losses parents were enduring. Being present at the time parents were told news of their prognosis was considered essential but unfortunately did not always occur. One daughter described the devastated state she found her mother in after the doctor told her "bad" news with no one there to support her and query the full meaning of what had been said.

In some situations informants felt impotent. One daughter talked about how

difficult she found seeing her father's heavy spirit. She felt incapable of helping him to open up and talk about his feelings and powerless to influence his will to recover. She remarked, "it's hard to talk to him, he's set in his ways and you can't talk to him about the future".

The desire to help rebuild their parents' competence and self-reliance was strong. This came through in many ways particularly in wanting to leave as much choice up to their parents as possible. One informant saw the process as being gradual:

*I think she's lost confidence from being in the hospital. I want to try to get her back into things, not as quickly as possible, when she's ready she'll know, you know. I want her to use what strength she does have, because I realize her strength's been weakened.*

### **Interaction with Health Professionals**

The third component addresses the adult sons' and daughters' interaction with health care professionals. Throughout the interviews, informants indicated that a significant aspect of the hospital experience was their relationship with members of the health care system. From their standpoint, it was a predominantly frustrating component. Such interaction was comprised of three patterns: information seeking, confidence in the system, and involvement in the system.

#### ***Relentlessly Seeking Information/Hitting a Wall***

The first pattern describes their relentless pursuit of accurate information and

inclusion into the circle of professional care. An enormous amount of energy was spent seeking knowledge and input into the care management and discharge planning of their frail parents.

What was portrayed suggests the paradoxical nature of the relationship between "informal" family caregivers and "formal" health caregivers. On the one hand, adult sons and daughters were viewed by professional caregivers as useful within the system, and on the other hand, sometimes offspring felt they were perceived as a nuisance. Informants had important understanding of their parents, as well, they would be instrumental in maintaining their parents in the community. However, in the busyness of the hospital wards, they felt they were not communicated with effectively.

The impact of not receiving timely and accurate information contributed to the informants' sense of uncertainty and worry about the future. The following remarks illustrate this frustration:

*We were prepared for some of the risks of the surgery but I don't remember anybody really telling us too much about how terribly hard anaesthetic can be.*

*I would like a debriefing, like, 'this is what to expect now, because of this and this' and just sort of clue you in to what is going on, you know. Without information you make everything out to be worse than it actually is.*

*It's very frustrating because from day to day you don't know when he's coming out. He should be more informed of what's happening to him and I feel that if I go looking for information sometimes it's like pulling teeth.*

As the above quote suggests, communication between health care personnel and patients also posed concerns. Informants reported that their parents were often left out of the information loop as well:

*Well, I sort of got the sense that she doesn't get much information either, you know. She had sort of mentioned a few times that this (a wound) was bothering her and everybody would say 'well, we'll look at it next time we change the dressing' and she was sort of frustrated that nobody would really come and have a good look at it.*

*She knew something was wrong but nobody really, her opinion wasn't counted. You know, she was sort of like the guinea pig, 'stay there, we know what we're doing'.*

### ***Confidence Undermined***

The second pattern related to their interaction with health professionals was that there was a crisis in confidence. Informants expressed unease and displeasure about a number of issues that were undermining their confidence in the health care system. For some, the loss of faith was in response to medical errors that led to serious complications. Informants' anger would be further inflamed by the doctors and nurses avoidance of the topic. Two informants were particularly shattered by the lack of credence their observations were given when they sensed (tacit knowledge) that something was terribly wrong with their parents. The dismissal of their concerns had resulted in serious consequences for their parents.

Informants emphasized the negative effect they felt health care reform was having on the system. The interviews took place over a period of time when the ratio of professional nursing staff was being reduced. They pinpointed a series of repercussions, including the lack of continuity in care, the lack of time nurses had to communicate and respond to their needs, and the lack of training the nurses aides brought to the bedside. The end result were reservations about the quality of care their parents were able to receive under these circumstances.

The following observations by informants reflect these fears:

*And one of her main complaints is, the nurse who would come in to change her dressing would be different from the one who had changed it before, so nobody knew how it was progressing. When they would change it every couple of days, of course it would be a different nurse so nobody had ever seen it and then she woke up one morning and it had been bleeding in the night.*

*I do these bits and pieces but what about people that can't do that, I really don't know. So I see the system not being what it could and I don't blame the system, I blame the cuts. So I think that the people are very good-hearted and they're doing their best. But when you see a person and you take care of them for two days and then you don't see them for three weeks, well you lose that.*

*As nice as the orderlies are, as nice as the aides are, they're not trained. They're helpful people but they cannot see if something is infected, they cannot, don't have that kind of experience, they don't have those skills.*

### *Pursuing Involvement/Receiving Guidance*

The third pattern related to their relationship with health professionals centered around how they achieved involvement. Informants were emphatic that the best approach was actively to pursue involvement. Asking questions on behalf of their parents was a common occurrence. The following are two comments made by informants:

*You need to involve yourself, people are helpful then. We've had a few meetings, I think when you approach people and involve yourself that everybody is very, very willing to help you. I've found people very helpful.*

*She's able to talk for herself but sometimes she doesn't always want to ask or she never thinks of it but I usually ask. I like to know who, what, when, where, and why.*

In spite of the frustration they encountered with health professionals, the majority of informants also recounted favorable experiences as expressed in these comments:

*It helps having the proper care and the Occupational Therapy care when people are in the hospital, in the geriatrics section. You know, therapy and stuff like that. Getting a person mobile and realizing that they're not three years old, they are 80 years old, so you have to just watch on the therapy that you give them, you know, because they're so fragile at that age, their bones and that.*

*I think she's recuperated a bit faster. The combination of the medication and the experience of the people on the ward. She knows that she is being taken care of and she is getting the care she needs. And I think psychologically that*

*makes her feel better and that helps her. So because she's feeling better I'm at ease when I'm at work.*

Informants were most grateful when nurses explained the changes they were seeing in their parents. This had a calming effect and helped them to maintain a sense of hope. Knowing what was involved in the rehabilitation phase and being kept abreast of discharge plans were also positive indicators. Being made to feel part of the team was particularly important as expressed by this informant, "some nurses will go out of their way and help you, you know, and they're friendly and they treat you as part of the team".

### **Coping Behaviors**

The fourth component emerging from the study is coping, specifically the mediators which helped informants manage the experience. Expressing emotions, attending to self, and asking for help were three important patterns in the process. Finding balance between caring for parents and caring for self represented a crucial dimension in informants' ability to cope effectively with the situation.

### ***Expressing Emotions***

The first pattern made evident related to informants' need to express emotion. The support of good friends, immediate family, and spouses of married informants was identified as essential to helping informants get through the difficult aspects of what was

happening to their parents and to weather its impact on their lives. Of particular value was sharing with people who had experienced similar situations. Having a safe place to vent and express anger was seen as crucial. The following quotes are illustrative of these sentiments:

*I have one friend that I talk to, she has a mother that's a little bit younger than my mother and she has a few problems and responsibilities with so she's comfortable with that.*

*It makes you feel like, it's not the only thing that's happening in your world, you're not alone.*

*Young people, old people, and everybody's got different experiences, different happenings, and it's not like you're one of a kind.*

### *Attending to Self*

The second pattern emerged in how participants coped related to their attending at some point to their own needs. For some informants, the crisis that led to hospitalization of their parents represented a turning point, a recognition of the need to draw back and take stock of what they were capable of taking on in their lives.

One daughter who had previously been involved in caring for her dying father had integrated the knowledge from that experience and was determined to prevent the exhaustion and frustration she had previously endured. She was mindful of the need to be clear of what she could do, and would not do, during the present situation. For example, she was perceptive of the difference between ensuring that her mother received



the help she needed and becoming the main provider of that help. She was watchful of her tendency to want to rush in and rescue her mother. Caring for her mother came to mean "enabling" rather than "doing for" her.

In addition to clarity around boundaries related to caregiving, a number of informants were cognizant of the need to attend to what was important and of value to their own lives. Having personal goals, even if some of the timelines were altered, seemed to be beneficial. Informants indicated that prayer, humor, having a good cry, and getting extra sleep had a positive impact on their ability to cope with the situation. Positive self-talk was valued by many informants as a means of coping:

*Well, I have to have a little talk with myself every once in a while. Sometimes it's hard on your nerves and I tell myself well, you can't let it get to you, you've got a mother to look after, your sisters are out of town, you're strong, be strong.*

*To go for walks sort of helps. You just have to sort of grab a hold of yourself because you can't let yourself get down and get too uptight in this day and age in society. You know you're not going off the deep end or anything. I guess that's how I sort of, maybe, have an inner strength and maybe retain my sanity a bit.*

### *Asking for Help*

The third pattern related to their coping behaviours described how they were able to ask for help. All of the informants reported themselves as providing the bulk of the

caregiving to their parents. The recognition that they needed to set limits in order to prevent resentment and burn-out led them to realize they could no longer "do it all". One informant reflected, "we don't really share responsibilities, like we should have been probably much more organized with visiting times, you know". Acting on this insight involved changing their expectations of themselves and letting siblings know they needed help. Overall, this was a difficult step because of its potential to lead to conflict and bitterness if siblings disagreed with the need to help.

### Response of Siblings

The relevance of the response of siblings was the fifth component to emerge as central to the adult children's process. Although the informants were the primary parental caregivers, they all had siblings with whom they discussed their parents' health and caregiving issues. All but one informant had at least one or two siblings residing in Manitoba. As well, the geographically distant siblings were involved in the family's response to the aging parent. Response of siblings was revealed in two patterns: tension and how it was sorted out.

### *Frustration and Friction*

The informants' description of their sibling relationships conveyed the complexity of the family dynamics that emerges during the process of caring for aging parents. Issues such as sharing the work and differing appraisals of the situation brought out feelings of frustration and friction.

*My sister hasn't been able to come in at all. I realize that she's on the farm and she's busy but it doesn't matter what month of the year it is, I've asked her to come in and stay with mom. I say I think your husband will survive without you for a few days, he can make his own meals, but no, she never comes in, she's always busy. So I've just got a little bit uptight and rather than blow my stack I've just kind of kept quiet and I've not said anything and I've said that's fine...It would be nice at a time like this for responsibility to be evened out.*

*I always have felt that the load is on me and I guess I just deal with it. Sometimes I'm resentful that my brother doesn't play a larger role.*

One critical issue involved the difference of opinion regarding what was in the best interest of parents' well-being. Simply put, in a number of situations, siblings who were less involved with their parents thought it was time for the parent to be placed in a nursing home. This contrasted dramatically with the view held by the informants, who were strongly inclined to help their parents attempt independent living in the community, even if the situation was potentially precarious.

In terms of whose appraisal would most influence the decisions being made for the future, a number of dynamics were at play. Family customs, personality traits, knowledge of parents' wishes and fears, and perception of resources were all entwined in the deliberations. The two single informants (daughters) who lived with their frail mothers were particularly concerned with the leverage their older brothers could marshal.

One of these informants was Japanese and she identified the influence that culture, gender, and age-related values had on who in the family would have the most sway in decision-making regarding the options for the parent. Both of these daughters were planning their strategies to argue their positions.

Distance, be it geographical, emotional, or rational detachment played a role in the appraisal of the situation and consequently the decisions being made within the family system. From the informants' point of view, their siblings did not have a full grasp of the slow but steady progress their parents were making or the impact premature institutionalization would have. Conversely, in some situations a sibling would not realize how many needs a parent had, for example one informant described her brother as unrealistic about their mother because he was not as close to the situation:

*And because he's a male and doesn't see things, because he's not privileged as much as to what happens as I am. And he also views it differently. My mother doesn't say to him, you know, I couldn't make it to the bathroom on time, she's not going to tell my brother that. But she brought a bag of laundry and asked me to do it, like saying I had an accident and I couldn't get to the washroom. And those are things that I'm more aware of, I don't even think he thinks about them. I don't think he thinks how does she get up and get dressed. Or does she, is she practising good hygiene when she goes to the washroom, where I'm worried about those things.*

However, there were also times when the objective outlook of a less involved

sibling was helpful to informants. One example cited was the merit in having a sibling approach a parent to discuss moving from a rural setting to an urban seniors' complex.

### *Sorting It Out*

The second pattern to emerge from the data was how informants eventually came to terms with sibling's roles:

*My sister calls periodically to see how's she's doing...So she's been calling and she's concerned, like what medication she's taking, what's wrong with her and everything. And she sort of disagreed with me at one time there, like maybe I should get on it, and I said well 'look if I have to get on it, I said how about if you come into the city and get on it'.*

*One sister does help out as much as she can, she comes in for a week and helps. And she came in when mom moved into the senior's home and she did all her packing and unpacking and washing her floors and her dishes and made her breakfast every morning and her meals for a whole week and that's the best that she could do and then she had to go back out west again. So I don't hold it against her at all. I think she's done what she can. But the other one is in a world of her own out in her little crop circle.*

Sibling tensions were counterbalanced by both appreciation of the strengths their siblings provided and recognition of the difficulties that precluded their participation. One informant's expressed appreciation and concern for her sibling:

*He is very good with my mom and they get along really well. And the last few weeks he's taken her out on Sunday's. I know that's really somewhat inconvenient and difficult for him but he's done it. And I feel bad because he's in the process of going through a divorce and he only has his children one week, like they stay with him for one whole week and then they go back to his wife on the other week. So on that week he has major responsibilities and I think he doesn't have someone to share them with so that's very difficult. On the other hand the week he doesn't have them I feel like he's very free.*

Overall, informants achieved a sharing of responsibilities with their siblings and an acceptance of their delimited roles. For some, the response to what was happening to their parents brought siblings closer together than they had been in years. Interestingly, many informants reasoned that in the grand scheme of things they were better suited to be the primary caregivers. They cited such things as having a more supportive spouse, a calmer disposition, and better coping skills that enabled them to handle the demands of the situation.

### Meaning of Caregiving

The final component proved to be the meaning of caregiving to the informants. Two aspects of meaning were addressed with these sons and daughters. The first concerned the impact caregiving was having on their immediate lives and the second was the deeper "gestalt" of caring for frail elderly parents as this stage of life. Three patterns emerged: life on hold, completing the circle, and feeling imprisoned.

### *Life on Hold*

Informants reported that caregiving was very stressful and was having a major impact on their lives. One informant remarked: "I don't really call it a burden. It's an extra responsibility, it's more responsibility in my life, I guess, more time, more hours, more days taken up." Balancing caregiving with their family and work responsibilities was taking its toll. Worrying about the future, feeling they were not spending enough time with either their parents or their children, not having any time for themselves, and feeling worn out were predominant stressors and strains related to the situation. The strain on families is evident in this informant's experience:

*My own family have resented me, you know, for not being at home for them as much. I guess the thing is once you know they're out of a crisis situation and it's so long term, that your own family responds with like well, 'you're not home, so what are you doing visiting (at the hospital) late in the day?' Until recently I would be working, I'd come from work and then I'd run home, make dinner, either say to the kids clean up or my husband would clean up...get here about 8:00, stay for an hour, an hour and a half, get home and be wiped out. Mentally and physically.*

Because of the ambiguity of what lay ahead, informants felt their lives were on hold. One informant declared "we haven't had a real life since this has happened, because I'm so involved in it". A number of informants were putting personal goals and plans on the back-burner. One son who was pursuing his university degree and working full time decided to curtail his commitments:

*I've been intending to take another course next year but I also work shift and I think that I may avoid it, depending on what kind of shape she's in when she gets out of here and how she progresses through the summer, but if she's going to be a lot more reliant on me then I'll have to forget the course at least for next year until we see what happens.*

Work commitments also had to be adjusted as described by this informant:

*I know I've had a few courses at work that I haven't taken because of my mother being in the hospital and being sick and it's just too much, I had to be home those days, I wasn't able to go in to take courses. So I sort of lost out in that respect. But I think I'll manage.*

One troubling source of discomfort was related to whether informants would have to become involved in personal or intimate aspects of caregiving such as toileting or bathing. The daughter (a nurse by profession) of one patient was worried that if her mother did not learn self-catheterization, she would be expected to provide this care. She saw this as crossing a boundary and was uncomfortable with it. The transition from providing instrumental aspects of support to performing direct personal care is a difficult shift.

### ***Completing the Circle/Give and Take***

The second pattern of making meaning out of the caregiving experience related



to their sense of life's rhythm. The personal belief that caring for their parents completed a circle and had meaningful purpose in their lives was strongly held by many informants. The following statements by a number of informants express this sentiment:

*And it really brings to mind that we're really just, you know, we're completing that cycle. I think it more than anything, it's kind of scary that it's going to happen to you. And I would hope that I would have someone really care enough about me to look after me.*

*I guess I never thought it would happen, so yeah, it feels like wow. I don't mind doing it. I think it's probably harder for them to handle that you're always there and having to do so much for them and stuff like that.*

*Dad's always been there for us, either it's been quiet, certainly not a close father like maybe some, but he's always been there...you could count on him.*

*I think looking after her, I suppose knowing that I'm able to help out, but it's times like that sometimes that you wish you were a nurse, you know, you need a little bit more medical on your ideas and ways and that. But I don't think I feel guilty, like hopefully she won't pass away for several years but if she does pass away I will not have a guilty conscience because I think I've done everything that I can do for her.*

*When you think about it it's only going to be sort of a relatively small part*

*of your time, like spread out over however long.*

The nature of the relationship with their parents also had a bearing on the sense of satisfaction they felt. One daughter expressed a deep respect for how her parents had coped with life. "So I've seen them, you know, go through some real heartbreak days, they did what they had to do and just got on with their lives. They were really good teachers. So hopefully I can teach my child some of those things". The motivation to give to parents emerged throughout the interviews:

*She's been a wonderful mother so you know, part of me wants to acknowledge that...She was very much part of my life, of growing up and being married and having children. My parents were certainly very much a part of that.*

There was a sense of "give and take" in these relationships, in that parents expressed their appreciation for the help they received and were perceived to be doing all they could to get better. One informant who had a history of bipolar depression valued the steady support her mother provided in spite of her own weakened condition. Another informant appreciated that her mother held off on making requests on days that she worked. "If she needs anything she'll call me up and tell me that she needs it but she says no rush, whenever you're available. I don't feel any pressure at all."

### ***Feeling Imprisoned/Guilt and Resentment***

In contrast to the "give and take" relationships described above, some informants

portrayed resentment for having to give up so much of their own lives. For some informants, the experience of parental caregiving was stirring up negative feelings. One daughter was beginning to "loathe" her mother's dependency. A son was feeling "smothered" by all the phone calls from his mother to run around and do things for her. The sense of being imprisoned was evident in the remarks of this informant:

*I'm stuck at the bottom of the barrel and in a hole and I can't get out.*

*I just, like I can't even say I love you any more because it's bad. I feel, it's beginning to feel indifferent and it's getting really hard. Now that she's in hospital I've been doing things that I would never get to do if she was at home.*

*When I look at the idea of her coming home, it feels like jail.*

Characteristics of parents that appeared to contribute to this emotion were demanding and critical behaviors and/or the sense that the parent was not helping themselves. One frustrated informant remarked, "and with him, he's quite demanding, like he can look after himself but he's demanding, and I couldn't just tolerate that, it's like bring me something and it's not please, it's just bring me something".

Some informants felt that whatever they did it would never be enough in their parents' eyes. This often resulted in their feeling resentful and guilty at the same time. These emotions are conveyed in the following passage from an informant's experience:

*I feel somewhat resentful. You know, the other day I didn't come to the hospital and it was the first time since my mom's been in the hospital and she was just furious.*

*She really was furious. She was very angry with me, it was on Thursday, and when I came to the house Friday because my mom came (a home visit from the hospital), HandiTransit brought her home on Friday and we all had dinner there, like she, when I walked in, she just, she wouldn't even talk to me.*

*And my brother called me on Thursday night about 10:00 and said to me, 'take your phone off the hook because mom is like if she gets a hold of you', he said, 'I suggest you go.' I said, 'what should I do'? He said, 'maybe you should go and visit her now'. And I go, 'it's 10:00 and I'm exhausted, I've been dealing with my own kids and my own issue with my daughter', I said, 'I can't, I just really cannot go'. I mean I felt terrible and I felt, I mean she was fine after.*

*...I suppose my concern is, like how successful I'm being at all of this. You know because I just give everybody part of me and nobody gets all of me. And I'm sure other people feel the same way...I suppose in the end really, you know, like am I giving enough to my mom and am I being enough of a support for her.*

### **Conclusion**

The narrative recounting of the informants' experience depicts the multidimensional and complex nature of what occurs when frail elderly parents are admitted to the hospital with an acute episode of illness. In the following chapter, the thematic analysis of the data will be presented.

The application of a metaphor will form the basis for the interpretation and

discussion of the findings. Specifically, the metaphor of the labyrinth will assist in understanding the knowledge gained from this study. An analogy will be drawn between the characteristics of the labyrinth and the comparable attributes of parental caregiving in the context of the hospital.

## CHAPTER V

### DISCUSSION

#### Introduction

The research findings are discussed in this chapter, focusing specifically on the analogy of the labyrinth to the caregiving experience of adult sons and daughters of hospitalized frail elderly parents. The findings will be discussed in relation to results reported in prior literature and the conceptual framework, and implications for nursing practice, education, and research will be provided.

#### The Caregiving Labyrinth

The themes that emerge from the findings of this study can metaphorically be described as a labyrinthine experience, one that is consuming, continually changing, and complex. Creating the image of a labyrinth in one's mind is a means to understand experientially the essence of the informants' caregiving experience.

Metaphorical labyrinths have been applied to a vast range of phenomena dating back to ancient and medieval times. The labyrinth has been used in mythology, literature, poetry, and theology to connote meanings touching on such themes as signs of complex artistry, inextricability or impenetrability, and difficult process (Doob, 1990). Contemporary applications of the metaphor "as difficult process" can be seen in Bolen's (1994) memoir of her midlife search for meaning and renewal and in McGowin's (1993) personal chronicle of her experience with the early stages of dementia.

The labyrinth metaphor has a number of essential characteristics that are reminiscent of the caregiving experience of adult sons and daughters of hospitalized frail elderly patients. Three distinct properties of the labyrinth as metaphor that highlight and bring clarity to this caregiving experience are: (a) the labyrinth as a symbol of a convoluted journey; (b) the complexity of choices as one makes one's way through the labyrinth; and (c) the center of the labyrinth as the core (heart) of meaning.

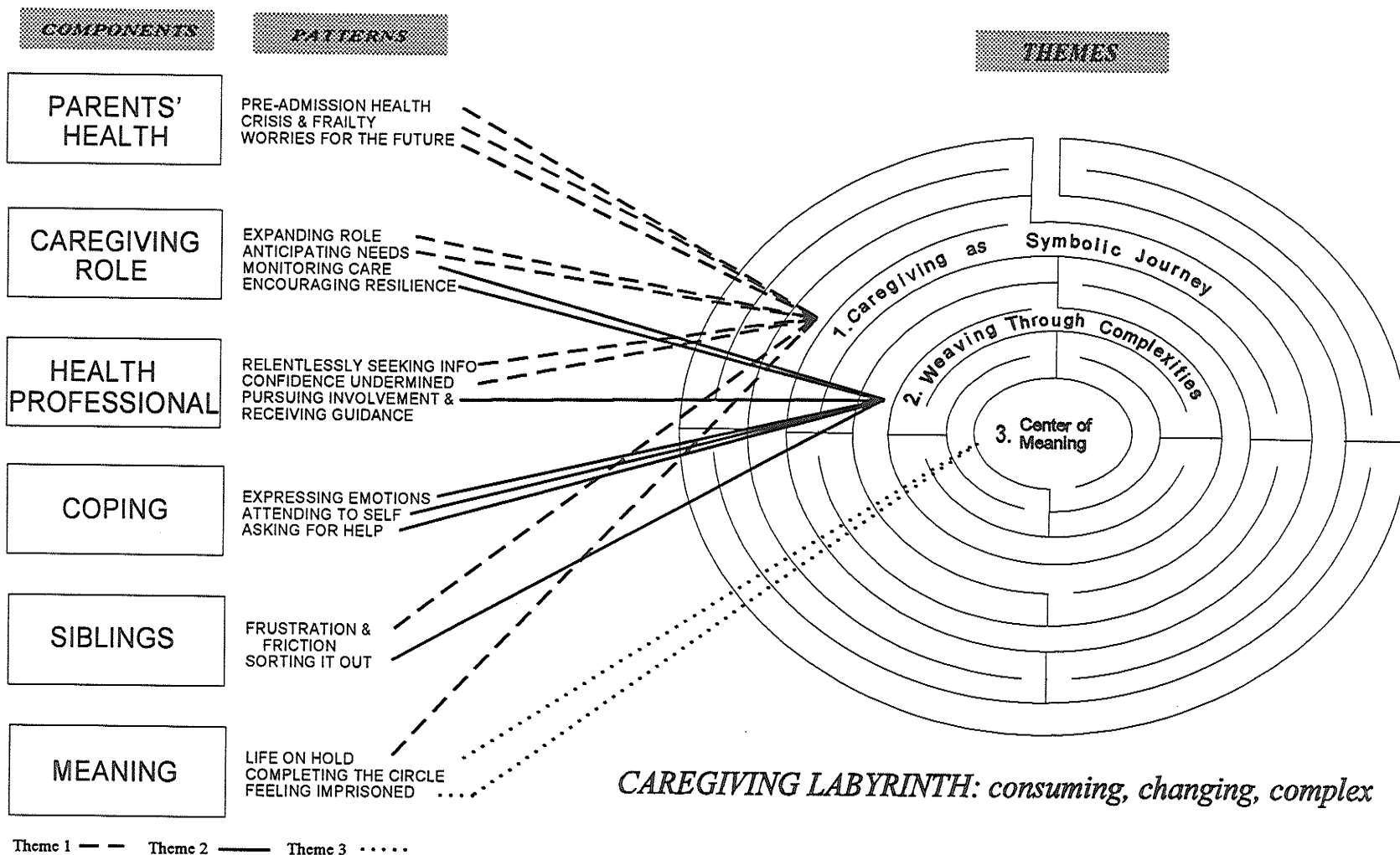
Analysis and synthesis of the data has resulted in the identification of the following three themes:

1. Caregiving as Symbolic Journey
2. Weaving Through Complexities, and
3. The Center of Meaning.

A conceptual scheme has been developed to assist in the discussion of the themes (see Figure 1, p.85). The diagram highlights the components, patterns, and themes of the study. The conceptual scheme explicates the relationship between the patterns and themes. The aspects of the experience which symbolize the notion of a consuming passage are illustrated by the broken lines leading to the first theme in the labyrinth diagram, "caregiving as symbolic journey". The process of how the informants make their way through the labyrinthine journey and manage the experience is depicted by the concrete lines leading to the second theme in the labyrinth diagram, "weaving through complexities". The competing nuances embedded in the caregiving experience are portrayed by the dotted lines leading to the third theme in the labyrinth diagram, "center of meaning".

Figure 1

# The Experience of Adult Sons and Daughters of Hospitalized Frail Elderly Parents





In the sections that follow, the themes will be interpreted within the framework of the labyrinth metaphor and discussed in relationship to findings from prior literature and the conceptual framework which guided the study.

### **Theme 1: Caregiving as Symbolic Journey**

The symbolism of a labyrinth pathway, one that is consuming, changing, and complex, is embodied in the subjective experience reported in this study. The image of a convoluted labyrinth clearly arises from the stories of the adult sons and daughters. The distinctive elements symbolizing the challenges encountered throughout the caregiving journey of the hospital experience are illustrated in Figure 1(a) (p. 87).

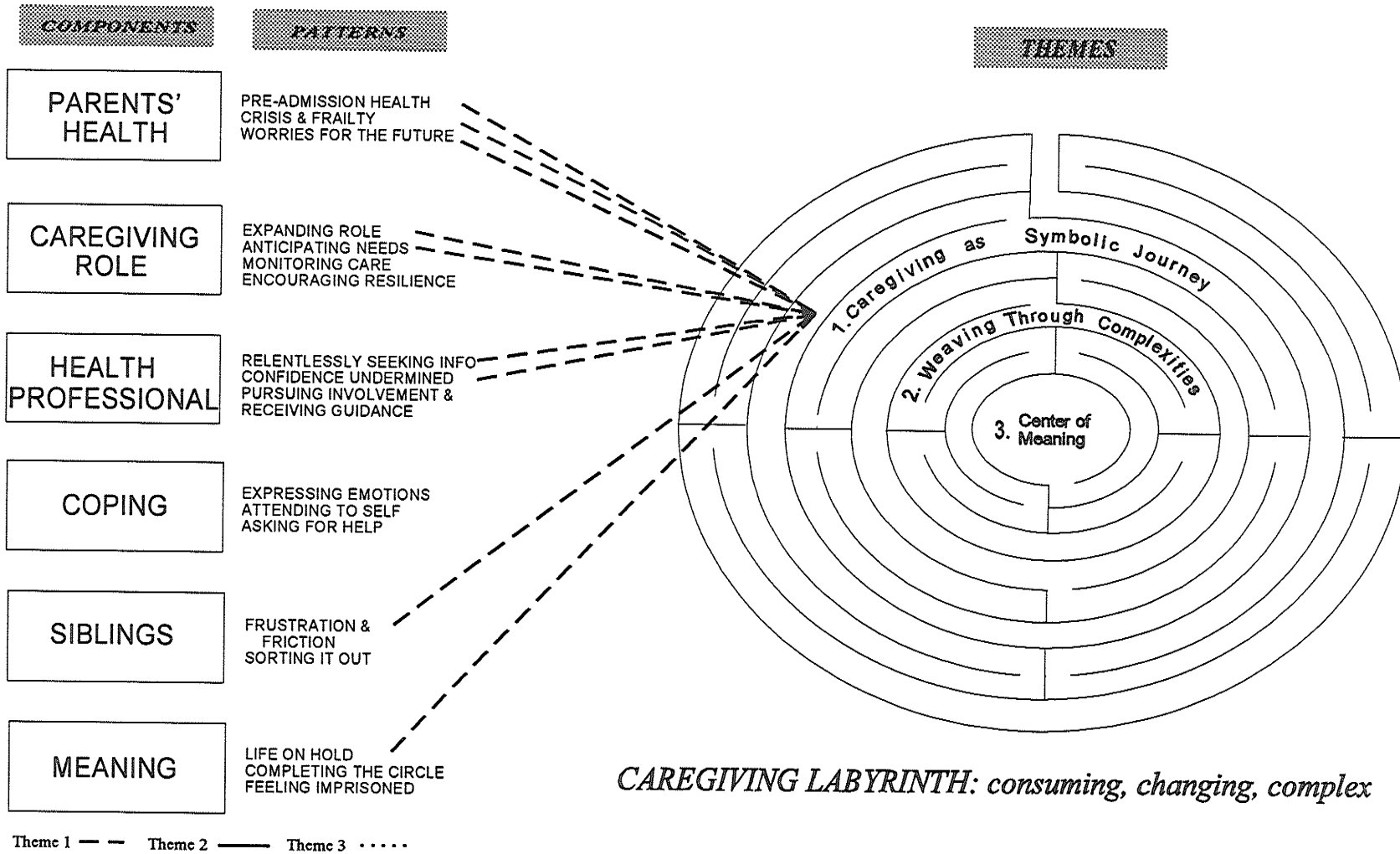
The essence of a labyrinth journey is confusion, doubt, and frustration as one ambiguity succeeds another (Doob, 1990). The pathway may be halting, episodic, and constantly shifting. Doob (1990) contrasts its unending choices and chaos, and its complex design. She states that one's orientation will shape the experience. A subjective position connotes being in the labyrinth and experiencing confusion, whereas an objective perspective signifies viewing it from above and seeing design or pattern.

Bolen (1994) suggests that once the labyrinth is entered, ordinary time is immaterial, one is in "the midst of a ritual and a journey where transformation is possible, we do not know how far away or close we are to the center where meaning can be found until we are there" (p. 34).

The data from this study illustrate that, from the time of crisis that precipitated their parents' hospital admission through to the life-threatening complications and the

Figure 1a

# The Experience of Adult Sons and Daughters of Hospitalized Frail Elderly Parents



continued uncertainty of the future, the caregiving journey was fraught with ambiguity. When in the subjective context of the hospital journey, informants conveyed that it was difficult to see far ahead, vision was curtailed. It was easy to become lost, not knowing how the experience would unfold.

The manner in which parents and informants entered the caregiving labyrinth was distinctive. In essence, the parents (patients) were abruptly thrust into the labyrinth of the hospital. The informants entered to bear witness and support their parents through the journey. They became immersed and at times felt helpless and overwhelmed as they stood by and watched what was happening. The personal lives of informants were put on hold as they dealt with competing demands, expectations, worries, feelings, and frustrations.

These data confirmed previous findings regarding the complexity of issues and vulnerability facing hospitalized frail elderly (Kuypers & Bengtson, 1983; Palmer et al., 1994; Silliman & Sternberg, 1988; Tappen & Beckerman, 1993). Rockwood et al. (1994) defined frail elderly individuals as "those in whom the assets maintaining health and the deficits threatening it are in precarious balance"(p. 492). One of the key assets was the availability of family members prepared to assist with care needs. The findings of this study bore out both the commitment of adult offspring to care for their parents and the norm that it is most frequently daughters who are identified as the primary caregiver as opposed to sons (Brody, 1981, 1985, 1987; Connidis, 1989; Rosenthal, Matthews, & Marshall, 1989; Shanas, 1980).

Hansson et al. (1990) suggested that involvement with parental caregiving follows

a progressive sequence, however, this study found that offspring were catapulted into a dominant role because of the nature of events leading to hospitalization and the subsequent sequelae. Although they may have begun the journey as indirect participants, their role quickly expanded as the complexity of caregiving issues unfolded. Bowers' (1987) model of caregiving, based on research from the perspective of family members, identified a number of key categories of care. In this study, the notion of "anticipatory" care was pervasive.

Bowers (1987) describes anticipatory care as occurring in the earlier stages of parental caregiving and as planning for "just in case" scenarios of what the future might hold. However, this study extends Bowers' meaning of anticipatory care to one which has a closer fit to the expanded typology of care described by Nolan, Keady and Grant (1995). They describe the changing character of anticipatory care as moving from "what would I do if...?" to "what will I do when...?". These researchers suggest that anticipatory care extends throughout the caregiving trajectory and changes in character from initially being an activity that is not shared with the elder to one that is shared as needs change and decisions have to be considered.

Elements of preventive and supervisory care (Bowers, 1987) were also evident in this study. Numerous obstacles were encountered as the informants monitored their parents' condition and care. One of the more frustrating walls they ran into was the interaction with health professionals, the formal members of the patient's care team. A number of troubling aspects affected the relationship including the fact that informants felt compelled to survey closely the care because of medical errors, lack of continuity,

and poor communication on the part of some health care professionals. These incidents heightened their sense of responsibility and vigilance. Their stress level increased when their expectations for care within the hospital conflicted with what actually happened.

Prior literature has confirmed the frustration and stress experienced by family members of the hospitalized elderly (Bull, 1990; Bull et al., 1995; Laitinen, 1994; Liston, Mann, & Banerjee, 1995; Silliman, 1993). An expanding body of literature recognizes the vulnerability and risk factors of the hospitalized frail elderly and the need for comprehensive geriatric assessment and management early on in the hospitalization (Germain, Knoeffel, Wieland, & Rubenstein, 1995; Hogan & Fox, 1990; Naylor, Brooten, Jones, Lavizzo-Mourey, Mezey, & Pauly, 1994; Reuben et al., 1995). According to this literature, the benefits of early intervention and follow-up by an interdisciplinary geriatric team are potentially shorter hospital stays and better functional and social outcomes.

An equally important facet that informants of this study struggled with was their relationship with siblings. Disparity in the appraisal of the situation and the contribution of time and assistance were hurdles informants confronted both on an internal level and in bringing issues into open awareness. Inner feelings of resentment and anger compounded an already difficult situation. These findings support earlier work by Matthews and Rosner (1988) and Pearlin et al. (1990). Pearlin and Turner (1987, cited in Pearlin et al., 1990) suggest that any threat to family relationships can create considerable strain.

The notion of a labyrinthine journey is conveyed by the experience of these adult

sons and daughters. The following section will discuss the challenge of managing the journey.

### **Theme 2: Weaving Through Complexities**

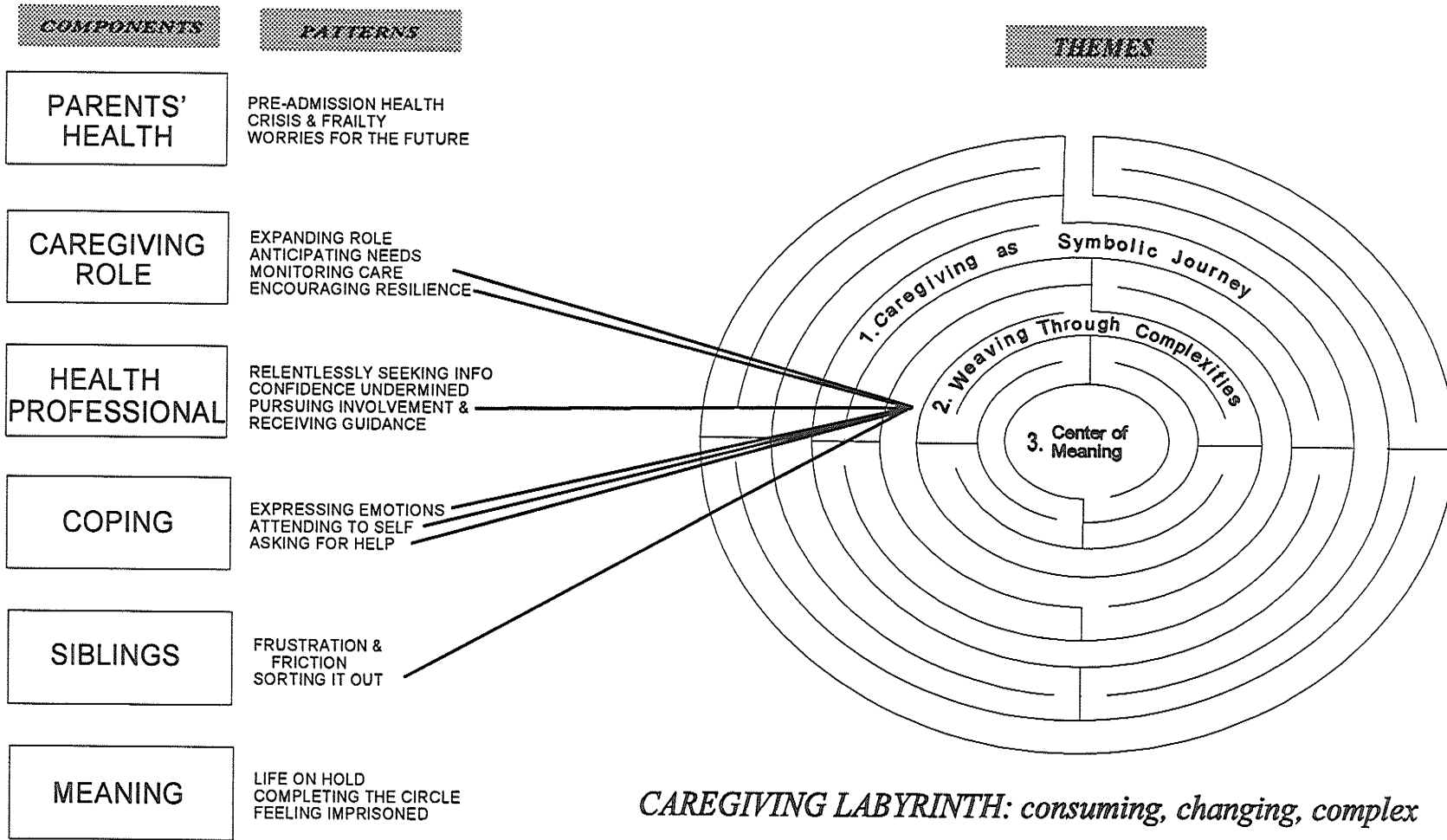
The second theme abstracted from the data involves the ways in which the informants managed the caregiving role, interacted with health professionals, coped with the situation, and shared the work with siblings. The factors representing how informants made their way through the labyrinthine journey of caring for hospitalized frail parents are portrayed in Figure 1(b) (p. 92).

One of the qualities of the labyrinth is the sense of "process" as the journey evolves. Getting through the labyrinth requires perseverance, pause for thought and discussion, and testing out various pathways. Sometimes experience, intelligence, guidance, signposts, or advice along the way serve to mediate the course to be taken (Doob, 1990). Confidence may be lost, choices may fail miserably, but frequent testing and repeated experience may lead to transcending the confusion and finding a sense of purpose and meaning (Bolen, 1994).

The notion of "process" was manifested repeatedly in the findings of this caregiving experience. There were times when the lack of clear direction was ominous and then a path became clear. Guidance came from a number of sources. For some, it was the inner value that they were doing the right thing or the perseverance they saw in their parents. For others, it was the advice of a good friend or from a nurse caring for their parent. Finding the right course to encourage resilience and independence in

Figure 16

# The Experience of Adult Sons and Daughters of Hospitalized Frail Elderly Parents



**CAREGIVING LABYRINTH: consuming, changing, complex**

Theme 1 - - - Theme 2 ——— Theme 3 ·····

their parents was achieved through trial and error. Respecting parents' wishes and decisions was finely weighed with facing the reality and consequences of frailty. The examples of how informants became more adamant in advocating for their parents and being involved with the patient care team personified this sense of unfolding clarity in their role.

One of the most disturbing findings was the perception informants had that they were not valued by the team but rather were seen as a "bother". Being seen as a bother presented in two ways. Sometimes this occurred when informants were actively pursuing information and involvement or conversely when they were perceived as not "being on board" with the team's care plan for the patient. Clearly, expectations were not always congruent between health professionals and these family caregivers.

In the first scenario, if family members are made to feel they are intruding rather than being valued as a crucial resource, a disservice is being done to them and ultimately the patient. One must question if this occurs partially because the model of hospital care has traditionally been disease-oriented and individual-focused versus family-centered. In the case of the frail elderly, however, this is not sufficient as the functional, social, and family components of care strongly influence positive outcomes.

The second scenario of being perceived as a "bother" if they did not agree with health professionals raises a number of significant issues. The trend in health care is to facilitate timely discharge and to expect family members to assume an active role in providing care to the frail elderly at home. In contrast to this expectation, many of the informants in this study indicated that the hospitalization of their parent had been a



turning point. That is, they wanted to set limits on how much care they would provide as they felt they were jeopardizing their own health and well-being.

The inherent risk in the potential cross-purposes of this situation is twofold. First, the needs of family caregivers may be overlooked and/or discounted and second, relations between the formal and informal caregivers could become conflicted. The potential consequences for family caregivers include guilt and a heightened sense of burden, both of which are detrimental to the well-being of caregivers and care-receivers.

In addition, putting pressure on families to assume a dominant role in caregiving raises ethical concerns regarding the role of health care professionals. Are physicians, nurses, and social workers being placed in the position of sometimes forcing untenable expectations? Previous literature has addressed the macro-system policy issues which have an impact on the role of family members and consequently on health professionals (Bornstein, 1994; Neysmith, 1981; Rosenthal, 1994; Wolfson et al., 1993). A closer examination of the issue of responsibility for elder care is called for during this time of dramatically reduced government-supported programs.

The data revealed that family relationships were very important to the informants. Sorting out issues with their siblings represented a crucial area that became more imperative as the demands of the situation intensified. It was evident that when family members differed with the informant in their appraisal of what should be done for the parent, it was highly stressful. The issue that provoked this most frequently related to whether a parent should be institutionalized or be discharged home. The findings support the work of Zarit et al. (1980) in that receiving emotional support and recognition from

their siblings had a bearing on the intensity of their stress level. However, there came a point when emotional support was not enough and physical assistance with caregiving responsibilities became paramount.

The coping strategies utilized by the informants, particularly the emotion-focused and problem-focused strategies confirm previous findings regarding mediating factors identified in the stress literature (Lawton et al., 1989; Lazarus & Folkman, 1984; Moos & Schaefer, 1986; Pearlin et al., 1990). While some patterns were similar across informants there were, of course, many differences in how the challenges were subjectively interpreted and confronted. As would be expected some informants had more resources to draw on, be it what they have learned from previous caregiving experience, their support network, their proactive behavior.

The process of weaving through the caregiving labyrinth was not straightforward. Whereas some caregivers managed the complexities of the situation without feeling tremendous burden, others felt predominantly overtaxed by objective and subjective aspects of the experience. Not only are there contrasts between individuals but also within one individual at different times. Individuals may feel centered and positive at one point and discouraged and resentful at another time. Characteristics identified in the stress and coping literature such as psychological, familial, social, and interpersonal factors influenced the meaning and purpose embodied in this experience.

This section has discussed the process of managing the multifaceted dimensions of caring for acutely ill hospitalized elderly parents. Metaphorically, the process has been compared with the complexity of responses, decisions, and actions involved in

making one's way through an intricate labyrinth. In the following section, the meaning ascribed to the caregiving journey will be considered.

### **Theme 3: Center of Meaning**

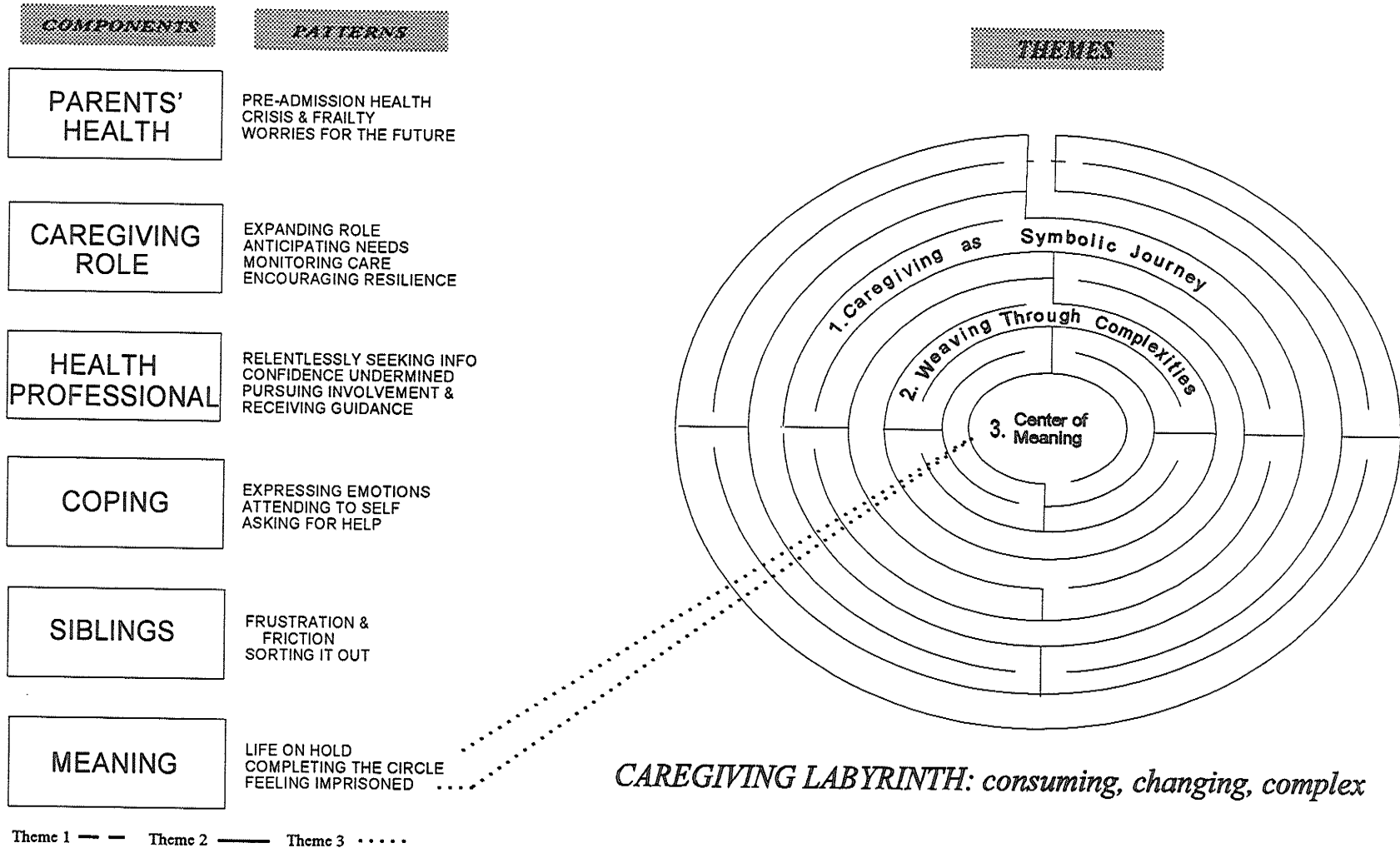
The data convey the tension of contrasting polarities existing within the caregiving experience (Figure 1(c) p. 97). Ideally, adult sons and daughters experience a sense of meaningful purpose and emerge successfully from the situation. Conversely, they experience a sense of inextricability and failure.

A characteristic of the labyrinth is its circuitous process which does not permit straightforward access to or egress from the center. Doob (1990) describes the center of the labyrinth as potentially containing something valuable. She proposes that how the labyrinth-walker copes with the challenges of the journey will determine what is learned and discovered. Bolen (1994) implies that if facing what lies ahead and not turning back or giving up, we shall integrate the experience and feel a sense of accomplishment. The process involves recognition that many of the circumstances encountered are beyond one's influence. There is much learning about living in the immediate present.

Whereas literary, metaphorical uses of the labyrinth suggest that one is either transformed or remains imprisoned, this particular connotation of the labyrinth metaphor diverges from the experience of the informants in this study. The complexity of parental caregiving in the context of the hospital did not lend itself to such a discrete categorization. The paradoxes informants' experienced in this caregiving experience

Figure 1c

# The Experience of Adult Sons and Daughters of Hospitalized Frail Elderly Parents



were intense, for example, one moment feeling the fear of losing the parent and at another point loathing the dependence of the parent. The informants felt frustration towards siblings and at the same time compassion for their difficulties. They wanted to be part of the circle of care but were frequently shut out from what was happening. The informants deeply wished to help the parent remain in the community but resented the personal sacrifices involved.

Findings from this study support work by Grant and Nolan (1993, p. 151) who identify sources of caregiver satisfaction as including the sense of "repayment for past services", the "expression of appreciation" on the part of the carereceiver, and the value of preventing premature institutionalization. However, this study did not find a sense of satisfaction derived from the feeling of "altruism" as was strongly supported in Grant and Nolan's (1993) findings. Additionally, the data suggested a relationship between the interpersonal dynamics of the informants and their parents and the perception of whether one feels imprisoned by the role or not.

This study found that the informants' process of integrating the caregiving experience was circular and its purpose and meaning shifted over time. The caregiving journey encompassed outer events and inner feelings and reflection. The findings suggest that the adult offspring in this study were in transition. Meleis and Trangenstein (1994) refer to transition periods as being characterized by "process, disconnectedness, perception, and patterns of response" (p.256). The types of transitions embedded in the context of this study included changes in the health and/or illness of elderly parents, family roles and expectations. Further work to confirm this analysis would be beneficial

to gain understanding of how meaning evolves over the trajectory of caregiving.

In summary the experience described by the informants embraces the essence and spirit of the labyrinth metaphor (Doob, 1990) in its complexity of chaos and design, choosing and retreating, imprisonment and enlightenment.

### **Conceptual Framework**

Pearlin et al.'s (1990) conceptual model on the caregiving stress process was used as a guiding framework for this study. As previously noted, this model emerged from work with family members caring for relatives with Alzheimer's disease. The purpose of this research was to understand the experience of caring for hospitalized frail elderly parents who were not cognitively impaired.

Whereas many of the conceptual components of the model were applicable to the informants' experience, a number of interesting elements emerged which are contextually relevant.

As might be expected, the primary stressors of the situation are different. Pearlin et al., (1990) state that the primary stressors are comprised of objective and subjective indicators related directly to the situation. In this study, the primary stressors appear to be the critical changes in parents' health and the ambiguity of their functional capabilities for discharge. As well, the interaction with health care professionals represents a significant stressor for caregiving offspring in this context. In contrast to caregivers of cognitively impaired relatives, the informants in this study did not express a deep sense of feeling they had lost their sense of relationship with their parents.

In terms of secondary stressors, two categories are identified by Pearlin et al., (1990), specifically role strains and intrapsychic strains. In this study, role strains experienced by informants included compression of social life, employment pressures, but most evident were family role strains and conflict. Issues related to the informants' families of origin and clear communication with siblings were problematic. The intrapsychic processes described by Pearlin et al., (1990), such as a sense of mastery, role captivity, and inner growth were captured in this study in the patterns which emerged related to the meaning of caregiving.

The mediators of coping and social support are described in the third domain of Pearlin et al.'s (1990) model. As previously discussed, mediators such as friends, humor, and self-talk played a crucial role in how the informants managed their situation. However, in the context of the hospital, another critical element appears to have an important mediating effect for many family caregivers: namely, having input and recognition in the patient's care team.

The final domain referred to by Pearlin et al., (1990) relates to the outcome of caregiving over the long haul. In this study, the informants were immersed in the process of caregiving. What lies down the road for them is unknown in terms of their ability to continue in the role.

In conclusion, the conceptual model was a useful guide for this research on caregiving. The findings from this study support the model's premise that caregiving is a stressful, dynamic process comprised of many interwoven components (Pearlin et al., 1990).

### Limitations of the Study

The greatest strength of a qualitative design is the potential for the data to provide a rich and meaningful description of the informants' lived experience. The primary method of data collection is through intensive interviews with informants. Herein lies both the strength and the limitation of the study's design.

The informants may be self-conscious and reluctant to discuss all aspects of their experience. The skill of the researcher to ask clear nonleading questions, to have good listening skills, and to expand or probe an informant's responses has direct bearing on the quality of the data obtained. At best, the researcher can be aware of these factors and approach informants in a forthright, sincere and interested manner. Reviewing the field notes during the course of data collection provided a mechanism for improving the researcher's interviewing ability and sensitivity to the informants' experience.

A related reality of this methodology is the time commitment required of the informants. An underlying premise of the conceptual framework relates to the notion of caregiving changing over time. Intensive and repeated interviews were not possible for informants, therefore, the findings represent only one slice in time.

Interpretation of interview data is also subject to the strength of the study's design. One of the goals of this study was to shed light on the family dynamics of older families facing change in their family system. A recognized difficulty in studying families is that frequently the focus of the study is on individual family members rather than the family as a whole (Costa & McCrae, 1983). Although there may be a primary caregiver supporting the elderly hospitalized patient, secondary caregivers are also



commonly involved. Assembling whole family units is problematic. This study was therefore limited in that it explored the adult son's or daughter's subjective viewpoint and their perception of other family members' appraisal of the situation. Therefore, caution must be exercised in interpreting the data beyond the individual perceptions of the informants interviewed.

### **Implications For Nursing Practice And Education**

The results of this study indicate three interconnected domains relevant to gerontological nursing practice. The therapeutic role nurses may play relates to:

1. Helping to ease the hospital journey of elderly patients and their families,
2. Guiding family caregivers through the caregiving maze, and
3. Being "present" to caregivers as they integrate the meaning of caring for parents.

Geriatric models of care suggest the need for gerontological expertise at the outset of the hospital experience, not only at the time the patient arrives on a specialized geriatric unit. Fragmentation and lack of continuity in terms of communication and information sharing with elderly patients and their family caregivers clearly emerged as a practice issue in this study. The findings pointed to the need for early and consistent involvement not only with elderly patients, but also with their family members.

A consistent health professional, such as a geriatric clinical nurse specialist, could gather pertinent information and communicate with families across the hospital stay, regardless of which unit patients were on as there are frequently a number transfers during the course of hospitalization. This approach would help promote "informed

anticipation" of care needs by adult offspring and provide the desired linkages between the formal and informal caregivers. The findings from Naylor et al.'s (1994) randomized control study on the benefits of comprehensive geriatric discharge planning by a specialized geriatric nurse are encouraging in terms of patient and family outcomes and cost-effectiveness.

Another implication for practice derived from the study is for nurses to be mindful of balancing the needs of patients with those of their family members. The findings from this study extend the existing understanding of the worries, stressors, family issues, and needs for information experienced by adult offspring caregivers. Experienced nurses are in a prime position to assess and clarify family expectations and perceptions, explain resources and options, and advocate on behalf of family members with the interdisciplinary care team.

An important domain for nursing practice is the recognition that adult offspring of hospitalized frail elderly patients are in a state of transition and nurses are in pivotal position therapeutically to affirm, validate, guide, and value this process. For example, in situations where caregivers are trying to sort out conflict with siblings and resolve the issue of caregiving responsibilities, a nurse can serve as a helpful sounding board for bringing issues into open awareness. The coaching role of nurses is also beneficial for helping caregivers establish boundaries with their parents that will promote parents' self-care abilities and prevent over-taxing the resources of adult offspring.

Last, recommendations for ongoing gerontological nursing education are: (a) to emphasize the impact of macro-level policy on practice issues, particularly in this time

of fiscal cutbacks and reconstruction of the health care system, (b) to accentuate the spectrum of care across the continuum for the frail elderly and their families as the period of hospitalization represents a discrete but limited phase in the caregiving trajectory, (c) to highlight the challenges and opportunities for gerontological nursing roles now and in the future and (d) to promote keeping current with the latest literature, attending educational rounds and conferences, and participating in gerontological nursing interest associations .

### **Implications For Nursing Research**

A number of research recommendations arise from this study. Further research into the efficacy and cost-effectiveness of various models of geriatric care, such as consultation teams and clinical nurse specialist roles is recommended. This is crucial given the predicted demographic proportion that suggest the absolute number of frail elderly individuals is increasing and their hospital utilization is significant. Collaborative studies with other disciplines including geriatricians, rehabilitation therapists, and social workers would be valuable.

Another important area of research would be longitudinal and multidimensional studies into parental caregiving throughout the caregiving process. This work would be a worthwhile contribution to gain better understanding of the patterns and meaning of caregiving over the long haul. It would be important to add to the body of knowledge of caring for cognitively aware elderly individuals in contrast to the cognitively impaired for the process of involvement may follow a different sequence, especially when health

changes occur suddenly as in the case of hospitalization for acute care management.

Meleis and Trangenstein (1994) propose that nursing research is needed on transitional experiences and nursing interventions that support healthy transitions (i.e. role mastery, well-being, energy, functional ability). Research on this area of study is urgently needed to support nurses working in acute care settings as the timeframe for involvement is shorter yet takes place in a very stressful context. By finding ways to help family caregivers manage the hospital experience and the transition to home more effectively, it may be possible to alleviate some of the stress associated with caring for elderly parents.

Last, further examination of the extended family system under stress would be worthwhile to gain a deeper understanding of how families can be effectively supported as they adapt to changing roles and expectations. Studies that address the different patterns of appraisal would shed light on how family members deal collectively with the complexities of caregiving.

### **Conclusion**

Findings from this study have resulted in a conceptual scheme that describes the experience of adult sons and daughters of hospitalized frail elderly parents as reminiscent of a consuming, changing, complex labyrinth. The sensitizing framework based on the caregiving stress process guided the research process. A qualitative methodology drawing on tenets from ethnography was used to produce findings that were rich and meaningful, allowing for the identification of patterns and themes significant to

understanding the phenomenon. Many of the findings validated results obtained in prior research. Additionally, some new perspectives and understandings emerged. Whereas findings from this study cannot be generalized to a larger population due to the limited sample size, some useful findings were obtained that may assist nurses and other health care professionals to provide more sensitive and family oriented care to hospitalized elderly patients. Recommendations for gerontological nursing practice, education, and research were offered.

## REFERENCES

- Aamodt, A. A. (1991). Ethnography and epistemology: generating nursing knowledge. In J. M. Morse, (Ed.). Qualitative nursing research, A contemporary dialogue, (pp. 40-53). London: Sage Publications.
- Archbold, P.G., Stewart, B.J., Greenlick, M.R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. Research in Nursing & Health, 13, 375-384.
- Barnes, C. L., Given, B. A. & Given, C. W. (1992). Caregivers of elderly relatives: spouses and adult children. Health & Social Work, 17(4). 282-289.
- Barer, B. M., & Johnson, C. L. (1990). Critique of the caregiving literature. The Gerontologist, 30(1), 26-28.
- Beckingham, A. C., & Baumann, A. (1990). The aging family in crisis: Assessment and decision-making models. Journal of Advanced Nursing, 15, 782-787.
- Benner, P. (1984). From novice to expert. Menlo Park, California: Addison Wesley.

- Benner, P., & Wrubel, J. (1989). The Primacy of Caring. Menlo Park, California: Addison Wesley.
- Blenkner, M. (1965). Social work and family relationships in later life with some thoughts on filial maturity. In E. Shanas and G. F. Streib (Eds.), Social Structure and the Family. Englewood Cliffs: Prentice-Hall.
- Blumenfield, S., Morris, J., & Sherman, F. T. (1982). The geriatric team in the acute care hospital: An educational and consultation modality. Journal of American Geriatric Society, 30, 660-664.
- Bolen, J. S. (1994). Crossing to Avalon. San Francisco: Harper Collins Publishers.
- Bornstein, J. (1994). Editorial: The caregiving dilemma. Canadian Journal on Aging, 13 (2), 135-137.
- Bowers, B. (1987). Intergenerational caregiving: adult caregivers and their aging parents. Advances in Nursing Science, 9(2), 20-31.
- Bowers, B. (1988). Family perceptions of care in a nursing home. The Gerontologist, 28, 361-368.

- Brody, E. M. (1981). "Women in the middle" and family help to older people. The Gerontologist, 21, 471-480.
- Brody, E. M. (1985). Parent care as a normative family stress. The Gerontologist, 25, 19-29.
- Brody, E. M. (1987). Work status and parent care: a comparison of four groups of women. The Gerontologist, 27, 201-208.
- Brubaker, T. H. (1990). Families in later life: A burgeoning research area. Journal of Marriage and the Family, 52, 959-981.
- Bull, M. J. (1990). Factors influencing family caregiver burden and health. Western Journal of Nursing Research, 12(6), 758-776.
- Bull, M.J. (1994a). Patients' and professionals' perspectives of quality in discharge planning. Journal of Nursing Care Quality, 8 (2), 47-61.
- Bull, M.J. (1994b). Elders' and family members' perspectives in planning for hospital discharge. Applied Nursing Research, 7(4), 190-192.



- Bull, M.J. (1994c). A discharge planning questionnaire for clinical practice. Applied Nursing Research, 7(4), 193-207.
- Bull, M.J., Jervis, L.L., & Her, M. (1995). Hospitalized elders: The difficulties families encounter. Journal of Gerontological Nursing, 21 (6), 19-23.
- Burnside, I. (1990). A scarce professional: the geropsychiatric clinical nurse specialist. Clinical Nurse Specialist, 4(3), 122-127.
- Carter, E. A., & McGoldrick, M.(Eds). (1984). The Family Life Cycle: A Framework for Family Therapy. New York: Gardner Press.
- Chappell, N. L. (1989). A vision for long-term care: The next ten years. Presentation to the Manitoba Health Organizations, May 12, 1989, Portage la Prairie.
- Cicirelli, V. G. (1988). A measure of filial anxiety regarding anticipated care of elderly parents. The Gerontologist, 28, 478-482.
- Connidis, I. A. (1989). Family Ties & Aging. Toronto: Butterworths.
- Costa, P. T., & McCrae, R. R. (1983). Contribution of Personality Research to an Understanding of Stress and Aging. In H. I. McCubbin, M. B. Sussman & J. M.

Patterson (Eds.). Social Stress and the Family: Advances and Developments in Family Stress Theory and Research. (pp.157-174). New York: The Haworth Press.

Coulton, C. J., Dunkle, R. E., Chun-Chung Chow, J., Haug, M., & Vielhaber, D. P. (1988). Dimensions of post-hospital care decision making: a factor analytic study. The Gerontologist, 28 (2), 218-223.

Davis, J. W., Shapiro, M. F., & Kane, R. L. (1984). Level of care and complications among geriatric patients discharged from the medical service of a teaching hospital. Journal of American Geriatric Society, 32, 427-430.

Department of Geriatric Medicine. (1994-95). St. Boniface General Hospital, Winnipeg, Manitoba.

Doob, P. R. (1990). The Idea of The Labyrinth. London: Cornell University Press.

Field, P. A., & Morse, J. M. (1985). Nursing research, The application of qualitative approaches. Maryland: Aspen Publishers, Inc.

Germain, M., Knoeffel, Wieland, D., & Rubenstein, L. Z. (1995). A geriatric assessment and intervention team for hospital inpatients awaiting transfer to a geriatric unit: a randomized trial. Aging Clinical Experimental Research, 7 (1), 55-60.

- Gillick, M. R., Serrell, N. A., & Gillick, L.S. (1982). Adverse consequences of hospitalization in the elderly. Social Science Medicine, 16, 1033.
- Gilliss, C. L. (1983). The family as a unit of analysis: strategies for the nurse researcher. Advances in Nursing Science, April, 5(3), 50-59.
- Guba, E. G., & Lincoln, Y. S. (1989). Fourth Generation Evaluation. Newbury Park: Sage Publications.
- Grandine, J. (1995). Embracing the family. The Canadian Nurse, 91(9), 31-36.
- Grant, G., & Nolan, M. (1993). Informal carers: sources and concomitants of satisfaction. Health & Social Care, 1, 147-159.
- Hall, B. L. (1989). The role of adult children in helping chronically ill hospitalized parents. Canadian Journal on Aging, 8(1), 68-78.
- Hall, B. L. (1990). Families of the hospitalized elderly: Untapped Resources. Canadian Journal of Community Mental Health, 9(1), 179-189.
- Hansson, R. O., Nelson, R. E., Carver, M. D., Neesmith, D. H., Dowling, E. M. Fletcher, W. L. & Suhr, P. (1990). Adult children with frail elderly parents: When

- to intervene? Family Relations, April, 39, 153-158.
- Hogan, D. B. & Fox, R. A. (1990). A prospective controlled trial of a geriatric consultation team in an acute care hospital. Age-Ageing, 19 (2), 107-113.
- Katz, S., Ford, A. B., Moskowitz, R. S., Jackson, B. A. & Jaffe, M. W. (1963). Studies of illness in the aged. The Index of ADL: A standardized measure of biological and psychosocial function. JAMA, 185: 94-98.
- Kennedy, L., Neidlinger, S., & Scroggins, K. (1987). Effective Comprehensive discharge planning for hospitalized elderly. The Gerontologist, 27 (5), 577-580.
- Kirschner, C. (1979). The Aging Family in crisis: A problem in living. Social Casework: The Journal of Contemporary Social Work. April, 209-216.
- Koch, T. (1994). Establishing rigour in qualitative research: the decision trail. Journal of Advanced Nursing, 19(5), 976-986.
- Kuypers, J. A., & Trute, B. (1978). The older family as the locus of crisis intervention. The Family Coordinator, October, 405-411.
- Kuypers, J. A., & Bengtson, V. L. (1983). Ecological issues in the aging family:

Intervention implications and the family support cycle. Canadian Journal of Community Mental Health, 2(2), 7-20

Kuypers, J. A., & Bengtson, V. L. (1984). Perspectives on the older family. In W. H. Quinn & G. A. Hughston (Eds.). Independent Aging, Family and Social Systems Perspectives. Maryland: Aspen Publications.

Laitinen, P. (1994). Elderly patients' and their informal caregivers' perceptions of care given: the study-control ward design. Journal of Advanced Nursing, 20, 71-76.

Lawton, H. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. Gerontologist, 9, 179.

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. Journal of Gerontology, 44 (3), 61-71.

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

Le Compte, M. D. (1987). Bias in the biography: Bias and subjectivity in ethno-science research. Anthropology & Education Quarterly, 18, 43-52.

- Leininger, M.M. (1985). Qualitative Research Methods in Nursing. Orlando: Grune & Stratton.
- Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic Inquiry. London: Sage Publications.
- Lipowski, Z. J. (1983). Transient cognitive disorders: Delirium and acute confusional states in the elderly. American Journal of Psychiatry, 140, 1426-1436.
- Liston, R., Mann, L., & Banerjee, A. (1995). Stress in informal carers of hospitalised elderly patients. Journal of the Royal College of Physicians of London, 29(5), 388-391.
- Mancini, J. A., & Blieszner, R. (1989). Aging parents and adult children: Research themes in intergenerational relations. Journal of Marriage and the Family, 51, 275-290.
- Matthews, S. H. (1987). Methods for studying older families. Paper presented at 40th Annual Scientific Meeting of the Gerontological Society of America, November.
- Matthews, S. H. (1993). The use of qualitative methods in research on older families. Canadian Journal on Aging, 12 (2), 157-165.
- Matthews, S. H., & Rosner, T. T. (1988). Shared filial responsibility: The family as the

primary caregiver. Journal of Marriage and the Family. 50, 185-195.

May, K. A. (1991). Interview techniques in qualitative research: concerns and challenges. In J.M. Morse (Ed.). Qualitative Nursing Research, A Contemporary Dialogue.(pp. 188-201). London: Sage.

McGowin, D. F. (1993). Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's. New York: Dell Publishing.

Meleis, A. I. & Trangenstein, P. A. (1994). Facilitating transitions: redefinition of the nursing mission. Nursing Outlook, November/December, (42), 255-259.

Montgomery, R. V., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of subjective and objective burden. Family Relations, 34, 19-26.

Montgomery, R. V. (1989). Investigating caregiver burden. In K.S. Markides & C. I. Cooper (eds). Aging, Stress and Health. Toronto: John Wiley & Sons.

Moos, R. H. & Schaefer, J. A. (1986). Life transitions and crises, a conceptual overview. (p 3-28). In R. H. Moos (Ed.) Coping With Life Crises. New York: Plenum Press.

- Morse, J. M. (1991). Strategies for sampling. In J. M. Morse (Ed.) Qualitative Nursing Research. (pp. 127-145). London: Sage.
- Murphy, S. (1986). Family study and nursing research. IMAGE: Journal of Nursing Scholarship, Winter, 18(4), 170-174.
- National Advisory Council on Aging. (May, 1989). Understanding Seniors' Independence Report No. 1: The Barriers and Suggestions for Action. Minister of Supply and Services Canada.
- Naylor, M. D. (1990). Comprehensive discharge planning for the elderly. Research in Nursing & Health, 13, 327-347.
- Naylor, M. D., & Shaid, E. C. (1991). Content analysis of pre- and post- discharge topics taught to hospitalized elderly by gerontological clinical nurse specialists. Clinical Nurse Specialist, 5 (2), 111-116.
- Naylor, M., Brooten, D., Jones, R., Lavizzo-Mourey, R., Mezey, M., & Pauly, M. (1994). Comprehensive discharge planning for the hospitalized elderly. A randomized clinical trial. Annals of Internal Medicine, 120 (12), 999-1006.
- Neugarten, B. L. & Hagestad, G. O. (1976). Age and the life course. In R. H. Binstock



- & E. Shanas (Eds.) Handbook of aging and the social sciences. New York: Van Nostrand Reinhold.
- Neysmith, S. M. (1981). Parental care: another female family function. Canadian Journal of Social Work Education, 7, 55-63.
- Nolan, M. R., & Grant, G. (1989). Addressing the needs of informal carers: a neglected area of nursing practice. Journal of Advanced Nursing, 14, 950-961.
- Nolan, M. R., & Grant, G. (1992). Helping 'new carers' of the frail elderly patient: the challenge for nurses in acute care settings. Journal of Clinical Nursing, 1, 303-307.
- Nolan, M. R., Keady, J., & Grant, G. (1995). Developing a typology of family care: implications for nurses and other service providers. Journal of Advanced Nursing, 21, 256-265.
- Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. The Gerontologist, 29, 798-803.
- Oktay, J. S., & Volland, P. J. (1990). Post-hospital support program for the frail elderly and their caregivers: a quasi-experimental evaluation.

American Journal of Public Health, 80 (1), 39-46.

O'Neill, C., & Sorensen, E. S. (1991). Home care of the elderly: A family perspective.

Advances in Nursing Science. 13 (4), 28-37.

Palmer, R. M., Landefeld, C. S., Kresevic, D. & Kowal, J. (1994). A medical unit for the acute care of the elderly. Journal of the American Geriatrics Society, 42 (5), 545-552.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: an overview of concepts and their measures. The Gerontologist, 30 (5), 583- 594.

Polit, D. F., & Hunglar, B. P. (1983). Nursing Research: Principles and Methods. (2nd Ed.). Philadelphia: Lippincott.

Quinn, W. H., & Hughston, G. A. (Eds.). (1984). Independent Aging, Family and Social Systems Perspectives. Rockville, Maryland: Aspen Publication.

Reuben, D. B., Borok, G. M., Wolde-Tsadik, G., Ershoff, D. H., Fishman, L. K., Ambrosini, V. L., Liu, Y., Rubenstein, L. Z., & Beck, J. C. (1995). A randomized trial of comprehensive geriatric assessment in the care of hospitalized patients.

The New England Journal of Medicine, 332 (20), 1345-1350.

Riley, M. W. (1982). The family in an aging society: A matrix of latent relationships. In A. S. Skolnick & J.H. Skolnick (1986). Family in Transition. Boston: Little, Brown.

Roach, M. S. (1987). The Human Act of Caring: A Blueprint for the Health Professions. Ottawa: Canadian Hospital Association.

Robinson, B., & Thurnher, M. (1979). Taking care of aged parents: A family cycle transition. The Gerontologist, 19 (6), 586-593.

Rockwood, K., Fox, R., Stolee, P., Robertson, D., & Beattie, B. L. (1994). Frailty in elderly people: an evolving concept. Canadian Medical Association Journal, 150 (4), 489-495.

Rosen, S. L. (1994). Managing delirious older adults in the hospital. Medsurg Nursing, 3 (3), 181-189.

Rosenthal, C.J., Matthews, S. H., & Marshall, V.W. (1992). Is parent care normative? The experiences of a sample of middle-aged women. Research on Aging, 11 (2), 244-260.

Rosenthal, C.J., Sulman, J., & Marshall, V.W. (1992). Problems experienced by

- families of long-stay patients. Canadian Journal on Aging, 11 (2), 169-183.
- Rosenthal, C. J. (1994). Editorial: Long-term care reform and "family" care: a worrisome combination. Canadian Journal on Aging, 13 (4), 419-422.
- Sandelowski, M.(1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.
- Seidel, J. V., & Clark, J. A. (1984). The Ethnograph: A computer program for the analysis of qualitative data. Qualitative Sociology, 7(1/2), 110-125.
- Shanas, E. (1980). Older people and their families: the new pioneers. Journal of Marriage and the Family, 1, 9-15.
- Shanas, E., & Sussman, M. B. (1981). The family in later life: social structure and social policy. In R.W. Fogel, E. Hutfield, S. Kiesler & E. Shanas (Eds). Aging, Stability and Change in the Family. New York: Academic Press.
- Silliman, R. A., & Sternberg, J. (1988). Family caregiving: Impact of patient functioning and underlying causes of dependency. The Gerontologist, 28(3), 377-381.
- Silliman, R. (1993). Predictors of family caregivers' physical and psychological health

- following hospitalization of their elders. Journal of the American Geriatrics Society, 41(10), 1039-1046.
- Springer, D., & Brubaker, T. H. (1984). Family Caregivers and Dependent Elderly. Beverly Hills: Sage Publication.
- Statistics Canada. (1990). Population projections for Canada, provinces and territories 1989-2010. Ottawa: Ministry of Supply and Services Canada.
- Sussman, M. B. (1976). The family life of old people. In R. Binstock & E. Shanas (Eds.). Handbook of Aging and the Social Sciences. New York: Van Nostrand Reinhold.
- Tappen, R. M. & Beckerman, A. (1993). A vulnerable population: multiproblem older adults in acute care. Journal of Gerontological Nursing, 19(11), 38-42.
- Tobin, S. (1987). A structural approach to families. In T. H. Brubaker (Ed.). Aging, Health, and Family, Long Term Care. London: Sage Publications.
- Wilson, H. (1989). Research in Nursing. (2nd ed.) Don Mills: Addison Wesley.
- Wolfson, C., Handfield-Jones, R., Glass, K. C., McClaran, J., & Keyserlingk, E.

- (1993). Adult children's perceptions of their responsibility to provide care for dependent elderly parents. The Gerontologist, 33(3), 315-323.
- Wright, L. M., & Leahey, M. (1984). Nurses and Families: A Guide to Family Assessment and Intervention. Philadelphia: F. A. Davis.
- Young, R.F., & Kahana, E. (1989). Specifying caregiver outcomes: gender and relationship aspects of caregiving strain. The Gerontologist, 29(5), 660-666.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feeling of burden. The Gerontologist, 20(6), 649-655.
- 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.

**APPENDIX A**  
**VERBAL REQUEST**

Ann Lemieux is a Registered Nurse and graduate student in the Master of Nursing program at the University of Manitoba. She is doing research here about elderly patients and their adult sons/daughters in a hospital setting.

Ann Lemieux would like to invite you to participate in her study. Would you be willing to have her talk to you to explain her study so that you can decide whether or not you would like to participate?

Whether or not you decide to participate will in no way influence the care your parent receives. All information is strictly confidential.

(If agreeable, the adult son or daughter's name is given to the nurse researcher and the nurse thanks them.)

(If the adult son or daughter declines the nurse thanks them for their time.)

## APPENDIX B

### EXPLANATION OF THE STUDY

My name is Ann Lemieux. I am a Registered Nurse and a student in the Master of Nursing Program at the University of Manitoba. As part of my nursing program, I am conducting a study on this unit entitled **"The Experience of Adult Sons & Daughters of Hospitalized Frail Elderly Parents: A Qualitative Study"**.

I am conducting this study to learn what it is like for adult sons and daughters as they adapt to health-related changes affecting their parent and family roles. Certain questions will ask for background information about your parent and yourself, such as marital status and living arrangement. Information about your parent's health condition will be obtained from his or her hospital chart.

You will be asked to respond to a number of questions about your personal experience and understanding of your parent's health condition and your role with your parent. This information will help me understand the experience of adult offspring of hospitalized elderly parents.

You are invited to participate in the study. Participation will involve one or two interviews, conducted by myself, and will take place at a time mutually convenient to us both. The interviews will take approximately one to one and a half hours. The interviews will be tape recorded if you are agreeable.

Although there may be no direct benefits to participating in the study for you or your parent the study findings may help nurses to understand better the experience of adult offspring of hospitalized elderly parents. The findings may also help nurses plan



care and respond to the needs of elderly patients and their family members in the future.

Whether or not you decide to participate, your parent's care will not be affected in any way. If you choose to participate, I will then read a consent form with you and respond to any questions you may have about the study. Your signature on the consent form indicates your willingness to participate. You are free to withdraw at any time, without effect on your parent's care.

You are assured of confidentiality. Neither your name nor your parent's name will be used on written notes or in any public report of the study. A summary of the results will be provided to you, if requested.

This Hospital as well as my thesis committee and the Nursing Ethics Committee of the University of Manitoba have given me their permission to carry out this study.

I will be happy to answer any questions you have about this study. I can be reached at [redacted]. If you wish to speak to my thesis chairperson, you may call Dr. Cynthia Cameron, at the Faculty of Nursing, University of Manitoba (474-8240).

Thank you for your time and attention.

With kind regards

Sincerely,

Ann Lemieux R.N.

**APPENDIX C**  
**CONSENT FORM**

**DESCRIPTION OF THE STUDY:**

Ann Lemieux, a Registered Nurse and a student in the Master of Nursing Program at the University of Manitoba, is conducting a study entitled "**The Experience of Adult Sons & Daughters of Hospitalized Frail Elderly Parents: A Qualitative Study**". The purpose of this study is to learn what it is like for adult sons and daughters as they adapt to health-related changes affecting their parent and family roles.

**PROCEDURES:**

If I agree to participate, my participation will involve one or two interviews, conducted by Ann Lemieux at a time mutually convenient to us both. I will be asked to respond to a number of questions about my personal experience and understanding of my parent's health condition and my role with my parent. Information about my parent's health condition will be obtained from his or her hospital chart. The interviews will take approximately one to one and a half hours. The interviews will be tape-recorded. I may choose to not have the interviews tape-recorded. I may refuse to answer any question during the interviews. I may choose to stop the interview at any time and may withdraw from the study at any time.

**BENEFITS AND RISKS OF PARTICIPATING IN THIS STUDY:**

Although there may be no direct benefits to participating in the study for me or my parent the study findings may help nurses to understand better the experience of adult offspring of hospitalized elderly parents. The findings may help nurses plan care and respond to the needs of elderly patients and their family members in the future.

**CONFIDENTIALITY:**

I am assured of confidentiality. Neither my nor my parent's name will be used on written notes or in any public report of the study. All interview transcripts will be held in the strictest confidence. Tape recordings and transcripts will be identified by code number only. I understand that Ann Lemieux's thesis committee will have access to the the transcribed data. I may receive a summary of the results if I so desire.

**INVITATION TO QUESTION:**

If I have any questions about the study, I may reach Ann Lemieux at [redacted] or [redacted]. If I wish to speak with her thesis chairperson I may contact, Dr. Cynthia Cameron, at the Faculty of Nursing, University of Manitoba (474-8240).

**VOLUNTARY PARTICIPATION:**

Participation in this study is entirely voluntary. Whether or not I decide to participate, my parent's care will not be affected in any way. If I decide to participate and then later want to withdraw, I am free to do so without any effect on my parent's

participate, my parent's care will not be affected in any way. If I decide to participate and then later want to withdraw, I am free to do so without any effect on my parent's care.

My signature on this form indicates that I have discussed the study with Ann Lemieux and have read a written explanation of it, that I have read this form, and that I give my consent to participate in this study.

**SIGNATURE OF PARTICIPANT** \_\_\_\_\_

**SIGNATURE OF INVESTIGATOR** \_\_\_\_\_

**DATE** \_\_\_\_\_

I wish to receive a final copy of this study:

Yes \_\_\_\_\_ No \_\_\_\_\_

Mail to:

## APPENDIX D

### EXPLANATION OF THE STUDY FOR PATIENTS

My name is Ann Lemieux. I am a Registered Nurse and a student in the Master of Nursing Program at the University of Manitoba. As part of my nursing program, I am conducting a study on this unit entitled **"The Experience of Adult Sons & Daughters of Hospitalized Frail Elderly Parents: A Qualitative Study"**.

I am conducting this study to learn what it is like for adult sons and daughters as they adapt to health-related changes affecting their parent and family roles. Participation will involve my interviewing your son/daughter about their personal experience and understanding of your health condition.

Certain questions will ask for background information, such as your marital status and living arrangement. With your permission, information about your health condition will be obtained from your hospital chart. This information will help me understand the experience of adult sons and daughters of hospitalized parents.

Although there may be no direct benefits to participating in the study for you or your adult child the study findings may help nurses plan care and respond to the needs of elderly patients and their adult children in the future.

Participation in this study is voluntary. Whether or not your son or daughter decides to participate, your care will not be affected in any way. You are assured of confidentiality. Neither your name nor your son/daughter's name will be used on written notes or in any public report of the study.

This Hospital as well as the Nursing Ethics Committee of the University of Manitoba have given me their permission to carry out this study.

I will be happy to answer any questions you have about this study. I can be reached at . If you wish to speak with my study supervisor, Dr. C. Cameron, you may call her at the Faculty of Nursing, University of Manitoba (474-8240). You are welcome to keep this explanation.

Thank you for your time and attention.

## APPENDIX E

## DEMOGRAPHIC DATA

THE HOSPITALIZED PARENT: (OBTAIN FROM CHART &/OR INFORMANT)

GENDER: FEMALE \_\_\_ MALE \_\_\_

AGE: \_\_\_\_\_

DATE OF ADMISSION TO SBGH: \_\_\_\_\_

DATE OF ADMISSION TO UNIT: \_\_\_\_\_

REASON FOR ADMISSION:

MEDICAL DIAGNOSES/HEALTH PROBLEMS:

MARITAL STATUS:

MARRIED \_\_\_\_\_

DIVORCED \_\_\_\_\_

SEPARATED \_\_\_\_\_

WIDOWED \_\_\_\_\_

COMMON LAW \_\_\_\_\_

EDUCATION:

GRADE 8 OR LESS \_\_\_\_\_

SOME HIGH SCHOOL \_\_\_\_\_

HIGH SCHOOL DIPLOMA \_\_\_\_\_

SOME COLLEGE \_\_\_\_\_

COLLEGE DEGREE \_\_\_\_\_

GRADUATE DEGREE \_\_\_\_\_

**PREADMISSION LIVING ARRANGEMENT:**

**LIVES:**

ALONE \_\_\_\_\_

SPOUSE \_\_\_\_\_

CHILDREN \_\_\_\_\_

SIBLINGS \_\_\_\_\_

FRIENDS \_\_\_\_\_

OTHER RELATIVES \_\_\_\_\_

OTHER \_\_\_\_\_

**PREADMISSION LIVING ARRANGEMENT:**

**TYPE OF HOME:**

APARTMENT \_\_\_\_\_

HOUSE \_\_\_\_\_

SENIOR HOUSING \_\_\_\_\_

OTHER \_\_\_\_\_



ADULT CHILDREN:

GEOGRAPHIC PROXIMITY:

---

---

---

---

---

---

---

---

---

---

---

---

**DEMOGRAPHIC DATA****THE ADULT SON OR DAUGHTER INFORMANT:**

**GENDER:** FEMALE \_\_\_ MALE \_\_\_

**AGE:** 25 TO 35 \_\_\_\_\_

36 TO 45 \_\_\_\_\_

46 TO 55 \_\_\_\_\_

56 TO 65 \_\_\_\_\_

66+ \_\_\_\_\_

**MARITAL STATUS:**

NEVER MARRIED \_\_\_\_\_

MARRIED \_\_\_\_\_

DIVORCED \_\_\_\_\_

SEPARATED \_\_\_\_\_

WIDOWED \_\_\_\_\_

COMMON LAW \_\_\_\_\_

## EDUCATION:

GRADE 8 OR LESS \_\_\_\_\_

SOME HIGH SCHOOL \_\_\_\_\_

HIGH SCHOOL DIPLOMA \_\_\_\_\_

SOME COLLEGE \_\_\_\_\_

COLLEGE DEGREE \_\_\_\_\_

GRADUATE DEGREE \_\_\_\_\_

## EMPLOYMENT STATUS:

CLERICAL \_\_\_\_\_ LABORER \_\_\_\_\_ PROFESSIONAL \_\_\_\_\_

RETAIL \_\_\_\_\_ MANAGEMENT \_\_\_\_\_ RETIRED \_\_\_\_\_

HOMEMAKER \_\_\_\_\_ OTHER \_\_\_\_\_

## NUMBER OF CHILDREN/DEPENDENTS:

## CURRENT LIVING ARRANGEMENT:

LIVES:

ALONE \_\_\_\_\_

SPOUSE \_\_\_\_\_

CHILDREN \_\_\_\_\_

GRANDCHILDREN \_\_\_\_\_

SIBLINGS \_\_\_\_\_

PARENTS \_\_\_\_\_

FRIENDS \_\_\_\_\_

OTHER RELATIVES \_\_\_\_\_

OTHER \_\_\_\_\_

TYPE OF HOME:

APARTMENT \_\_\_\_\_

HOUSE \_\_\_\_\_

OTHER \_\_\_\_\_

**APPENDIX F****INFORMANT'S APPRAISAL OF****ELDERLY PARENT'S (PATIENT) FUNCTIONAL STATUS****INSTRUMENTAL ACTIVITIES OF DAILY LIVING:**

1. Shopping:
  - on own
  - needs to be accompanied
  - unable to shop
2. Food Preparation:
  - prepares meals on own
  - needs help
  - maintains adequate diet
  - meals prepared by someone
3. Housekeeping:
  - on own
  - occasional assistance
  - does light daily tasks
  - needs help with heavy tasks
4. Laundry:
  - by self completely
  - small items
  - needs help with all
5. Transportation:
  - travels independently
  - arranges own
  - needs assistance
  - does not travel
6. Medications:
  - takes own correctly
  - takes own if prepared
  - not capable
7. Ability to handle finances:
  - manages own completely
  - needs help with major item
  - not capable

8. Ability to use phone:  
operates phone on own  
answers phone, can't dial  
does not use phone

**ACTIVITIES OF DAILY LIVING:**

1. Bathing:(sponge,bath,shower)  
self  
some help  
a lot of help
2. Dressing:(chooses clothes,  
puts clothes on in correct sequence)  
self  
some help  
a lot of help
3. Toileting:(bowel and urine)  
goes on own  
cleans self  
receives assistance  
incontinent
4. Mobility/Transfer:  
can walk 50 yards  
can climb stairs  
gets in and out of bed  
needs help  
unable
5. Feeding:  
self  
self with assistance  
fed

**SOCIAL NETWORK/SUPPORT:**

1. Visits/outing with family/friends  
once a week  
1-3 times a month  
less often  
never

2. Talks on phone with family/friends
  - once a day
  - less often
  - more often
  - not at all
3. Has someone to confide in?

references: (Katz et al, 1963; Lawton & Brody, 1969)

**APPENDIX G****THE INFORMANT'S CAREGIVING ROLE****PRIOR TO ADMISSION AND PERCEPTION OF WHAT IT NOW INVOLVES**

1. Home maintenance/housework:
2. Transportation/groceries
3. Bureaucratic mediation (obtaining information, services)
4. Money management/personal business
5. Psychological Wellbeing  
(monitoring emotional status, social participation, cognitive status, stress)
6. Physical Health  
(monitoring general health, diet, drs. visits, meds)
7. Personal Care  
(monitoring exercise, personal care, hygiene, eyesight, mobility)
8. Supervisory Care  
(coordinating and supervising the care provided by other people)
9. Protective/Preservative Care  
(protecting the parent's self-concept and self-esteem)

References: Brody, 1987; Hannson et al, (1990).



**APPENDIX H****INTERVIEW GUIDE****THE EXPERIENCE OF ADULT SONS AND DAUGHTERS OF  
HOSPITALIZED FRAIL ELDERLY PARENTS**

I understand your parent's (patient's name) health condition has changed since.... and that your role with your parent is also changing. I would like to learn more about your experience and how you are coping with these changes.

**1. DEMOGRAPHIC DATA**

I would like to begin by asking you for some background information about your parent and yourself.

**The Hospitalized Parent:** [See Attached]

**The Adult Son or Daughter Informant:** [See Attached]

**2. Informant's perception and interpretation of the hospitalized parent's change in health/functional status.**

I would like to get a sense of how you feel your parent was doing with everyday activities before being admitted to hospital and what concerns you may have now. [SEE ATTACHED IADL & ADL GUIDE]

How do you understand (parent's) present health condition?

Can you tell me what goes through your mind when you think about (parent's) health? [Probe: Now and in the future].

What concerns you most about (parent's) health?

What is your understanding of the decisions being made concerning (parent). [Probe: medical decisions, discharge plans, sense of truthfulness about what to expect etc.]

**3. Informant's perception and interpretation of what the change in the parent's health will imply for his/her role with the parent.**

In what ways were you helping your parent before his/her admission and how you see yourself helping now/or when your parent goes home. [SEE ATTACHED GUIDE]

Can you tell me what goes through your mind when you think about helping your parent

like this? How will it affect your own life?

What concerns you most about helping your parent? [Probe: capability, resources, motivation, health]

**4. The informant's ascribed meaning of parent care.**

Sons and daughters often express that caring for an older parent stirs a number of emotions. Can you describe what it has meant for you.

[Probe: (a) feelings, attitudes, emotions,

(b) developmental issues i.e. putting it into perspective in the overall schema of life, switching roles, rethinking one's attitudes, priorities, restructuring one's life;

(c) sense of purpose/significance ....protection from guilt]

Can you tell me what your relationship was like with your parent over the years? [Probe: were ties close, affectionate, strained, conflictual etc, how have they changed?]

**5. The informant's appraisal of how he/she is coping with the changes and demands of the parent's situation.**

Can you tell me what you have been doing to cope with the changes in (parent's) health and the changes in your role with your parent.

[Probe: seeking information, maintaining & developing social support, family unity and flexibility, recognizing options, having an action plan.]

Have your efforts to cope helped? Overall, how do you feel you are doing?

[Probe: -attempts to reduce painful emotions,

-feels optimistic, pessimistic,

-has a sense of mastery/confidence/hope, self-esteem,

-have there been some things that may be harmful in the long run eg. overeating, denying their is a problem etc.]

How have you faced other situations in your life that have been stressful? [Probe: Is this one as stressful, more, less; crisis?]

**6. The informant's understanding of the similarities and differences between his/her appraisal, perceptions and interpretations of parental health and caregiving, and other family members.**

I would like to learn more about your other family members. Can you tell me what

happened when (parent) was first hospitalized?

[Probe: Who identified the problem, who was called, when, what was their response. How was informant designated primary person?]

Can you describe for me how your (other family members) are responding to the situation?

[Probe: what is their definition of the seriousness of parent's condition and the need for caregiving activities]

Is your understanding of what the doctors have told you different from your (family members)?

[Probe: who agrees, disagrees]

Can you tell me how you and (family member) are working out how to deal with the situation?

[Probe: -what alternatives are being discussed,

-who thought of the plan,

-how are you deciding what to do,

-are you able to talk to each other,

-who does most of the talking,

-can you share feelings with each other, openly, guardedly, indirectly,

-how do you let each other know how you are feeling,

-how do you get your ideas across,

-do you feel that (family) understand you,

-what happens when you don't agree]

When you compare how you are coping with the situation to others in the family who do you think is having the hardest time? The least difficulty? How so? Has the situation surfaced previous areas of strain/conflict?

**7. The informant's perception of what may be helpful to adult offspring of hospitalized patients.]**

What suggestions could you make for other adult sons/daughters who are facing a similar situation?

Are there suggestions you would like to make for others (including health care professionals, family and friends) that would help you deal with the situation?

\*\*\*\*\*

**APPENDIX I  
FIELD NOTES**

**Observational**

**Personal**

**Methodological**

- \* **Observational Notes** = description of events (where interview held, who was present, what happened etc)
- \* **Personal Notes** = researchers feeling, reactions, interpretation of events
- \* **Methodological Notes** = how study is being conducted, interview techniques etc.