

THE IMPACT OF CAREGIVING

By

KAREN LOUISE LARSON

B.S.N., The University of British Columbia, 1980

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE
IN NURSING

in
THE FACULTY OF GRADUATE STUDIES
(School of Nursing)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

August 1985

© Karen Louise Larson, 1985

In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Department of Nursing

The University of British Columbia
1956 Main Mall
Vancouver, Canada
V6T 1Y3

Date August 16, 1985

ABSTRACT

The increased incidence of chronic illness among the elderly makes long-term care a health concern as the population ages. Little is known about the impact of chronic confusion on the family. This study used a qualitative approach to look at the impact on the caregiving wife of caring for a chronically confused, elderly husband. Six wives whose elderly husbands experienced chronic confusion and who lived alone with their husband were interviewed using the phenomenological method described by Giorgi (1975). The findings indicated that there is a substantial impact when the husband depends on his caregiving wife to remain in the home, especially when the wife is older and experiences chronic illness herself. Overall, these negative effects were congruent with those reported by other researchers, suggesting that the general impact of long-term care is burden.

The themes in the caregivers' accounts revolved around three main concerns: the management of the husband's dependency, the maintenance of the family as a unit, and the acceptance of the caregiving situation. Chronic confusion occurred with other chronic illnesses and compounded the husbands' impairments. Interpersonal relations were also adversely affected, and the wives had to learn to take control of the family amidst physical strain and social

isolation. The caregiver found that her life came to revolve around the needs of her husband; she derived meaning from fulfilling her perceived duty as a wife. The presence of chronic illness and aging intensified her experience of burden. Despite the costs to her well-being, the wife was devoted to maintaining her husband at home.

The caregiving wife needs support to deal with the husband's care and its negative consequences, but her desire to remain as independent as possible appears to conflict with her utilization of outside support. Nursing intervention should be directed toward assisting the caregiver to cope with the husband's care and with its negative effects on her. Nursing education should prepare the practitioner with a broad background in community health nursing, gerontology, and geriatrics to enable her to provide nursing care to these kinds of families. Future nursing research should focus on furthering the understanding of the impact of caregiving as a basis for planning the most helpful interventions to support the caregiver.

TABLE OF CONTENTS

| | PAGE |
|---|------|
| ABSTRACT | ii |
| LIST OF FIGURES | viii |
| ACKNOWLEDGEMENTS | ix |
| CHAPTER 1: INTRODUCTION | 1 |
| Background Of The Study | 1 |
| Statement Of The Problem | 4 |
| Purpose Of The Study | 5 |
| Definition Of Terms | 5 |
| Assumptions | 6 |
| Limitations | 7 |
| Summary | 7 |
| CHAPTER 2: REVIEW OF THE LITERATURE | 8 |
| Introduction..... | 8 |
| Professional Literature | 9 |
| Chronic Mental Impairment And The Family | 9 |
| Research Literature | 13 |
| Studies Related To The Caregiver and Chronic Illness | 13 |
| Studies Related To The Caregiver and Chronic Illness In The Elderly | 17 |
| Studies Related To The Caregiver and Chronic Mental Impairment In The Elderly | 24 |
| Summary | 29 |

| | |
|---|----|
| CHAPTER 3: METHODOLOGY | 30 |
| Introduction | 30 |
| Selection Of A Method | 30 |
| Rationale For Choosing A Qualitative Approach | 30 |
| The Phenomenological Method | 31 |
| Selection of the Study Group | 34 |
| Subjects | 34 |
| Criteria For The Caregiving Wife's Participation | 34 |
| Criteria For the Husband's Participation | 35 |
| Procedure For Obtaining The Participants | 36 |
| Procedure For Data Collection | 37 |
| Procedure For Data Analysis | 37 |
| Summary | 38 |
| CHAPTER 4: PRESENTATION OF THE FINDINGS | 39 |
| Introduction | 39 |
| The Caregiving Situation | 39 |
| Characteristics Of The Caregiving Households | 39 |
| Characteristics Of The Caregiving Wives | 40 |
| Characteristics Of The Dependent Husbands | 42 |
| The Caregivers' Accounts | 42 |
| Management Of The Husband's Dependency ... | 43 |
| Changes in the husband's functioning | 43 |
| Caregiving tasks | 45 |
| Effects on the caregiver | 45 |

| | |
|---|-----|
| Maintenance Of The Family As A Unit | 53 |
| Effects of confusion on relationships | 53 |
| Changes in the caregiver's role in the family | 57 |
| Acceptance Of The Caregiving Situation ... | 60 |
| Minimizing the changes in the home environment | 60 |
| Valuing the caregiving role..... | 62 |
| Summary | 66 |
| CHAPTER 5: DISCUSSION OF THE FINDINGS | 68 |
| Introduction | 68 |
| Conceptual Framework | 68 |
| A Discussion Of Burden | 75 |
| Burden And The Management Of Dependency | 75 |
| Burden And The Maintenance Of The Family | 79 |
| Burden And Acceptance Of The Situation | 82 |
| A Synopsis of Burden | 87 |
| CHAPTER 6: SUMMARY, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS | 89 |
| Summary | 89 |
| Conclusions | 91 |
| Implications For Nursing | 92 |
| Implications For Practice | 92 |
| Implications For Education | 96 |
| Implications For Research | 97 |
| Recommendations | 99 |
| REFERENCES | 101 |

| | |
|---------------------------------------|-----|
| APPENDIXES | 106 |
| Appendix A: Introductory Letter | 106 |
| Appendix B: Consent Form | 108 |
| Appendix C: Sample Questions | 109 |

LIST OF FIGURES

| | PAGE |
|--|------|
| Figure 1. The Conceptual Framework Derived From The Literature | 71 |
| Figure 2. The Conceptual Framework Modified On The Basis Of The Findings | 86 |

ACKNOWLEDGEMENTS

Special thanks are due to my professors, Margaret Campbell and Kirsten Hyde, for their indefatigable effort and valuable feedback. Nor could I have carried out this study without the participation of the caregiving wives, and I am indebted to them for inviting me into their homes and sharing their experiences with me. I appreciate the contribution of Lynda Thornton, Judy Kelly, and the other nurses in the Burnaby Health Department who helped me to contact the participants for the study. Finally, I would like to thank my husband Randy for his inspiration, sustenance, and facility with computers.

CHAPTER 1

INTRODUCTION

Background Of The Study

The population of most industrialized nations appears to be aging. This social trend is documented in Canada where both the number and the proportion of Canadians living beyond the age of 65 years have risen since the turn of the century. In 1901, 5% of the population was over 65 years of age, and in 1976, this ratio had increased to 8.7%. By 2001, it is estimated that the proportion of elderly will reach between 11% and 13% of the population (Statistics Canada, 1979). This growth is both absolute and relative. By 1976, the general population had quadrupled in size, while the elderly population was seven times larger.

One consequence of this increase of elderly is a concomitant increase in chronic illness (Branch & Jette, 1981; Commission on Chronic Illness, 1957). Combined with other trends such as the eradication of many acute infectious diseases, the increase of chronic illness makes chronic care a major health concern for this and future decades (Brody, Poulshock & Masciocchi, 1978; Mechanic, 1979). The Canadian government has acknowledged that the elderly population is at risk for the occurrence of chronic illness and that the health care needs of this group will multiply (Lalonde, 1974).

The area of chronic illness has received limited attention in health care in the past, and the need for research is substantial (Klein, Dean, & Bogdonoff, 1967; Litman, 1974). More studies need to be done on the various types of chronic disabilities and their impact on different kinds of families (Litman, 1974). The nature of chronic illness calls for a more comprehensive approach than that found in acute illnesses: "To treat medically the problems of any chronically ill patients, one has to supplement the strictly medical knowledge with psychological and social knowledge - about the patient's family and other intimates, as well as about the patient himself" (Strauss, 1975, p. 4).

A serious chronic condition that occurs in the population is deterioration in mental functioning (Kay, 1972). It has been suggested that "mental impairment, by whatever name, is the most critical deterrent to the quality of life in later years" (Wolanin & Phillips, 1981, p. ix). Chronic confusion is a significant mental impairment, although its operational definition as a nursing diagnosis is not well developed (Wolanin & Phillips, 1981).

Confusion may occur as an acute or chronic condition, and some of its features are loss of memory, lack of judgement, and disorientation to time, person, or place. Many physical, psychological, and social variables may be linked to this condition. Chronic confusion is not a static state and may be aggravated by such variables as malnutrition, certain medications, isolation, or depression (Wolanin & Phillips, 1981). Chronic confusion in the elderly

is commonly associated with a variety of medical diagnoses including chronic organic brain syndrome, cerebral vascular accidents, hypertension, diabetes and anemia (Wolanin & Phillips, 1981).

As the number of aged people with chronic confusion increases, managing their long-term care will pose problems for caregivers in the home and institutional environment (Brody, 1982; Burnside & Moehrlin, 1980; Wolanin & Phillips, 1981). Wolanin and Phillips (1981) state that "with the increase of confused elderly in their own homes, in hospitals and in long-term care units, the problems of caregiver burnout deserve intensive study. The caregiver may be the family member or the person hired by an institution; both need study" (p. 375). The care of the chronically confused makes great demands on personal and societal resources (Burnside & Moehrlin, 1980; Kay, 1982). Morycz (1980) elaborates on the need for research on the impact of mental impairment:

The study of stress on relatives of mentally impaired older persons is thus crucial. As a first step, it is important to describe and enumerate the burdens placed on the family by an elderly individual who has a chronic organic brain syndrome. (Morycz, 1980, p. 25)

One family member who is likely to be placed in the caregiver role is the wife. Women, as a group, have traditionally been allocated the nurturing roles in society (Brody, 1974). Recent evidence continues to support this notion and indicates that the vast majority of caregivers in

the home are women (e.g. Goldstein, Regnery, & Wellin, 1981; Pringle, 1982). Women tend to be married to men older than they are and to live longer than their husbands, leading to an increased probability that wives will be called upon to care for ill husbands (Fengler & Goodrich, 1979). In addition, elderly men are more likely to be married than elderly women. Thus, when these men are ill, they are more likely to have their wives care for them (Shanas, 1979). Lopata (1973) found that 40% of widows who had taken care of their husbands during the husbands' last illness had been in the caregiving role for one year or more. Elderly wives caring for disabled husbands are in particular need of support and have been described as hidden patients (Fengler & Goodrich, 1979).

Statement of the Problem

The management of chronically confused elderly persons poses long-term care concerns to caregivers (Wolanin & Phillips, 1981). Not only is there a paucity of data on the management of long-term illness in general, but even less is known about the effects on families caring for confused elderly dependents (Morycz, 1980). No studies could be found that assessed the impact on the caregiving wife of caring for a confused elderly husband.

The ability of the wife to cope with the caregiving situation plays a key role in keeping the family unit intact, as caregiver burnout has been identified as a major cause of

the institutionalization of the chronically ill adult (Sanford, 1975; Smallegan, 1981). The experience of the wife providing long-term care merits study (Brody, Poulshock, & Maschiocchi, 1979; Crossman, London, & Barry, 1981) in order to describe the stresses that lead to caregiver burnout (Goldstein et al., 1981; Morycz, 1980) and to provide a knowledge base for planning the most helpful ways to support the caregiving wife (Fengler & Goodrich, 1979). The focus of this study is the experience of the older caregiving wife whose elderly husband experiences chronic confusion.

Purpose of the Study

1. To examine the impact on the caregiving wife of caring for a chronically confused, elderly husband.
2. To analyze the data to determine the themes and constituent categories present in the experience of caregiving.
3. To determine the implications of these constituent categories for nursing practice, education, and research.

Definition of Terms

Caregiving

The provision of care to a person who is dependent on another for the satisfaction of his basic human needs. The process of assisting a dependent with activities of daily living.

Caregiving Wife

A married woman who is responsible for the care of a confused elderly husband and who is unable to leave the home without transferring responsibility for his care to another person.

Chronic Confusion

A mental impairment associated with such behaviors as disorientation to time, person, and place, loss of memory, lack of judgement, and impaired reality-based communication.

Chronically Confused Elderly Husband

A married man over 70 years of age who has exhibited signs of confusion for at least one year, has been diagnosed as confused by a health professional, and is dependent on a caregiver for the satisfaction of his basic human needs.

Long-term Care

The provision of home care for periods longer than one year.

Assumptions

The assumptions of the study are that:

1. Caregivers in this study constitute a type of culture by virtue of their similarities: being an older person in society, being married to a husband who is dependent, and confronting the problems of confusion on a daily basis.
2. These caregivers are potential sources of data about their culture and the experience of caregiving.

3. Each person's views constitute reality for that person, and participants are honest about their views when they answer questions.
4. The participants are willing to share their interpretation of reality.

Limitations

This study looks at the experience of long-term caregiving in one group of wives whose husbands experience confusion. It does not seek an objectified truth for all caregivers.

Summary

With the expansion of the elderly population in industrialized nations, the management of chronic confusion will be an important area of study for health professionals. Caring for chronic illnesses and disabilities requires a perspective that integrates the family. The likelihood that the older wife will be called on to look after a disabled family member is high. Little is known about the effects of long-term care, especially on the caregiving wife. This study will examine the impact of long-term care in a particular situation: the experience of the older caregiving wife whose elderly husband is chronically confused.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

The long-term care of the chronically ill elderly and the effects on family caregivers have received little attention in the literature. No studies could be found that addressed the impact on the wife who cares for the confused elderly husband. Consequently, broad parameters were necessary to review the relevant literature. The review is presented in two parts consisting of the professional and the research literature.

The first part contains discussions on the impact of mental impairments associated with aging. Due to the paucity of data on chronic confusion, this behavioral diagnosis is considered under the broader category of mental impairments.

The second part of the review deals with caregiving situations in the research literature. Studies of caregivers and chronic illness in general are presented in the first research section. In the following section, the discussion turns to the research on the impact of caring for chronic illness in the elderly. The final section contains more specific studies on the effects of caring for the elderly with mental impairments.

Studies are arranged in chronological order within each section. To reflect the community rather than institutional setting of the studies, the term "dependent" replaces the

word "patient" found in the literature. The review of the literature was carried out simultaneously with the process of data collection, but is presented prior to the presentation of the findings as a basis for comparison.

Professional Literature

The Effects of Chronic Mental Impairment On The Family

This part of the literature review considers the effects of senile dementia, a condition commonly associated with chronic confusion in the elderly (Wolanin & Phillips, 1981). Other terms used to label senile dementia are chronic organic brain syndrome and Alzheimer's disease.

Morycz (1980) determines the impact on the family of chronic organic brain syndrome in a family member by reviewing forty articles pertaining to mental impairment in the elderly. This author identifies burden as the major concept that characterizes the impact on the family and describes the family breakdown that can result from the burden of care: "Many families collapse under the strain of multiple burdens" (Morycz, 1980, p. 24).

Morycz organizes the sources of burden into four categories: problems associated with the dependent, problems associated with the caregiver, problems arising from the environment, and problems arising from combinations of these three categories. Physical dependency, deviant behaviors, and personality changes are dependent problems associated

with the first category of burden. The limitations of the caregiver create a second source of family burden. Morycz identifies such caregiver characteristics as anxiety, depression, negative feelings toward the dependent, physical ailments, and aging that reduce the caregiver's ability to cope with the dependent. Problems in the environmental category include inadequate living facilities, insufficient finances, and lack of supportive community resources. This author notes that adequate housekeeping and nursing services for caregivers are costly. Isolation is an example in the fourth category of burden. The dependent's need for constant attention creates confinement for the caregiver and contributes to isolation. Feelings of embarrassment elicited by the dependent's deviant behavior cause the family's social withdrawal, compounding the problem of isolation.

Kapust (1982) discusses the family problems that accompany senile dementia, using data drawn from professional experience in social work. The effects of a disabling mental condition create two dilemmas for the family: the lack of recognition from society of the "psychological death" of the significant other caused by dementia, and the continual deterioration of the dependent despite good care from his family.

The author notes that while the family members mourn the loss of a significant other, they also have to deal with other social and psychological effects of dementia. Kapust describes major role changes that disrupt the family's equilibrium, such as the necessity for members to take over

the dependent's roles and responsibilities. Kapust also suggests that older couples have more difficulty coping with the inevitable role changes because they have to alter long-established patterns. One example given is the older wife in the traditional role who has to learn to manage the finances for the first time when her husband becomes disabled.

Kapust considers some of the psychological effects on family members such as embarrassment, anger, or guilt that contribute to the development of feelings of rejection toward the dependent. Family members are often embarrassed by the dependent's inappropriate behavior. Older spouses experience anger and resentment due to the loss of retirement dreams. The author also explains that guilt usually follows these negative feelings because family members realize that the dependent is not responsible for his behavior.

Kapust differentiates another source of guilt for families, the prospect of institutionalization. Even when caregivers become exhausted and have no other alternative, hospitalization is associated with feelings of failure as a caregiver and guilt for abandoning the relative. In addition, Kapust notes that the costs of institutionalization over a long period can impoverish the remaining spouse, especially the older wife.

Hayter (1982) presents the experience of the caregiving family from a nursing perspective by describing the needs of families caring for a member with Alzheimer's disease. In addition to the author's clinical experience, this article is

based on communication with over 100 families who contacted the nurse over an eight year period, following an article on Alzheimer's disease written in 1974.

Hayter suggests that the family needs more information about the dependent's condition and prognosis, although little is known about Alzheimer's disease. The author notes that lack of knowledge contributes to the family's strain. Hayter also discusses the family's need to deal with negative feelings caused by the dependent's inappropriate social behaviors. Particularly burdensome behaviors are aggression, paranoia, and personality clashes. Hayter elaborates on the guilt that accompanies the anger or embarrassment of family members when they realize that the mentally-impaired dependent is not intentionally causing hardship.

Hayter points out that caregivers need reassurance that their actions benefit the dependent, because dependents with dementia generally deteriorate despite good care (c.f. Kapust, 1982). The author suggests that caregivers have given up many activities, including full-time employment, to focus on the dependents' care and need positive feedback that they are doing all that they can do for the dependents. Hayter notes that role changes, loss of previous outlets for stress, and loss of emotional support from the impaired person contribute to the caregiver's strain.

Finally, this author emphasizes that families need to deal with the guilt that accompanies the decision to institutionalize. Although families express determination to keep their dependent relatives at home, Hayter suggests that

such attitudes diminish a family's ability to judge when home care is no longer a realistic goal.

From the previous descriptions offered by these three authors, it can be observed that the care of a mentally-impaired relative has a burdensome effect on the family. Dependency and deviant behaviors in one family member create strain for other members. Families must adjust to the role changes and isolation accompanying the gradual deterioration of a mentally-impaired relative, that, along with such feelings as anger and guilt, create burden. The next part of the literature review contains descriptions of more systematic investigations into the caregiving situation.

Research Literature

Studies Related To the Caregiver And Chronic Illness

Researchers recognize the significance of the caregiver in maintaining the chronically ill at home and the importance of studying the impact on the caregiver. Two studies of caregivers in general situations are presented in this section.

Golodetz, Evans, Heinritz, and Gibson (1969) explore the role of the caregiver in 59 families participating in a home care program. They label the primary caregiver the responsor because of the large degree of responsibility in this role: the caregiver has to respond to the needs of the dependent and to assume responsibility for the dependent's affairs. The

respondors were mainly wives and daughters, ranging in age from middle-age to elderly.

The researchers describe aspects of the caregiving role and the complexity of the home care situation, but do not report how they collected data. In spite of this methodological weakness, the researchers' descriptions of the study group yield useful information about the impact of caregiving. In most of the cases, these caregivers are the only adults available to take on the role and half suffer from chronic illness themselves. Their main purpose in life appears to be to care for the dependent, and the researchers remark on the apparent lack of outside involvement: "Our home-care households were small, isolated and pre-occupied with the care of illness" (Golodetz et al., 1969, p. 388).

Golodetz et al. state that the tasks of caregiving arise from the activities required to maintain the chronically ill person in the home and list several caregiving tasks that challenge the caregiver, such as management of the dependent's medication, diet, and exercise routines. The researchers also suggest that, in addition to the caregiving tasks, the nature of the dependent's illness, the attitude of the caregiver toward the illness, and the past and present relationship with the dependent influence the amount of caregiver strain. Finally, the researchers note the complexities of evaluating the effects of home care on particular caregivers and suggest that: "While illness in the home is a burden, an emotional cost-benefit analysis may suggest that the family would suffer more by relinquishing

care to an institution" (Golodetz et al., 1969, p. 393).

Goldstein, Regnery, and Wellin (1981) examine the role of the caretaker and the problems of caretaking, using a qualitative approach. They observed 90 households involved in a long-term care program and interviewed 25 of the caregivers. Eight of those interviewed were wives, five were husbands, and the rest consisted mainly of close relatives such as a sibling, child, or parent. The ages of the caretakers ranged from thirty-five years to eighty-seven years and the average age was sixty years. The median duration of caretaking was three years. The dependents had diverse conditions, but all of them required substantial help from the caretakers.

Goldstein et al. note that caretaking has adverse effects on the physical and mental well-being of caretakers. The tasks of caretaking cause physical strain and about one third of caretakers experience sleep disturbances due to the dependents' restlessness at night.

The researchers report that a predominant effect of caretaking is role constriction. They describe role constriction as the process where the activities and relationships in the caretaker's life become centered on the dependent and all other activities become subordinate to the caretaking tasks. The researchers conclude:

Some caretakers have multiple roles and do report problems of role conflict. But the most frequently mentioned and most severe effects for over half the caretakers involve confinement within the home and

restrictions on their activities outside it. For the majority of caretakers, then, the hardest problem is role fatigue. (Goldstein et al., 1981, p. 26)

The researchers also describe another effect of role constriction: the lack of opportunity to obtain relief from the caretaking role through other activities and relationships.

Futhermore, Goldstein et al. observe that there appears to be no optimal age for being a caretaker. Older caretakers, more likely to suffer from insufficient finances, poor health, declining energy, and physical strain, are also more susceptible to role constriction because they tend to have fewer conflicting roles and more time to devote to their dependents. Conversely, younger caretakers are more likely to suffer from the problem of role conflict.

The researchers suggest that, in addition to role constriction or conflict, other variables that influence the impact on the caretaker are the dependent's condition, the caretaker's physical capabilities, the opportunity for caretaker role relief, and the amount of social support obtained. The researchers also point out that not all caretakers perceive caregiving to be a struggle, if adequate role relief and social support are available.

In spite of their recognition of the negative impact of caretaking, caretakers also show devotion to the dependent. Goldstein et al. identify this paradox: "Although they tend to talk candidly about the burden and stresses of caretaking, nearly all caretakers express their determination to maintain

the patient at home as long as possible" (Goldstein et al., 1981, p. 27).

Studies Related To The Caregiver
And Chronic Illness In The Elderly

The impact of caring for an elderly dependent has been studied in a variety of situations. The first two studies in this section make use of measures of life satisfaction to determine the impact of caregiving. The remaining two studies are concerned with the impact on a specific caregiver, the adult offspring of the dependent.

Fengler and Goodrich (1979) explore the needs of older wives caring for disabled elderly husbands. The researchers interviewed 15 disabled men participating in a workshop program and their wives. The first three interviews were carried out at intervals of 2 months, and a fourth interview was administered one year later. The researchers obtained life satisfaction scores at these interviews and calculated the average score on all the tests for each participant.

Measures of life satisfaction are generally low in wives and appear to be related to the husband's life satisfaction. Because the wife's score prior to the husband's disability is not known, the effects of disability on life satisfaction can not be examined. Instead, the 6 highest-scoring and the 6 lowest-scoring wives are compared to suggest characteristics related to better coping.

These 2 sub-groups of wives are reported to have similar

perceptions of their health status, and their husbands experience similar levels of disability, except that two of the wives with low morale are married to husbands who experienced aphasia. The researchers suggest that this difference indicates that a reduction in the amount of meaningful communication is present in wives with low morale.

Other variables that appear to differentiate wives with low morale from wives with high morale are income, role overload, and social support. The findings indicate that wives with low morale perceive their income to be inadequate and half of them have full-time employment outside the home, whereas none of the wives with high morale have to work to support the couple.

Fengler and Goodrich note that role overload is more common in wives with low morale. These researchers attribute this finding to the fatigue and emotional strain experienced by wives who carry out the roles of worker and caregiver.

Wives with high morale identify their husbands as confidantes more often than wives with low morale. Meaningful communication and a valued relationship with husband seem to offset feelings of entrapment within the home. Isolation, the most common concern of wives in general, is more prevalent in wives with low morale:

Old activity and friendship patterns are disrupted, often quite suddenly. There is little planning for the future, and beneath the surface are feelings of resentment as wives recall things they would have done if their husband had not become disabled. (Fengler &

Goodrich, 1979, p. 180)

The husband's impaired mobility contributes to the problem of social isolation by limiting potential outside activities.

Furthermore, wives with low morale receive less assistance from their children and have even less contact with friends. The data indicate that these wives have less freedom to engage in meaningful activities outside the home, due in part to inadequate income and full-time employment.

Pringle (1982) also investigates the impact of caregiving on life satisfaction in caregivers and their elderly dependents. This researcher compared life satisfaction scores and depression measures in 140 pairs of caregivers and dependents to determine whether the same variables are related to psychological well-being in dependents and caregivers. Most of these caregivers were either spouses or adult offspring. The average age of the spouses was 76 years and the average age of the adult child caregiver was 53 years. Separate interviews were carried out with dependents and caregivers to measure life satisfaction.

Overall, this researcher concludes that these caregivers are moderately satisfied with life but that a mild level of depression is also present. The psychological well-being of caregivers appears to be correlated with three variables: their perceptions of their health, the adequacy of their finances, and the quality of the interpersonal relationship between the dependents and caregivers. Most caregivers in this Canadian study perceive that their income is sufficient.

The interviewers point to a discrepancy in the

perceptions of the quality of the interpersonal relationship between caregivers and dependents. The dependents "consistently described the relationships in more positive terms than did the caregivers" (Pringle, 1982, p. 7). Good interpersonal relations appear to "offset much of the negative impact resulting from the constraints in the caregiver role" (Pringle, 1982, p. 6).

Archbold (1980) describes the impact of being an adult child caregiver for an elderly parent who has experienced a stroke. The study used a qualitative approach to interview 6 families where a member had been treated at a stroke rehabilitation unit one or more years before. The content of the semi-structured interview was determined from the perspective of the daily problems of living with chronic illness. The dependents and the family caregiver were interviewed separately.

Problems in the caregiving situation revolve around the basic regimes of care for the stroke patient such as therapeutic exercises. Dependents experience difficulties in carrying out regimes due to discomfort or embarrassment. Families agree that insufficient home care services were provided following discharge from the rehabilitation unit. Inadequate finances and social isolation also concern these families.

Although dependents worry that they are burdensome to their caregiving children, Archbold notes that dependents do not appear to be aware of the full impact on the caregiver. Caregivers raised additional concerns in their interviews

about the consequences of long-term care including strain, lifestyle changes, and lack of informal social support.

Strain is a common concern for these caregivers. Archbold reports that the physical demands on caregivers are taxing and that some caregivers deprive themselves of necessary rest and medical care to meet all their obligations. Emotional strain is also reported and appears to arise from feelings of anger, resentment, and ambivalence that caregivers do not feel free to express.

Many caregivers structure all their time around the dependents' regimes, even when they do not live with the dependents. The ensuing lifestyle changes involve losses of personal freedom, leisure activities, and social support.

Archbold notes that the caregiving role adversely affects the nuclear family because caregiving demands conflict with the caregiver's familial responsibilities. The researcher also concludes that the caregiver's siblings provide insufficient support. The siblings often allocate the role to the caregiver, and some caregivers express resentment at the inequitable distribution of responsibility. Caregivers also report feeling ill-prepared to handle the responsibility for patient advocacy in medical decisions. Although some siblings occasionally offer money or sitting services to the caregiver, caregivers are still in great need of regular respite periods.

Nissel and Bonnerjea (1982) examine the impact on adult children of caring for elderly parents. Those researchers looked at 22 homes where an elderly, dependent relative had

been incorporated into the nuclear family. This comprehensive study involved 44 interviews over a period of two months. The group of elderly were substantially impaired and over half experienced confusion to some degree.

The study used an introductory questionnaire addressed to the wife, a time diary completed by the wife and husband for one day, followed by an audio-taped interview with these individuals the next day. The semi-structured interviews lasted much longer for the wives than for the husbands. The researchers did not use a random sample because the study was originally intended to be a pilot study for the development of methodology.

Nissel and Bonnerjea report that the wife is the family member burdened with total responsibility for the dependent's care in all households. The wives tend to be resigned to their roles and feel obligated to carry the burden by themselves. The time diaries of the husbands and wives document that the daily activities of the caregivers center on the dependents, and that husbands and children do not help with the caregiving tasks.

The data indicate that physical strain is universal but caregivers have more difficulty coping with the mental strain that accompanies repeated episodes of incontinence and nocturnal disturbances by the dependents. These caregivers also have difficulty dealing with the dependents' inability to reason and temper outbursts.

Confinement and social isolation are prevalent. Over half of the caregivers gave up paid employment to devote full

time to the relatives' care, leading to loss of financial status and social contacts. Nissel and Bonnerjea show both the direct and indirect financial costs of taking in the elderly relative. Because this study was carried out in England, the financial details are not directly comparable to the Canadian situation and will not be reviewed here. Lack of social support from siblings and friends is noted. For instance, neighbours who offer to sit with the caregiver's children do not offer assistance with the elderly person's care.

Commitment to the dependent is evident in these caregivers. Although the researchers intentionally avoided dwelling on the negative aspects of home care, these participants stress their burdens and problems in the interviews. The interviewers point out that the caregivers are devoted to the dependents, although the presence of confusion threatens this affectional bond:

The real problems were in those situations where the relative was too confused to be able to understand or appreciate what was happening. However kind and compassionate the family and carer may be, it is difficult to derive pleasure where no emotional communication can take place. (Nissel & Bonnerjea, 1982, p. 30)

The researchers also note that confusion in the elderly relative aggravates the relative's dependency and increases the caregiver's burden.

Again, the findings of this study show a deleterious

impact on the nuclear family. The main effect on the family is to disrupt normal family dynamics, causing conflict, tensions, and loss of privacy. Two thirds of family members report that life has changed for the worse since the relative joined the household. Originally the dependent relatives were supposed to contribute to the household routines and chores, but as time passed, they generally became weaker and more dependent.

Studies Related To The Caregiver And Chronic Mental Impairments In The Elderly

The studies related to the effects on caregivers of mental impairments in the elderly are reviewed in this section. As in the first part, chronic confusion is subsumed under the broader category of mental impairments.

Sainsbury and Grad de Alarcon (1970) document burden in families caring for elderly dependents with various psychiatric diagnoses to compare the effects on the family of community-based care versus hospital-based care. The researchers interviewed a random sample of 119 families in two communities, where one community had community psychiatric services and the other relied on hospital services.

Participants received a basic survey in which they selected appropriate responses to questions on the effects on aspects of family life. The homes were visited at the time of referral, at one month following intervention, and after

two years with either hospital or community-based care. The level of disability of the dependents varied from minor to severe, and one third of dependents had conditions severe enough to require constant surveillance by a caregiver.

The descriptions of burden at the time of referral provide data on the burden of mental impairments on the family. The impact on the family is profound: "The mentally ill old person very clearly takes a heavy toll on his family physically, emotionally and socially" (Sainsbury & Grad de Alarcon, 1970, p. 39). Burden is present in three quarters of the families at the onset of the study and 40% of these families report severe burden.

The researchers describe the characteristics that appear to be related to severe burden in caregiving families:

When the patient was first referred, five symptoms were significantly related to severe burden: aggression, delusions, hallucinations, confusion, and a patient's inability to care for himself. Neurotic and depressive symptoms were not those that severely affected the household; rather it was the demented, bedfast patient who interfered drastically with home life. (Sainsbury & Grad de Alarcon, 1970, p. 33)

Emotional strain is a major contributor to burden that is present in 63% of family members. The most common concern is that the dependent may harm himself.

Poor health is present in over half of the caregivers. Family routines and social activities are markedly disrupted. The effects on families differ according to their

composition. Families in the lowest income group and those where dependents live with adult children report the most problems. Conversely, the fewest problems occur in high income families and where dependents live with their spouses.

Sainsbury and Grad de Alarcon also note that these families are devoted to their dependent relatives despite the negative effects of caregiving. The professionals who initially visited the households "were impressed by the families' readiness to cope with really burdensome patients" (Sainsbury & Grad de Alarcon, 1970, p. 39), and the amount of time the families struggled before seeking professional help. The study concludes that families with severe burden are helped equally by community-based and hospital-based care.

Sanford (1975) approaches the study of caregiving from a different perspective by analyzing the problems of the principal supporter who could no longer cope with a chronically ill dependent at home. This researcher studied 50 admissions to a geriatric unit over an 8 month period. None of the admissions was due to a medical emergency and the major diagnosis for over half the admissions was senile dementia.

Most of the caregivers interviewed were either spouses or adult children. Sanford recorded the data on a standard form, categorized the problems of caregiving into three main categories, and asked which problems would have to be ameliorated before the caregivers would accept the dependent back in the home. This researcher acknowledges that the use of a standard form may have decreased the amount of

information obtained from the subjects. It is not clear from the report how Sanford collected the data or arrived at the categories of problems.

The first category, problems arising from the dependent's behavior, contains the majority of problems discussed by the caregivers. The most frequently-mentioned problems, in order of occurrence, are sleep disturbances, incontinence, falls, excessive dependency, aggression, and disregard for safety. In addition, most of the problems that caregivers feel would need to be alleviated prior to accepting the dependent back in the home are in the first category. The second category, problems arising from the supporter's limitations, includes emotional strain due to anxiety or depression, personality conflicts with the dependent, and physical limitations such as inadequate strength or chronic illness. The third group, problems associated with the social and environmental context, contains the fewest number of problems. About one half of the caregivers report personal confinement and social restriction as problems: "Many supporters had not had a holiday or evening out for years and welcomed the idea of a 'granny sitter.' This was a real unfulfilled need" (Sanford, 1975, p. 473). Almost one third of caregivers are unable to leave the dependents alone and have to give up all outside activities. Financial strain is noted too.

For Sanford's sample, institutionalization has been put off as long as possible at the expense of the caregiver's well-being: "Most supporters were clearly devoted to the

dependents and had suffered considerable strain over a prolonged period" (Sanford, 1975, p. 473). This researcher also emphasizes that almost all of the caregivers are able to articulate the problems that they can or cannot manage at home, even when the institutionalization process is a time of crisis.

Zarit, Reever, and Bach-Peterson (1980) attempt to correlate the impairments accompanying senile dementia with the amount of burden perceived by the caregiver. Their sample consisted of 29 elderly dependents with senile dementia and their family caregivers. The sample of elderly was recruited from a program that offered memory training and social support for the elderly with mental deterioration. Zarit et al. administered a series of tests to the dependents to measure the severity of mental impairment, the frequency of memory and behavior problems, and the degree of impairment in activities of daily living. The scores indicate that the dependents are substantially impaired. Other variables measured were the number of family visits and the duration of the illness.

The researchers devised a questionnaire to measure burden which they defined as the level of discomfort that caregivers associated with certain statements. The results of the questionnaire indicate that the amount of burden is moderate. None of the caregivers was considering institutionalization at the time of the study. Caregivers most frequently identify the "lack of time for oneself, the excessive dependency of the patient ... [and] fears about

further deterioration in the patient's behaviors" (Zarit et al., 1980, p. 652) as burdensome.

An analysis of the relationship between burden and the previously identified variables reveals that only the frequency of family visits is correlated with the level of burden, in an inverse relationship. Zarit et al. collected no other data about the quality of these visits except that caregivers receive an average of nine family visits per month. The researchers also conclude that caregiving daughters and caregiving spouses experience the same amount of burden.

Summary

A diverse group of caregiving studies was examined in this chapter to place the research question in a theoretical context. The impact on the caregiver has been operationally defined and studied in numerous ways. Studies of the experience of caregivers in specific situations are lacking. Despite the variety of methodologies found in these studies, the findings indicate that generally the impact on caregivers is negative. The need exists to obtain more descriptive research about the experience of the older wife caring for the elderly, impaired husband that can provide data for clinical intervention and further study.

CHAPTER 3

METHODOLOGY

Introduction

The methodology used to carry out this study is presented in this chapter. The rationale underlying the use of a qualitative approach is discussed, followed by a description of a particular kind of qualitative methodology, the phenomenological method. Then the selection of the study group, the criteria for the participants, and the data collection procedure are described.

Selection of a Method

Rationale For Choosing A Qualitative Approach

Qualitative researchers consider that social reality and the phenomena of the social world are not fully comprehensible by quantitative means alone (Schwartz & Jacobs, 1979). It has been argued that the meaningful study of the human experience requires an approach that incorporates the participant's active involvement in constructing his social reality (Davis, 1978). The intent of this approach has been summarized:

The basic position of this [qualitative] orientation is that in order to understand social phenomena, the researcher needs to discover the actor's "definition of

the situation" - that is, his perception and interpretation of reality and how these relate to his behavior In order for the researcher to come to such an understanding, he must be able, (albeit imperfectly) to put himself in the other person's shoes.

(Schwartz & Jacobs, 1979, pp. 7-8)

Rather than dealing with only observable behavior as found in quantitative methods, the qualitative approach enables the researcher to study the participant's perception of the meaning of his experience.

A qualitative approach seemed to best address the research question about the impact on the caregiver. This approach enables the researcher to make a meaningful study of the impact on the caregiver by eliciting her perception of the meaning of the experience. The literature indicates that little is known about the experience of the older caregiving wife whose husband is chronically confused. The lack of knowledge about the relevant variables also suggests the use of the qualitative approach to answer the research question because this approach involves "an open theoretical scheme in which variables ... are to be discovered rather than a scheme in which variables are decided upon in advance" (Becker, Geer, Hughes, & Strauss, 1961, p. 18).

The Phenomenological Method

One type of qualitative methodology, the phenomenological method, was used to answer the research

question. Omery (1983) offers a general description of this inductive, descriptive method: "The phenomenological method is approaching the phenomenon with no preconceived expectations or categories, performing some form of bracketing to define the limits of experience, and then exploring the meaning of that experience as it unfolds for the participants" (p. 54).

Determining the meaning of a client's situation is particularly relevant to the practice of nursing and the research questions that arise (Davis, 1978; Omery, 1983). Davis has explained this relationship: "The clinical approach which emphasizes observation, interviews, interaction, and interpersonal relations in an attempt to understand the patient's definition of the situation ... more perfectly fits conceptually the phenomenological approach" (p. 194).

Giorgi (1975) is one of several researchers who describe systematic methods for carrying out phenomenological research. This researcher discusses several characteristics of phenomenological research. The unit under investigation is the entire situation, including the researcher's and the subject's perspectives. Giorgi (1975) defines the goal of phenomenological research: "The task of the researcher is to let the world of the describer, or more concretely, the situation as it exists for the subject, reveal itself through the description in an unbiased way" (p. 74). To accomplish this task, the researcher approaches the phenomena with minimal assumptions and grounds observations in the everyday

world of the subject, rather than applying a pre-developed framework to the unit under investigation. The major concepts are developed only after the researcher's initial encounter with the data.

Giorgi outlines five steps in data analysis, using the transcript of a taped interview. First, the researcher reads through the entire transcript to become familiarized with the data. Second, the researcher reads the transcript again, but this time with more attention to detail. In this second step, the researcher categorizes the units or constituents in the participant's experience by isolating central themes. These units are defined by changes of the meanings in the data. Third, the researcher puts together the related units by elucidating the meanings of each unit, and by relating them to each other and to the whole. Fourth, the researcher continues to analyze the constituents, translating them from the language of the participant into the language of scientific concepts. This analysis continues until no new themes emerge in the data. Fifth, the researcher unifies the insights about the constituents into a comprehensive description of the meaning of the experience.

The researcher strives to make the final description of the meaning of the experience as rigorous as possible. A major hallmark of phenomenological research is the reader's ability to see how the data were organized:

The chief point to be remembered with this type of research is not so much whether another position with respect to the data could be adopted (this point is

granted beforehand), but whether a reader, adopting the same viewpoint articulated by the researcher, can also see what the researcher saw, whether or not he agrees with it. (Giorgi, 1975, p. 98)

In Giorgi's method, the sample of participants is usually small because of the long duration of the interviews. Omery (1983) suggests that the number interviewed be limited to four or five participants. Interviews with the same participant may be continued at different intervals.

Selection Of The Study Group

Subjects

The aim of this study was to identify the impact on the caregiving wife whose husband experienced confusion. A total of 6 wives were interviewed. The criteria for their participation are discussed below.

Criteria for The Caregiving Wife's Participation

Little was known about the characteristics of the caregiving wife prior to contact with the subjects. The following criteria were designed primarily to identify those caregiving situations where the older couple lived alone and the wife managed independently. The caregiving wife was to be married to a confused, elderly husband. The age of the wife was not specified as it was assumed that she would be

close in age to the husband and therefore, elderly herself. The wife was to be the major caregiver responsible for helping the husband meet his basic human needs, as evidenced by her inability to leave the home without transferring the husband's care to another person.

The wife was not to be employed outside the home, nor responsible for the care of other family or non-family members, thereby ensuring that the wife's major responsibilities were related to her husband. The wife was to be the primary caregiver in this situation and no other persons who could help with the husband's care were to reside at the same address.

Criteria for the Husband's Participation

The basis for the wife's participation in the study was the presence of chronic confusion in her husband. Thus, it was necessary to delineate the criteria for the husband's participation in the study. The husband was to be at least 70 years of age and to have exhibited signs of confusion for at least one year. The age of 70 years was given as a guideline to ensure that the husbands who were referred had confusion associated with mental impairments found in the elderly and to avoid conditions associated with middle age such as pre-senile dementia. The one year duration of the confusional state was specified to rule out confusional states that were acute.

The presence of confusion would be evidenced by such

behaviors as disorientation to time, person, and place, loss of memory, and impaired reality-based communication. The husband's confusion would impair his participation in the family unit and his ability to care for himself. It was expected that other physical disabilities would be present since more than one chronic illness may be present in the older adult and chronic confusion often accompanies other chronic conditions.

Procedure For Obtaining The Participants

The research proposal was sent to a community health agency in the Greater Vancouver area, after approval was obtained from the University of British Columbia Behavioural Sciences Screening Committee For Research and Other Studies Involving Human Subjects. The nurses in the home care and long-term care programs distributed the explanatory letter that invited participation in the study.

Potential participants returned a form indicating their interest in the study. The researcher then phoned each respondent to answer any questions, confirm her participation, and arrange an initial meeting in her home. At the initial meeting, the researcher reviewed the purpose and expectations of the research. The respondent then signed an informed consent form that stated she agreed to participate in the research and that she allowed the interview to be tape-recorded. The introductory letter can be found in Appendix A, and the consent form found in

Appendix B.

Procedure For Data Collection

The data collection took place over a period of four months, from April to July 1983. Data were obtained by carrying out in-depth interviews with each wife on two to three occasions. Interviews were loosely structured to allow each wife to describe her experience and to identify areas that were significant to her. The initial interviews were guided by sample questions designed to set the participants at ease by offering possible topics of discussion. Once the wives began to describe their experiences, other questions were developed for use at succeeding interviews to clarify and elaborate the themes identified in their accounts. Sample questions are found in Appendix C.

All interviews took place in the caregiver's home and were audio-taped to enable the researcher to concentrate on what the participant said and to observe the research situation. The length of home visits varied, but generally interviews lasted one hour. Transcripts of the data were made following the interviews.

Data Analysis

The descriptions of the participants were analyzed as described by Giorgi (1975). Central themes were identified and notes on the meanings of themes were filed and

cross-referenced. The constituent categories were later refined and their meanings clarified. The next chapter provides discussions of the concepts found in the data that describe the meaning of the experience of caregiving.

Summary

The phenomenological method was employed to carry out this study because it enabled the researcher to approach the research situation with minimal knowledge and to describe the subject's perspective of reality. Because little is known about the experience of caregiving, the phenomenological approach sought to explore the meaning of the experience of caregiving as described in the caregivers' accounts. Six wives in independent households were interviewed. The seventeen interviews were tape-recorded to allow continual analysis of the data and collation of major themes. The themes and constituent categories identified by the researcher are described in the next chapter.

CHAPTER 4

PRESENTATION OF THE FINDINGS

Introduction

This chapter contains a description of the impact on the older wife of caring for a chronically confused, elderly husband. First, the pertinent characteristics of the caregiving situation are presented to provide an introduction to the context of the study. Then, the major themes found in the caregivers' accounts are discussed under three main areas of content. A discussion of burden, the concept that best unifies these content areas, concludes the presentation of the findings.

The Caregiving Situation

The selection of the participants was guided by the criteria given in the previous chapter. The characteristics of the households, the wives, and their husbands are considered in this section.

Characteristics of the Caregiving Households

The criteria for sample selection yielded similarities in the household settings. The 6 households in the study were independent units each consisting of a chronically ill elderly husband and his wife. Five of these elderly families

lived in apartment dwellings and had changed their residence following the husbands' retirement. Three families had children living in the general vicinity who could visit them or assist with chores.

The families participating in the study retained responsibility for such chores as managing the household, preparing the meals, and shopping for groceries. Community nurses visited the homes at varying intervals to monitor the health status of the husband or wife or both, to assess the home situation, and to provide support. Community services also supplied homemaker assistance for the four households that were eligible for this type of assistance.

The level of help obtained from the government-sponsored homemakers depended on the severity of the husband's condition and the size of the couple's income. Four homes received three to four hours of assistance each week. The forms of assistance ranged from help with the husband's care to help with heavy household chores. One family was ineligible for subsidized support because the husband was ambulatory and their income was greater than average. One wife hired additional homemaker services for the mornings because her husband was confined to a wheelchair and required a great deal of assistance.

Characteristics of the Caregiving Wives

The 6 wives in this study ranged in age from 68 years to 85 years and had been married for almost all of their adult

lives. The minimum duration of caregiving was two years. The length of the caregiving period ranged up to 13 years, the exact duration being difficult to determine in situations where the husband's condition had deteriorated gradually. In accordance with the guidelines set out in the research proposal, none of the caregivers was employed outside the home.

Although the wives may be categorized under the age group of elderly, an age distinction appeared between younger caregivers (in their late sixties) and older caregivers (who were 75 years and older). Two of the three younger caregivers were able to drive and still had their family automobiles, while older wives had never learned to drive. As a result, the younger wives were more mobile because of their access to transportation. One of the younger wives held a volunteer position on her church council, whereas the remainder of wives had forgone all outside commitments.

The wives experienced the accompanying losses of aging such as diminished muscle strength and energy. Chronic illness was present to some extent in all of them. Three wives had substantial medical conditions that included one or more of the following disorders: hypertension, arthritis, glaucoma, and cancer. The remainder experienced less severe physical disturbances related to mobility disorders.

Characteristics of the Dependent Husbands

The 6 husbands in the study experienced chronic confusion. Their age range followed that of their wives, from 68 years to 85 years. One husband was 13 years older than his wife while all the other couples were close in age.

Consultation with each wife confirmed the presence of confusion in her spouse. Some of the features of confusion included memory loss, altered temperament, impaired judgement, and inappropriate social behavior. In addition, confusion did not occur in isolation. A diverse group of medical conditions accompanied the behavioral diagnosis of confusion, including Parkinson's disease, inadequate vascular circulation, past cerebral vascular accidents, and diabetes. Incontinence was a continual problem for four of the husbands. Impairments in mobility left two husbands confined to wheelchairs and three others dependent on walking canes due to unsteady gait. All the husbands required assistance or supervision to meet nutritional and hygienic needs.

The Caregivers' Accounts

The impact of being a caregiver is described in this section. The phenomenological approach described by Giorgi (1975) was used to analyze the data constituting the caregivers' accounts. The themes in their accounts were found to reflect three overall concerns: (1) the management of the husband's dependency, (2) the maintenance of the

family as a unit, and (3) the acceptance of the caregiving situation. These three areas are used to describe the effects of caregiving.

Management of the Husband's Dependency

The characteristics of the husbands indicate that five of them experienced physical impairments as well as confusion. This combination of physical and mental impairments produced changes in their functioning and resulted in caregiving tasks for their wives. This section deals with the changes brought about by the confused husband's dependency and the direct effects on his wife.

Changes in the Husband's Functioning

Three of the most common changes associated with the husband's dependency were incontinence, nocturnal restlessness, and disregard for safety. These behaviors caused the most prominent concerns for caregivers and are the same problems faced by caregivers in other studies. Sanford (1975) identified these troublesome behaviors as the most common obstacles to successful home management of dependent relatives.

Incontinence was a common problem that was unpredictable and persisting. Four of the wives had to be prepared to deal with incontinence at any time. Affected husbands were unable to anticipate their physical needs, making the management of incontinence difficult for the wives.

A second change in the dependent husband's functioning was the occurrence of nocturnal restlessness. Nightly awakenings were characteristic of all husbands to varying degrees. Some of the causes of nighttime disturbances were awakening due to incontinence, needing assistance with toileting, and requiring assistance with physical comfort. Confusion was directly related to nocturnal restlessness when the husband awoke and, due to disorientation to time, initiated a conversation with the sleeping wife. Two of the ambulatory husbands often wandered about the house in the night carrying out such activities as rummaging through the kitchen to find food.

A third troublesome change was the confused husband's general disregard for safety and lack of environmental awareness. Both his physical condition and mental state placed him at risk for injury. Unsteady gait, loss of agility, and loss of physical strength predisposed him to falls. Confusion and lack of alertness placed him at risk for errors of judgement and of omission. Some of these more worrisome behaviors were leaving on a stove element, forgetting to extinguish cigarettes, forgetting the caregiver's instructions to stay within the boundaries of the home, and neglecting to ask for needed assistance during positional changes.

Caregiving Tasks

The husband's dependency gave rise to caregiving tasks. Unable to manage his personal hygiene, nutritional needs, and medical regime, he required assistance and supervision in activities of daily living. Five husbands were unable to initiate such personal grooming tasks as bathing, oral hygiene, and shaving. In four cases, homemakers helped bathe the husbands during their weekly visits.

Each wife looked after her husband's nutrition. Four husbands required physical assistance with the process of eating because of difficulties with manipulating utensils, chewing, or swallowing. Examples of management of medical regimes included preparing the diabetic diet, administering diabetic or hypertensive medications, and providing foot care.

The husband's incontinence created additional cleaning and laundering chores that took time away from other daily chores. In addition to direct caregiving tasks, the wives retained traditional household tasks such as cleaning, menu planning, meal preparation, and grocery shopping.

Effects on the Caregiver

The changes in the husband's functioning and resulting caregiving tasks had a substantial impact on the wife. The major effects were fatigue, confinement, and strain. They will be examined in this section.

Feelings of fatigue were present in varying degrees in all the wives. Two major sources of fatigue were the

husband's incontinence and his nocturnal restlessness. Incontinence caused the most concern for four of the wives. Dealing with the resulting tasks was physically and emotionally taxing. These particular chores required immediate attention to minimize the consequences of incontinence. The wife's powerlessness to prevent tiresome episodes of incontinence and to decrease her workload created frustration:

W: It's hard to cope. It's difficult to explain how hard it is and difficult to keep your temper. It's hard to tell a person who's doing things that they shouldn't do, that they are doing it, because they don't know they're doing it.

At the same time, the wife felt reluctant to express disapproval because she knew that her husband was not intentionally causing hardships.

The effects of nocturnal restlessness were equally troublesome. The husband's sleep disturbances caused loss of rest, interrupted sleep, and chronic fatigue for five wives.

W: It's too much to lose your sleep every night, you know, because he's up and down, up and down all night.... He makes noises in the nighttime and talks to himself and things that keeps [sic] me awake. Makes you ill, just listening to someone mumbling away. You know, that is very disturbing to me.

The husbands did not seem aware of the deleterious effect of their nightly activities. The wife's persisting

fatigue diminished her ability to cope at a time when she needed extra energy. One wife speculated that she could manage better if she were rested.

W: The nights are bad. I could handle everything in the daytime as long as I had a good night's sleep. It's not that he needs constant care, but the disruptions in getting back to sleep, four or five times a night. It gets to you. I'm tired all the time and yet I can't sleep.

Two wives relied on sleeping medications to aid them in falling asleep while two others used sleeping medications less frequently.

These findings on sleep disturbances in caregivers are substantiated in the literature. One third of caregivers in the study carried out by Goldstein et al. (1981) experienced sleep disruptions due to the dependent's restlessness at night. Nissel and Bonnerjea (1982) found that the combination of restlessness and incontinence in a dependent was particularly difficult for the caregiver to endure.

Another prominent theme in the experience of caregiving was confinement. The wives perceived that their lives now revolved around the dependents. This concern was identified early in the first interview when each wife was asked to describe the experience of being a caregiver.

W: It's rough. You're really tied down.

W: You're tied in--you do get fed up with it--you're in your own home. You don't see anybody, only

yourselves and maybe the neighbour will drop in once in a while.

Several interacting aspects of the caregiving situation exacerbated the wife's confinement. First, safety considerations dictated that someone be nearby at all times lest the husband require assistance or wander away. Hayter (1982) identified this relationship of caregiver restriction due to the dependence of the impaired person. Second, the wife could not alleviate her confinement by engaging in activities that took her husband out of the home. Difficulties with incontinence made his care outside the home unmanageable. Consistent with earlier findings by Fengler and Goodrich (1979), the husband's loss of physical agility restricted his mobility. Only one husband was able to accompany his wife on outings, while the remainder rarely left the home. Third, the husband's loss of interest and social withdrawal occurring with his confusion precluded regular outings.

W: Now he doesn't want to go shopping or anything. It's got so that he just doesn't want to go out. It means that I have to stay home to look after him, see. I couldn't leave. I couldn't leave him by himself, see.

Fourth, the wife lacked the resources necessary to relieve confinement. She sacrificed personal freedom and significant activities to cope with the husband's care.

W: You're constantly on the go. It's a full roundabout-the-clock job.... You've got to have a

routine. There's not enough hours in the day to cope with it all.

The caregiver's experience of restricted mobility in the present study was consistent with the findings of other studies. Reports in the literature confirmed the prevalence and emphasized the extensiveness of confinement among all types of caregivers. The proportions of caregivers who have reported this concern ranged from 33% (Sanford, 1975) to over 50% (Goldstein et al., 1981), with this latter group citing confinement with its restrictions in personal freedom as the most common concern. Caregivers tended to structure all their time around the dependents and to centre their daily activities on the tasks of caregiving (Archbold, 1982; Goldstein et al., 1981; Golodetz et al., 1969; Nissel & Bonnerjea, 1982). Moreover, all caregivers in the present study were affected by confinement, consistent with the observation made by Goldstein et al. (1981) that older caregivers were more prone than younger caregivers to role constriction. Older caregivers tended to have fewer conflicting roles and more time to devote to their dependents.

Finally, the husband's dependency created emotional and physical strain for his wife. For example, incontinence produced an emotional as well as physical burden. It acted as a continual reminder to the wife that her husband was no longer his normal self and that her resources to cope at home were finite. No one else was available to help with these concerns that could arise at any time, day or night. Caring

for the husband's incontinence contributed to the wife's realization that she carried the burden of responsibility for her husband. As one wife described, the most difficult aspect of home care "from the purely physical point of view ... is the utter dependency that the person has on you for all their needs."

The husband's confusion also caused strain for the wife because she had to compensate for his disregard for safety. She had to be thinking constantly about potential hazards. Concerns for his safety were described as "the little things that are constantly at the back of your mind." The fear that the husband might fall was a constant concern that sometimes led to troubled sleep.

W: You worry all night. You don't sleep sound.

You're listening when you hear him get up. Safety considerations were noted in the literature when the dependent was mentally impaired. Sainsbury and Grad de Alarcon (1970) found that concern for the dependent's safety was the major contributor to emotional strain in the caregivers.

Perceptions of strain were inherent in the caregiver's experience.

W: There is pressure, of course. I try to keep it down--although, at times, I get tired myself or, everything has gone wrong that could--I just have to go off and have a good cry and get it over with and that's it. You just can't keep it built up inside.

Although this account indicates one way to deal with strain, other accounts demonstrate that the wife did not have many ways to deal with tension. The lack of opportunity to express frustration and concerns led to the wife's inability to relax and fall asleep.

W: To fall asleep is sometimes very difficult. You start worrying about something, usually it's trivial, and then you can't get to sleep, even though sometimes you're just exhausted and you get mad at yourself.

The caregivers were aware that their physical limitations reduced their ability to cope with strain. The appearance of chronic illness in these caregivers was consistent with reports in the literature, where chronic illness was present in up to half of the caregivers (e.g. Golodetz et al., 1969; Sainsbury & Grad de Alarcon, 1970). The combination of the aging process with chronic illness compounded the strain felt by these caregivers.

W: It's hard too, I think, when you get older, you know. Well, you're just not so fast, and that's the truth. There are days when you just don't feel good. There are days when you think, I'm just never going to cope with this any longer.

This perception was consistent with that of Sanford (1975) who found that aging and chronic illness contribute to emotional strain, and that of Goldstein et al. (1981) who described the decreased strength, declining energy, and poor health that typify the older caregiver.

The wife's confinement thwarted the development of ways to manage her strain. By sacrificing meaningful activities and recreations such as going to a hairdresser, to a senior's club, or to visit friends, she lost access to what Goldstein et al. (1981) defined as role relief. Nor could she deal with stress by focussing on the positive aspects of her situation. In most cases, the wives could not identify any benefits of having the husbands at home because they could no longer participate in shared activities. Having a routine was important in helping the wife to cope with her workload. Being too structured, however, could intensify the strain.

W: You plan generally. Just like you do your budget for a month. But from day to day, you have to be more-or-less open within that time, because you don't know what's coming up. But, if you try and plan too tightly, you're locking yourself in. The tension is going to get to you.

Planning for each day was limited due to the vicissitudes of the husband's condition and produced a situation where "you don't know what each day will bring."

Strain was a common theme among caregivers in the literature. Zarit et al. (1980) noted that extreme dependency was burdensome; Archbold (1982) remarked on the role of unexpressed negative feelings in the caregiver's strain; and Nissel and Bonnerjea (1982) found that physical strain was pervasive, although caregivers were even more concerned about the emotional strain caused by incontinence and sleep disturbances. These last two researchers also

suggested that the presence of confusion in the dependent magnified the degree of dependency and thereby increased the caregiver's burden. Sainsbury and Grad de Alarcon (1970) placed confusion and inability to care for oneself among the most burdensome dependent characteristics.

This section has discussed the direct effects of caring for a chronically-confused husband. Physical impairments usually accompanied his confusion, and the combination of incontinence, nocturnal awakenings, and disregard for safety presented particularly difficult management problems. The main effects of the husband's dependency are fatigue, confinement, and strain. These problems have been reported by caregivers in other long-term care situations.

Maintenance of the Family as a Unit

The effects of the husband's dependency and confusion extended to the social realm of the family. The quality of the marital relationship changed because the husband was no longer able to function in previous roles. The number of relationships outside the family decreased markedly. The wife had to maintain the family as a unit in the face of major changes in the functioning of the family and in her role.

Effects of Confusion on Relationships

Dealing with confusion on a continual basis had a major impact on the caregiver's marital relationship and on the family's relationships with others. Within the family, the

wife had to interact with a husband whose personality had changed and whose verbal communication had deteriorated. All the husbands reportedly had some degree of memory loss ranging from forgetting the day of the week to "forgetting that something has been done or asked about." One wife found it difficult not to "hound" her husband with details he had forgotten.

Lack of comprehension on the husband's part prevented in-depth conversation between his wife and him. In two families, conversation had become almost unilateral with the husband initiating speech but being unable to respond to the wife's concerns. Verbal exchanges thus initiated were generally confined to instances when the husband wished to request something or to reminisce.

The wives found that the personality changes accompanying confusion were disturbing. Two wives had to adjust to dramatic changes in their husbands' temperaments. One husband's personality had changed from being quiet and good-natured to being vocal and easily agitated. This wife found that dealing with the effects of confusion meant "constant concentration that you say the right thing" so as not to provoke the husband's temper.

One major change in the marital relationship caused by confusion was the loss of social support from the husband. The husband lacked receptivity to the wife's concerns. This deficit was compounded by the loss of social contact with the outside world. Social isolation, a prominent theme in the caregivers' accounts, was linked to three aspects of the

caregiving situation: the husband's social withdrawal, the wife's confinement and fatigue, and the concomitant decline in visitors to the home.

First, the husband's confusion appeared to decrease his interest in and diminish his ability to communicate in previously-established friendships. His subsequent social withdrawal prevented opportunities for the family to socialize with others. His wife was not accustomed to going out alone, nor did she approve of living life as a single person in the social world.

W: As I say, it upsets me to have to go [out] alone, you know. I rush off to somewhere and he's not there. It's not right to be that way.

Second, social isolation was a natural outcome of confinement. The wife was no longer able to participate in outside recreations or perform tasks that previously enabled her to get out with others.

W: How can I get to a hairdresser? I can't do anything myself--I mean, I wouldn't sit at a hairdresser and leave my husband all by himself. There's nobody. I can't ask anybody [to look after him].

Third, a decline in visitors to the home was caused by the family's inability to reciprocate social obligations.

W: I think that a lot of people find that when there's an illness or something, your friends disappear. I mean just, you're not as free, and you know, I think they do disappear.

Most of the family's friends were older too and were similarly confined because of chronic illnesses.

At the same time, social isolation occurred because the wives were reluctant to invite friends to the home. They were apprehensive about potentially embarrassing situations brought about by unpredictable, socially awkward, or socially inappropriate behavior on the part of their husbands. Elements of normal social interaction, such as eating and conversing, were impossible for all but one husband. The wife perceived that the husband's impairments bothered not only him, but also their guests. Friends did not know how to deal with the personality changes in the confused husband, and even members of the immediate family felt uncomfortable in the presence of a confused relative.

W: Our son comes, not as much as I would like him to come, he says "Mother, you know, Dad doesn't talk to me the way he used to and I find it difficult to talk with him." Then you realize that other people find it difficult too.

The wife's fatigue discouraged her ability to counteract the isolation of caregiving. The challenges in the caregiving situation deterred her from undertaking social events that could lead to fatigue, embarrassment or both. Health professionals in the literature identified the role of embarrassment in aggravating social isolation when the dependent experienced mental impairment (e.g. Hayter, 1982; Kapust, 1982). The research literature also documented the pervasion of the problem of social isolation (e.g. Golodetz

et al., 1969; Sanford, 1975). Fengler and Goodrich (1979) reported that social isolation was the greatest concern of older caregiving wives whose husbands were disabled.

Changes in the Caregiver's Role in the Family

As the husband's confusion increased, the wife became responsible for the family and the family's affairs. Decisions that were previously shared or relegated to the husband, now came under the wife's domain. Long-standing patterns of decision-making were destroyed. The wife had to learn to make decisions independently and perceive herself as being capable of directing the family unit. She found that the loss of dependency and the transition to independent functioning was difficult.

W: The role reversal, I have found to be perhaps, much more difficult than home care because I had to revert to making decisions. That is to me, a little more traumatic than the actual [physical] care.

One skill that had to be learned was financial management. Related tasks were finding out where the insurance policies were kept, learning to pay the household bills, and deciding whether or not to take Power-Of-Attorney for the confused husband. One wife described how she had first learned to write a cheque at the age of 79 years. Kapust (1982) identified the new financial roles that often confronted the elderly wife whose husband became mentally impaired. Part of the difficulty in taking control of the family as a unit was

that the wife had to relinquish dependency on her husband and learn to rely on herself instead.

W: This is what bothers me, is that F. [my husband] can't really help you to think it out [i.e. deciding on conflicting advice] seemingly. He isn't capable, you see. If he were really capable, like as your husband, I mean, he would phone up [my doctors] and say "I'd like to know what's going on."

As described earlier, the confused husband lacked receptivity to the wife's concerns and need for support. In the midst of social isolation and loss of support, then, independence became a necessary attribute if the caregiving wife desired to maintain the family unit in the home. Independence was evident in the wife's desire to be self-sufficient: "You've got to learn to help yourself." It produced conflict in the situation where the wife required social support, but rejected initial overtures of help from health professionals:

W: I wouldn't have help either, for a long time. Oh, I didn't need any help. I could manage, you know. But my blood pressure went up to over 220. So the nurse said "You've got to have help whether you want to or not!" So that was when I started to get help. They said I was too independent. That's the way I've always been, really.

(It should be noted that after receiving homemaker services, caregivers were grateful for the assistance).

Independence became a requisite in the caregiving situation because a general lack of support existed. The adult children of the three families within travelling distance tended to serve as sources of emotional support.

W: I've never had to call on my son [and his wife] for any extended time, but they're there.

W: I talk to the kids sometimes, but I don't like bothering them too much because it upsets me. No, I can handle it.

Nissel and Bonnerjea (1982) found that families tend to support the caregiver rather than being directly involved in caring for the dependent. The present study showed that wives did not want to burden their children who had "worries of their own." They felt that seeking support would be inconsistent with the notion of being independent.

Friends were mentioned infrequently as providers of assistance. Two of the younger caregivers had friends who had helped in the past but these wives did not like to ask for help. In one case the husband did not respond favorably to outsiders. In the second case, the wife was concerned about potential embarrassment. Generally, wives felt unable to repay their obligations to friends who had assisted in the past.

The provision of formal and informal support to caregivers has not been examined in great depth in the literature, but most studies pointed to a deficit in this area (e.g. Archbold, 1982; Sainsbury & Grad de Alarcon,

1970; Sanford, 1975). Low morale in older wives was found to be associated with less contact with friends and family (Fengler & Goodrich, 1979), and family visits appeared to offset the negative impact on caregivers (Zarit et al., 1980).

Confusion in the husband had a negative effect on the wife's social functioning. Social isolation, found in chronic illness in general, was aggravated by the husband's loss of social skills. The wife faced major changes to her traditional role following her decision to maintain a home environment for the husband.

Acceptance of the Caregiving Situation

Despite the profound impact on personal and social functioning, the caregiver was resolved to keep her husband out of an institution. She accepted her husband's confusion, dependency, and the self-sacrifices she incurred as a result of trying to keep him at home. This section deals with the wife's acceptance of her situation.

Minimizing the Changes in the Home Environment

It has been shown that the husband's confusion brought changes to the family's functioning and the interpersonal relationships, as well as to the wife's well-being. In spite of these changes, the wife accepted the caregiving role. She wanted to keep her husband at home and provide a normal life as far as possible. She tried to maintain a normal

environment and showed acceptance of the situation by overlooking his lost abilities and de-emphasizing the effects of confusion.

For example, one wife who became exasperated with her husband's incontinence re-directed her frustration toward herself.

W: I used to get impatient with him and I'd get so mad at myself because he couldn't help it--I think I must have been put on this earth to learn patience, because I don't have much of it.

Rather than place blame on her husband, the wife chastized herself for not being able to cope more successfully.

The wife desired to keep her husband oblivious to his lost abilities and roles.

W: He always did the banking and paid his Chargex and things like that. He's forgotten about everything. I don't want to hurt his feelings and make him feel lesser than a man. I say "You've been doing it all these years, and now you're not well, I'll do it. There's nothing to it. I can pay the bills and keep the bank account straight and you just relax."

The wife minimized her husband's difficulties to allow him to retain his identity in the familiar surroundings of his home.

Consequently, the realities of each husband and wife appeared to differ considerably from one another. The husband seemed unaware of the wife's added responsibilities and burden. Instead, he expected that she would continue in the same role as always toward him.

W: He doesn't understand how much I sacrifice. He just wants to let life go on and let everything be for him.

W: He doesn't seem to consider me at all. He doesn't seem to consider me, you know. This is what my son says "I've spoilt him [my husband] by doing everything when he wants it done."

The wife accepted her husband as a changed person who no longer provided emotional support, while the husband continued to display behaviors that had ill effects on his wife. Two previous studies referred to discrepancies between the perceptions of the caregiver and of the dependent. Pringle (1982) noted that dependents perceived the quality of interpersonal relations to be better than that reported by the caregivers. Archbold (1982) pointed out that dependents did not seem to be aware of the full negative impact on the caregivers of the caregiving role.

Valuing the Caregiving Role

It was observed that the caregiving role was highly valued by the caregiver. The wives considered that accepting the role and the attendant sacrifices was their "duty" as wives.

W: Well, it's a thing I have to do. I have no choice. I mean, he's my husband and he needed looking after and [there was] nobody else to do it.

Her confinement and social isolation contributed to a

narrower perspective on life where her focus in life became the care of her husband. As Golodetz et al. (1969) noted, "home care households were ... isolated and pre-occupied with the care of illness" (p. 388). Each wife recognized that she was her husband's sole provider.

Because of her devotion and commitment to her husband, the wife accepted the changes in her life as a caregiver, such as social isolation:

W: I think what I've seen happen is that people just don't come. Certain people who are best friends still do, but there has been a falling off of that, and I accept that, that people can't cope with it and that's the way it is.

Guilt feelings accompanied the wife's failure to fulfill her wifely obligation, as evidenced by the account of one wife who had to call on her daughter to take care of the husband for one month.

W: I felt guilty about her being burdened with him.

It was my responsibility, not hers.

This particular wife ended her recuperation from surgery two weeks earlier than recommended to resume the caregiver role.

The wife's acceptance of the caregiving role was to such an extent that she felt guilty about sharing the burden or needing moral support.

W: My sister calls everyday and we have a little chat, and, of course, I unburden myself some days, which, I think is a shame because she's not well herself and I think she doesn't know what to say to me

sometimes.

The wife did not want to be perceived as demanding because this characteristic was not congruent with an independent self-image.

The longevity of the marriages attested to the devotion of each wife. Their resolve to try to cope as long as possible remained undaunted by opposition from family or health care providers, or by jeopardized health.

W: Well, you know, you try to do things as long as you can. Just like I told the nurse, "I don't want to give up, yet."

W: Now my son [and his wife] think I have long gone past that stage, that he should be [institutionalized]. They say "It's too hard on you, you have your own life to live." I said yes, but that part of my life is with him and I could not just dump him, which it would be in my mind, into the hospital and say "Now I'm going to live my life." That's not what I bargained for when we got married.

These accounts also epitomize the feelings of failure and dissatisfaction aroused by the prospect of institutionalization.

At best, institutionalization represented a second rate solution to the confused husband's care. At worst, institutionalization was viewed with distress and with fear of depersonalized care:

W: I don't want to put my husband in a nursing home if I can help it. You hear so many tales that they're not good.

The wife's ability to maintain the home environment was shadowed by the prospect of institutionalization. She was concerned about her ability to continue to provide care when she was already experiencing strain:

W: What I get frightened of [is] that one day, I won't be able to look after him. What's going to happen to him?

The wife felt that her husband still enjoyed his home surroundings and benefitted from her personal care. She also derived some comfort from her decision to accept the caregiving role by projecting herself into his position and hoping that her husband would have made the same sacrifices as she had made if their positions had been reversed. Reports of the association of institutionalization and guilt are documented throughout the literature (e.g. Goldstein et al., 1981; Nissel & Bonnerjea 1982; Sainsbury & Grad de Alarcon, 1970).

The notion of acceptance is also wide-spread in the research. Two such examples are the identification of the caregiver's resignation to the situation (Nissel & Bonnerjea, 1982) and the impression of the family's willingness to cope with the dependent at home as long as possible (Sainsbury & Grad de Alarcon, 1970). The theme of acceptance occurred in the presence of the caregiver's awareness of the sacrifices endured in being a caregiver. This observation corroborates

the paradox voiced by Goldstein et al. (1981) that "although they [caregivers] tend to talk candidly about the burden and stresses, ... nearly all express their determination to maintain the patient at home as long as possible" (p. 27). The affectional bond between caregiver and dependent identified by Nissel and Bonnerjea (1982) was obviously a major source of motivation in the acceptance of the situation and the valuing of the caregiving role.

These wives accepted the responsibilities and sacrifices attendant with the caregiver role. They were committed to their husbands and tried to provide a home environment as long as possible. Caregiving had become their major purpose in life. They viewed institutionalization with distress and felt morally obligated to try to prevent it at the expense of their own comfort.

Summary

In this chapter was presented a description of the impact of long-term care based on the accounts of older caregiving wives whose elderly husbands experience confusion. Confusion was linked to such problems as incontinence, nightly restlessness, and safety hazards. Confusion prevented the husband from being aware of his dependency on his wife and of her experience of strain, fatigue, and confinement. The social consequences of being married to a confused husband were extensive and included the loss of spousal support, the necessity of independent

decision-making, and social isolation. Her desire to prevent institutionalization and her devotion to her husband impelled the caregiver to accept her situation. A discussion of these findings in relation to the literature is found in the next chapter.

CHAPTER 5

DISCUSSION OF THE FINDINGS

Introduction

The concurrent analysis of the data and the review of the literature led the researcher to generate a conceptual framework on the impact of caregiving. The first section of this chapter contains a description of the concepts that summarize the current status of knowledge. The following section discusses the findings of this study in relation to the conceptual framework, identifying additional concepts where relevant.

Conceptual Framework

This framework is designed to summarize the impact of caregiving as described in the literature. A major concept that appeared throughout the literature was burden. Two examples of its usage were Golodetz et al.'s (1969) observation that "illness in the home is a burden" (p. 393) and Morycz's (1980) suggestion that "many families collapse under the strain of multiple burdens" (p. 24). Most studies, however, failed to clarify or elaborate the meaning of burden.

For the purposes of this conceptual framework, burden can be defined as the negative impact caused by providing care for a dependent. This negative impact does not deter

the caregiving efforts. Rather, the caregiver usually feels obligated to take care of the dependent as long as possible: "the general attitude seems to be: whatever the physical, psychic and other costs of caretaking, they are the price one pays to avoid institutionalizing the patient" (Goldstein et al., 1981, p. 27). If the burden becomes overwhelming for the caregiver, the home care situation breaks down, often leaving institutionalization as the only solution to the dependent relative's care (Morycz, 1980; Sanford, 1975).

In this conceptual framework, burden is characterized as the net result of the interaction of the following components: the dependent's characteristics, the caregiving tasks, the effects on the caregiver, and the intervening variables. A diagram of these and related concepts is found in Figure 1. The dependent's characteristics that appear to contribute substantially to burden are excessive dependency, incontinence, nocturnal restlessness, confusion, and deviant social behaviours that accompany mental impairment (Nissel & Bonnerjea, 1982; Sainsbury & Grad de Alarcon, 1970; Sanford, 1975). These characteristics and other aspects of the dependent's illness impair the dependent's abilities and create tasks for the caregiver. Caregiving tasks are those activities required to maintain the dependent at home and may include management of diet, medication, exercise regimes, and personal care (Archbold, 1980; Golodetz et al., 1969).

The caregiving tasks and the troublesome dependent behaviours have negative effects on the caregiver's personal and social functioning. Physical and emotional strain are

common concerns for the caregiver (Archbold, 1980; Goldstein et al., 1981; Nissel & Bonnerjea, 1982; Sainsbury & Grad de Alarcon, 1970). When the dependent is elderly and experiences mental impairment, an additional source of emotional strain is worry about the dependent's condition, further deterioration, and safety (Hayter, 1982; Sainsbury & Grad de Alarcon, 1970). The presence of confusion in an elderly dependent magnifies the caregiver's physical and emotional strain (Nissel & Bonnerjea, 1982).

Emotional strain is also associated with the caregiver's reaction to the losses and changes occurring in the caregiving situation. It may be manifested by anger, resentment, and guilt. The lifestyle changes resulting from the caregiving role may cause anger and resentment toward the dependent person (Archbold, 1980; Fengler & Goodrich, 1979). Deviant behaviour accompanying mental impairment may arouse feelings of embarrassment, anger, or resentment in the caregiver (Kapust, 1982; Morycz, 1980). Feelings of rejection toward the dependent may develop, followed by feelings of guilt when caregivers realize that the person with mental impairment is no longer himself and not intentionally causing difficulty (Hayter, 1982; Kapust, 1982).

In addition to negative personal effects, caregivers experience negative social effects in the caregiving situation. Role changes are common in chronic illness as each caregiver learns to adjust to new roles that the impaired person can no longer carry out (Golodetz et al.,

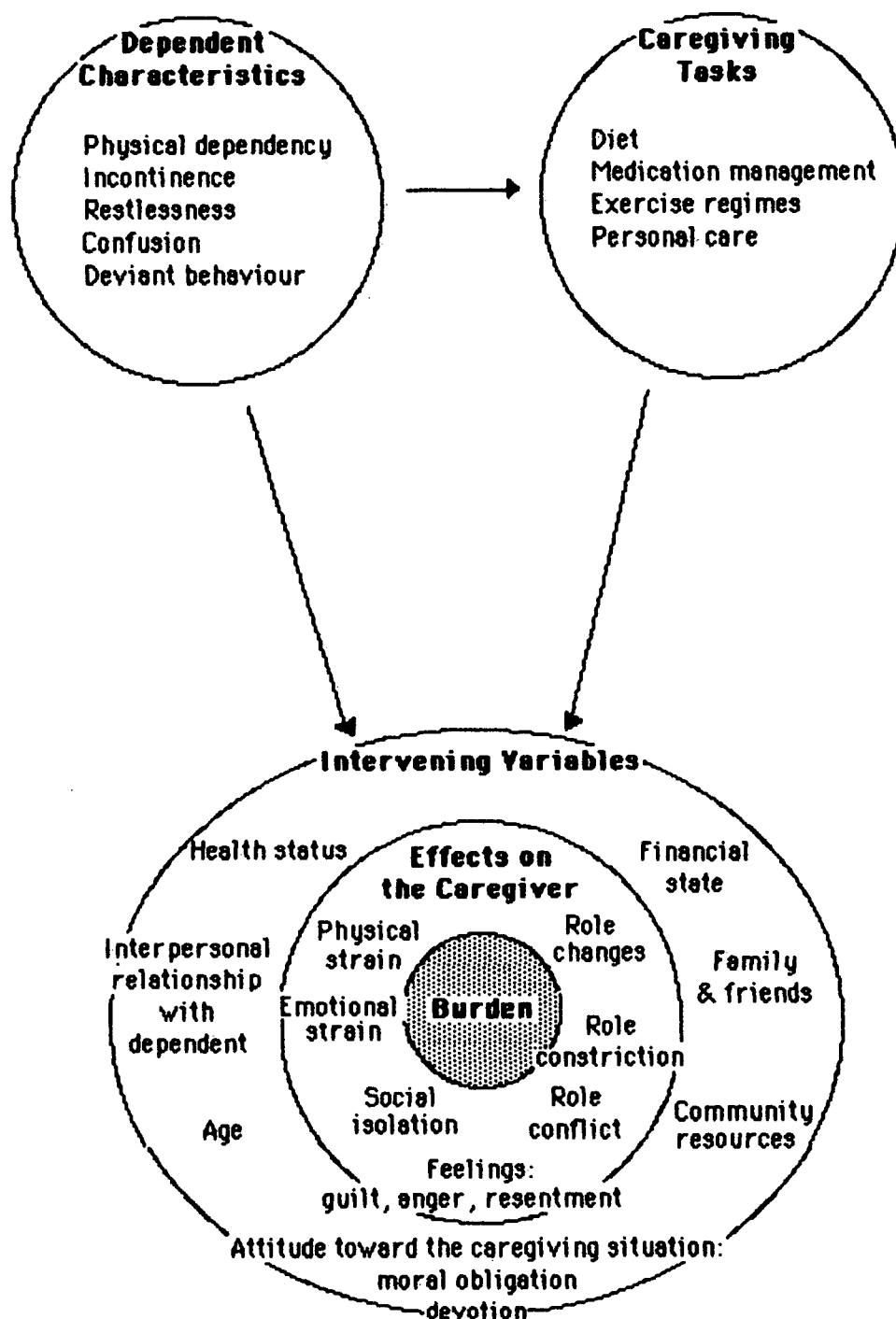


Figure 1. The conceptual framework derived from the literature

1969; Kapust, 1982). Feelings of inadequacy sometimes occur in the new roles, especially in the role of dependent advocate in medical decision-making (Archbold, 1980).

Role constriction is a prevalent social effect found throughout a variety of caregiving situations (Goldstein et al., 1981). Most caregivers give up multiple roles that conflict with their caregiving responsibilities, and consequently, their lives begin to revolve around the dependents (Archbold, 1980; Goldstein et al., 1981). Confinement to the home, loss of meaningful outside activities, and the social withdrawal of the family contribute to the problem of social isolation among caregivers (Fengler & Goodrich, 1979; Golodetz et al., 1969; Morycz, 1980).

The impact on the caregiver of the caregiving tasks and dependent characteristics appears to be influenced by intervening variables. The health status of the caregiver is one such intervening variable. Chronic illness in the caregiver appears to be a common problem. It was present in as many as half of the caregivers in a particular study (Sainsbury & Grad de Alarcon, 1970). The presence of chronic illness tends to increase the burden by decreasing the caregiver's physical capabilities to cope with difficult tasks (Goldstein et al., 1981).

The age of the caregiver also influences the impact. Older caregivers are more susceptible to role constriction and role fatigue (Goldstein et al., 1981), while younger caregivers are more likely to encounter role conflict and

family strain (Archbold, 1980; Nissel & Bonnerjea, 1982). Advancing age is also associated with increased chronic illness and physical strain (Goldstein et al., 1981).

The relationship between the dependent and the caregiver can affect the impact on the caregiver. A good interpersonal relationship appears to decrease the mental strain involved in caregiving (Fengler & Goodrich, 1979; Pringle, 1982). The presence of mental impairment adversely affects the relationship and virtually eliminates the dependent as a source of emotional support (Hayter, 1982; Nissel & Bonnerjea, 1982). The influence of the type of kin relationship on the impact has not been established. Fewer problems are found in families where dependents live with their spouses than with adult offspring (Sainsbury & Grad de Alarcon, 1970), yet there is no difference found between the amount of burden perceived by caregiving wives and the amount perceived by caregiving daughters (Zarit et al., 1980).

Other examples of intervening variables are the existing support systems. Formal support is available from community resources. Informal support is drawn from family and friends. The lack of social support from or contact with one's family appears to increase the level of burden (Fengler & Goodrich, 1979; Zarit et al., 1980). Friends and neighbours offer less assistance to the caregivers than families do (Nissel & Bonnerjea, 1982). Even younger caregivers, who have greater potential support from the members of their nuclear families, usually carry the burden alone (Nissel & Bonnerjea, 1982). The lack of supportive

community resources for the mentally-impaired elderly indicates that society does not yet recognize the burden of the family that cares for the mentally-impaired elderly (Kapust, 1982; Morycz, 1980). Generally, caregivers need more support and more positive feedback about their caregiving efforts than they presently receive (Hayter, 1982).

The financial state of the caregiver affects the impact of burden on the caregiver. Financial inadequacy is common in situations where the caregiver is an older wife (Fengler & Goodrich, 1979; Hayter, 1982) and where the caregiver has given up outside employment to look after the dependent (Goldstein et al., 1981; Nissel & Bonnerjea, 1982). Financial inadequacy is associated with lower morale in caregivers (Fengler & Goodrich, 1979; Pringle, 1982).

Finally, there is indication that the caregiver's attitude toward the caregiving circumstances influences the burden. The caregiver's determination to continue in the situation despite the burden, often noted in the research reports, was rarely examined further. The attitude varies among different caregivers. Some caregivers are very willing to cope with the burden and are devoted to their dependent relatives (Goldstein et al. 1981; Sanford, 1975). Other caregivers are resigned to fulfill their moral obligation to the dependents and would feel guilty if they abandoned their duty (Nissel & Bonnerjea, 1982). In the latter case, caregivers may resent the burden imposed on them (Archbold, 1980). The prospect of institutionalization commonly raises

feelings of guilt in most caregivers because it symbolizes the failure to fulfill one's obligations (Goldstein et al., 1981; Hayter, 1982).

A Discussion of Burden

The findings of this study generally support the conceptual framework suggested by the literature. This section compares the description of burden given in the findings with the conceptual framework described in the literature. For the purposes of this discussion, references to the caregiver indicate the literature and references to the wife specify the present study.

Burden And The Management Of Dependency

The first content area, management of the husband's dependency, contains descriptions of the caregiving situation that are similar to the framework's summation of the literature. In both the findings and the literature, burden can be depicted as originating from the dependent person and the related caregiving tasks. The changes in the husband's functioning that occur when confusion is present can be compared to the dependent characteristics that caregivers find troublesome. The dependent's physical limitations cause problems, whether or not mental impairments are present. The addition of confusion to physical disability exposes the older wife to a potentially more difficult caregiving

situation. Confusion limits the dependent husband's environmental awareness, removes his ability to appreciate the changes he has undergone, and makes safety hazards a constant possibility.

The findings of this study indicate that caregiving tasks are extensive for these wives. Medication regimes, although not used to treat confusion, accompany the treatment of other chronic illnesses such as Parkinson's disease and diabetes. Most of the wives have to alter the husband's diet to enable the ingestion of food. As well, personal care tasks are prominent concerns for these wives, especially when incontinence is present.

It is interesting to note the lack of specific plans of care that are addressed to the problem of confusion in these husbands. The wives did not identify any systematic approaches to deal with the husbands' loss of environmental awareness or with nightly awakenings. At first, an exercise regime may seem superfluous when the presenting problem is confusion. The prominence of nocturnal restlessness and mobility disturbances in the husbands, however, causes one to question the adequacy of present activity levels. These wives may not have identified any activity plans used in the husbands' care because the exercise regimes had become deeply engrained into the daily routine to the extent that the wives forgot to mention them, or the need for activity was neglected as husbands became weaker and less ambulatory. A lack of exercise could account for the husbands' restlessness at night.

The effects on these wives of providing care are substantiated in the descriptions of caregivers in the literature. Physical and emotional strain are reported under fatigue, confinement, and strain, further supporting the notion that burden is present. The wife's fatigue appears related to the changes in the husband's functioning and to the caregiving tasks. The husband's nocturnal restlessness interrupts his wife's sleep and these disturbances largely contribute to her fatigue. Although both mates experience sleep disturbances, only the wives appear to use sleeping medications. Two wives rely on their use, prompting the question whether the sustained use of sleeping medication is contributing to the disturbances in the quality and quantity of sleep for some wives, but is not yet recognized as a problem.

Confinement, a particularly noticeable effect in this group of wives, is designated as role constriction in the framework suggested by the literature. A primary cause of confinement is the necessity to constantly supervise the husband. The wife's perception that it is her duty to be in constant attendance may be causing her to exclude others from being considered for temporary replacement. Confinement is also caused by decreased mobility associated with chronic illness and fewer outside roles, characteristics found more often among older caregivers.

The manifestation of strain in the wives corroborates its presence among caregivers in general. In the present study, the principal antecedents of strain appear to be the

husband's physical incapacities, the mental changes attending chronic confusion, and the wife's loss of physical stamina accompanying chronic illness and aging. Common health risks, such as the increased risk of falls among the elderly, are accentuated in this situation. The wife worries about her husband's safety and her own ability to continue to cope with the physical and emotional demands of caregiving.

The literature is tentative about the specific effects of chronic confusion on caregivers. The present study indicates that the wife is not able to include the husband in planning for or carrying out his personal care. As well, impairments in verbal communication sharply curtail communication between the spouses and virtually eliminate conversation and reciprocal sharing of feelings. Confusion, then, alters the quality of the marital relationship and removes the husband as a vital source of support for the caregiving wife.

The framework's interpretation of the literature suggests that caregivers may experience anger and resentment in response to the changes accompanying the caregiving role. These reactions are not emphasized in the findings. More typical responses are frustration, which accompanies the wife's failure to prevent incontinence, and embarrassment, which follows a potential or actual public display of the husband's deviant behaviour. These feelings are more inner-directed than anger, indicating that these wives place responsibility for difficulties on themselves rather than on the dependent significant other. The findings raise more

questions than they answer about the caregiver's emotional reaction to caregiving and her adjustment to the effects of chronic confusion. More can be understood about the wife's emotional reaction by considering the social impact of being a caregiver.

Burden And The Maintenance Of The Family

The impact of caring for someone with chronic confusion extends into the social realm of the caregiving experience. The literature suggests that social changes accompany the chronic illness in a family member. The present findings expand upon such changes and their significance in the elderly nuclear family. The consequences for the wife include social isolation and role changes.

Social isolation is clearly a consequence for caregivers throughout all settings. When chronic confusion is present in one's elderly husband, the experience of social isolation appears even more intense. Confinement brings isolation to the wife, while fatigue inhibits her desire to counteract isolation. The lack of reciprocal communication with her confused spouse adds to social isolation. Embarrassment may also play a part in social isolation, if it causes the wife to withdraw from outside social situations. By avoiding contact with everyone except for close family members, the wife may be intentionally or unintentionally reinforcing her social isolation.

The amount of available social support influences the

severity of the social isolation, thus influencing the impact on the caregiver in general. The framework's summation of the literature sets forth that social support can be viewed as an intervening variable. The findings suggest that support is important to assist the older wife to cope with burden and maintain the family as a unit. Family support does not appear to be extensive and often either the adult offspring or the family has moved away from one another. Those wives with familial support are thankful for the help received from their families, but do not wish to be perceived as demanding. Although existing services that are received are well appreciated, these wives do not utilize or seek out other forms of social support. The utilization of community resources appears to be limited to the services of the government-sponsored homemakers. Friends do not appear to have a part in helping the older family remain in the home.

In addition to social isolation, role changes within the family are prominent effects found in both the findings and the literature. The role changes are considerable. Coping with confusion means the wife has to adjust to altered familial responsibilities and to focus all her time and energy upon the activities related to the husband's care and the maintenance of the home. The restriction of the wife's activities to the caregiving role is congruent with the description of role constriction given in the framework. Role conflict is not identified as a concern for these older wives, as noted in the literature.

One noticeable role change that is not highlighted in

the literature is the move to independent decision-making accompanying chronic confusion in one's spouse. Whether done gradually or abruptly, these wives have to learn to be independent. To relinquish dependency on one's spouse and take over control of the family is difficult, especially when the wives have been in the traditional female role. It is apparent that role changes have been made successfully. For example, the wives have learned to take charge of financial matters and appear to be managing on income derived from pensions. Financial adequacy appears to be less of a concern for these wives than for caregivers in the literature.

An independent self-image enables the wife to muster confidence to undertake new roles and added responsibilities. These wives may have to have been fairly independent at the outset to assume responsibility for the care of another and to endure the resulting isolation. The construction of an independent self-image is a finding not considered in the framework's interpretation of the literature. An independent self-image could be added as an intervening variable to the conceptual framework, for it is a caregiver characteristic that influences the ability to cope with burden.

The wife's desire to be independent may be partly related to the avoidance of embarrassment. By being able to maintain the home as independently as possible, she is able to operate in a relatively closed environment where she does not have to confront social reactions to her husband's confusion, such as stigma. Independence appears to reduce the likelihood that outsiders will remind her of the

husband's altered state.

The findings suggest that the social impact on the older wife is extensive when chronic confusion is present. The chronically confused husband no longer participates in the family to the same degree, so the wife learns to depend on herself. The term "independence" rather than "self-reliance" is used to suggest that independence may not be as positive as the wives perceive it to be. Independence has negative consequences when it is associated with the rejection of the need for social support. The wife, feeling that an independent person should not need help, views dependency on others as incongruent with her self-image and turns down offers of help. When the negative implications are taken into account, independence may actually contribute to alienation in caregivers.

Burden And The Acceptance Of The Situation

The meaning of the caregiving situation to the caregiver is not explored in the literature, although there is indication that the caregiver's attitude toward her circumstances influences her perception of burden. The content area of acceptance shows that incorporating the caregiver's attitude into a description of caregiving is integral to understanding her experience.

The literature indicates that the caregiver feels obligated to take care of the dependent as long as possible, and that the existence of burden does not deter the

caregiver's efforts. The framework suggests that moral obligation and devotion influence burden. The findings of this study support these observations, but emphasize that devotion and affectional ties to the husband, rather than resignation or avoidance of guilt, underlie the wife's acceptance of the situation.

The actions of these wives do not appear to be motivated by guilt, except that they recognize that they would feel guilty if forced to institutionalize their husbands. Nor do the wives appear to be resigned to their burden. Perhaps the lack of emphasis on "negative" feelings in the wives' accounts could be due to their desire to create a favourable impression for the researcher as a health professional. A more likely explanation may be that these wives are fulfilling their expectations of their wifely duty and have come to accept the negative consequences that follow.

The affectional bond identified in the literature, then, most aptly explains the attitude of acceptance in these wives in this study. It may be that the closeness of the kin relationship, in this case the marital relationship, is a relevant intervening variable. It is not clear that chronic confusion in the husband detracts from the wife's acceptance of her circumstances, although it has been reported to threaten the affectional bond in a group of caregiving adult daughters.

The wife's values and beliefs lead her to accept her circumstances. The volitional nature of her sacrifices is manifested by two aspects of this situation: her

minimization of the changes in the husband's functioning and the value she gives to the caregiving role, neither of which are identified in the literature.

The wife minimizes the losses of her husband and the effects of chronic confusion, in spite of the negative consequences she experiences. These behaviours suggest that denial is part of the process of acceptance. Like independence, denial has both positive and negative aspects. Denial may be an important mechanism whereby the wife can overlook the losses of the husband and focus instead on the parts of her environment that have remained constant. On the other hand, denial may mean that the wife accepts a situation that she cannot realistically expect to continue to manage. In addition, it suggests that she will not be able to judge when she becomes overburdened and should relinquish the caregiving role.

The wife also appears to be denying that she deserves and requires relief. Believing burden to be an unavoidable part of the caregiving experience, she is reluctant to consider taking respite periods or to leave her husband under another person's care. One wonders if she would not be more cognizant of her own needs if society gave greater recognition to the sacrifices made by caregivers.

The wife's tenacity reveals the values she holds about the roles of wife, homemaker, and caregiver. These roles have come to constitute her life's vocation. Being a caregiver involves a magnification of the responsibilities associated with the former two roles. Although she

experiences burden, she is assured that the family unit will continue to exist. Conversely, giving up the husband's care and absolving herself of the burden would mean the loss of her main purpose in life. Abdicating her caregiving role would bring about a perceived greater burden: the disbandment of her family and the forfeiture of a meaningful identity as a caregiving wife. A diagram of the modification of the conceptual framework based on the discussion of the findings is presented in Figure 2.

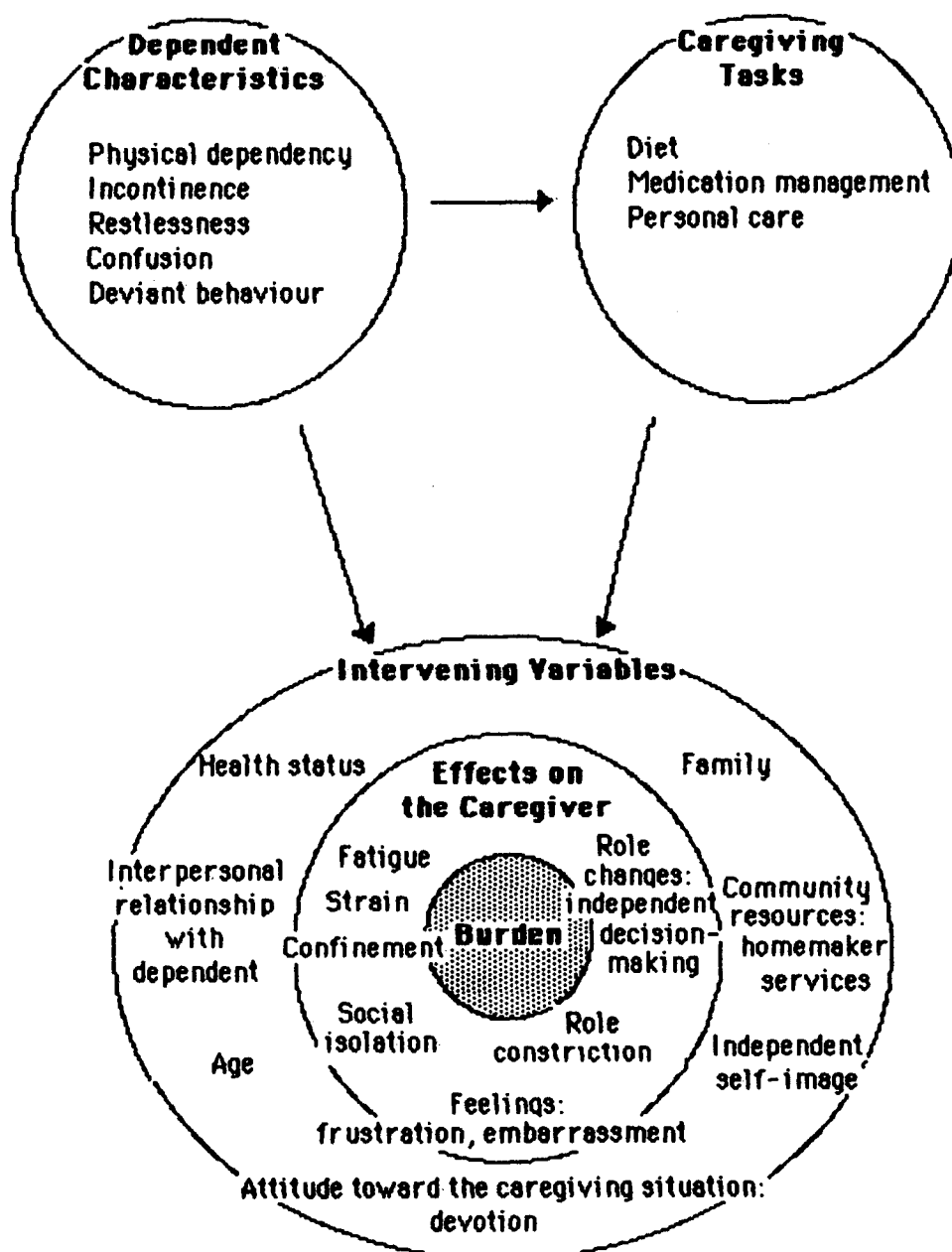


Figure 2. The conceptual framework modified on the basis of the findings

A Synopsis of Burden

The caregiving wife's perspective of the impact of caregiving has been interpreted to consist of managing the husband's dependency, maintaining the family as a unit, and accepting the caregiving conditions. These processes typify the wife's responses to the caregiving situation and imply that caregiving has a negative impact. The negative impact produced by the care of a dependent confused husband is congruent with the interpretation of burden given in the framework's rendition of the literature.

The area of managing dependency contains descriptions of the husband's impairments and the caregiving tasks that arise from these impairments. The effects of fatigue, confinement, and strain support the use of burden to describe the impact on the caregiver. The second area of content concentrates on social effects. Chronic confusion impairs the husband's capacity for discourse, with negative consequences for interpersonal relationships. As well as contributing to burden, confusion creates conditions that are unfavourable to its amelioration. Social isolation is a prime example. Independence seems to become the categorical imperative when an older wife loses her dependency on the confused husband and takes over the family. Finally, the third area explores the wife's acceptance of a burdensome situation. A seemingly paradoxical situation exists where the wife accepts the negative impact of caregiving. The personal costs are high, the benefits few, but these wives are committed to placing

the husband's needs before their own.

CHAPTER 6

SUMMARY, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Summary

As the number and proportion of elderly persons in industrialized nations increase, the long-term care of those with chronic confusion will pose concern for caregivers in the community. The older wife has an increased chance of finding herself in the role of caregiver because women have traditionally carried out nurturing roles in society. The needs of the caregiver merit examination to determine the implications for nursing.

This qualitative study examined the impact of long-term care on the older wife when the dependent was her chronically-confused, elderly husband. Six wives whose elderly husbands had experienced chronic confusion for one year or longer were interviewed using the phenomenological method discussed by Giorgi (1975). A qualitative approach enabled the researcher to explore both the effects on the caregiver and the meaning of the experience to her.

As directed by the phenomenological method, the researcher approached the caregiving situation with no pre-conceived framework and with minimal assumptions. To achieve this open perspective on the data, the review of the literature was completed at the end of the data collection. Data collection took place over a four month period. Initial interviews with each wife used open-ended, semi-structured

questions to elicit her perception of the impact. As the data were gathered, they were analyzed, compared, and coded into themes. Subsequent interviews were carried out to clarify and elaborate the themes found in the caregivers' accounts. The review of the literature proceeded simultaneously with the data analysis. In general, the impact on the caregiver was negative and could be summed up by the concept of burden.

The inductive analysis of the caregivers' accounts generated three major areas of content: (1) management of the husband's dependency, (2) maintenance of the family as a unit, and (3) acceptance of the caregiving situation. These areas represent the caregiver's perspective of and response to coping with the long-term care of a confused, dependent husband. Overall, this interpretation of the data affirmed the description of burden derived from the literature.

Many of the caregivers' concerns revolved around the management of the husband's dependency. Confusion rendered the husband dependent, but this mental impairment did not occur in isolation. Other chronic illnesses were present and produced physical impairments. Some of the most prominent concerns were incontinence, nocturnal restlessness, and disregard for safety. Chronic illness was present to some degree in all of the wives too, and the physical losses accompanying aging diminished each wife's ability to manage her husband's dependency. The experience of fatigue, strain, and confinement was common.

Besides the direct effects on the caregiver of providing

care, the impact of confusion reached the level of the family. The social dimensions of coping with chronic confusion included additional family responsibilities and social isolation. Following the onset of confusion, each wife learned to assume roles and responsibilities previously held by her husband. This older caregiving wife altered many years of traditional patterns to learn to function independently, without emotional support or feedback from her confused husband. Social isolation was intensified by confinement, fatigue, and the husband's impairments.

Finally, the caregiving role held significance and purpose for the caregiver. She valued her commitment to her husband and accepted her situation because she felt obligated to prevent her mate's institutionalization. Her main purpose in life came to revolve around his welfare and the independence of the family unit. Her perception of her duty as a wife and her devotion to her husband dictated her course of action, despite the burden and sacrifice it entailed.

Conclusions

This study has shown that being a caregiver has a marked impact on virtually every aspect of the caregiver's life, except that she is able to remain in a familiar environment with her husband, a person with whom she has shared her adult years. The caregiver's main concern is for her husband's welfare and for the elderly, nuclear family's continued existence. The caregiver appears to make sacrifices to

fulfill her perception of her duty as a wife, suggesting that she values her husband's needs more than her own.

The caregiver appears to need to learn about the importance of meeting her own needs. She needs support to deal with physical, psychological, and social effects of caregiving. As well, she needs to be realistic about her ability to tolerate the burden independently and to seek adjuncts to her personal management of the husband's care. In sum, the caregiving wife needs nursing care herself.

Implications For Nursing

Given that the older caregiving wife's needs may be unfulfilled and that support is required to cope with the burden of her confused husband's care, nursing intervention is warranted on several fronts. Although these findings are not generalizable, they do suggest implications for nursing practice, nursing education, and nursing research. These implications will be considered in this section.

Implications For Practice

The role of the nurse is to nurture both the husband and the wife in this situation. The caregiving situation is complex and the professional nurse has many facets to consider in balancing the needs of the caregiver with those of the husband and of the family. The findings justify nursing intervention for the caregiver and the dependent

husband. The caregiver needs an advocate who is concerned about the impact of caregiving on her and her ability to deal with the negative effects. The professional nurse can use the knowledge contained here as a basis for assessment, planning, and intervention. Nursing interventions include counselling the wife and coordinating community resources.

The nurse could use this framework in conjunction with a nursing model to assess the impact of caregiving during regular visits to the family. The nurse is guided to collect data on the existence of troublesome dependent characteristics, the extent of the caregiving tasks, the effects on the caregiver, and the role of intervening variables. In conversing with the wife, the nurse could use the content areas as conversational topics while looking for difficulties in managing the husband's dependency, maintaining the family as a unit, or accepting the situation.

The nurse then can use her assessment of the situation to identify areas that require intervention. The nurse should counsel the caregiver in three areas: how to take care of herself, how to take care of her husband, and how to make use of existing resources. First, the nurse needs to provide support to the caregiver to assist her to cope with the burdensome effects of strain, fatigue, confinement, and isolation. The wife needs to recognize the validity of her own needs for rest, recreation, and social interaction. The nurse can use therapeutic communication to explore the wife's values and beliefs about self-denial, while reinforcing the significance of the caregiver's well-being to the

continuation of the family unit.

To foster the wife's well-being, the nurse can teach health promoting behaviours such as relaxation techniques to cope with unavoidable strain and with chronic fatigue. The nurse can provide the positive feedback necessary to bolster the wife's confidence in her ability to handle independent decision-making. Communication skills are particularly important in intervening with wives in situations where chronic confusion is present, because the wife's communication with the husband has been irreversibly disrupted and social isolation has hampered her communication with other people. By being an empathetic listener, the nurse can provide the wife with the opportunity to discuss her experience, to share her concerns, and to express such feelings as frustration and embarrassment.

Second, the nurse can counsel the wife on how best to care for the husband. Many husbands might benefit from programs of bladder training or from an increased, planned activity level. The nurse can act as a resource for the management of troublesome behaviours accompanying physical impairments and chronic confusion, and caregivers should feel free to refer to the nurse for advice. Reality orientation and validation therapy are two communicative techniques for interacting with chronically confused people that the nurse can teach and role-model to wives.

Third, the nurse can coordinate community services for the elderly family. The wife's perspective on support services and her attitude toward accepting help are crucial

in planning the most acceptable services. The nurse may have to explore the caregiver's reticence to pursue or use community services. Community programs could include respite services for one weekend, adult day hospital programs for the husband, or volunteer visitors to the home. The nurse may have to explore the wife's expectations of her duty as a wife, and whether it is realistic to try to be in constant attendance. The nurse's ability to communicate will be critical in helping her learn to hand over control of the husband's care to others.

The nurse can help the wife increase her use of community services by helping the wife budget for additional homemaker services or arranging for the wife's participation in a group of caregiving wives in similar circumstances. The nurse could organize and run such support groups where information about community resources could be taught at a group level. Through such groups, the wife could become aware of the importance of relieving confinement and the strategies used by other wives. The wife needs help to rebuild her identity apart from the caregiver role, develop new relationships, and renew past friendships and meaningful activities.

In considering community services and programs, the nurse can provide help and information about alternatives to home care. Part of the caregiver's anxiety about the future would be allayed if she had specific plans for the potential hospitalization of the husband. By encouraging her to rebuild her identity outside of the family, the nurse could

strengthen the caregiver's resources to deal with institutionalization if it becomes necessary.

Implications For Education

The complexity of the caregiving situation requires a broad nursing education that integrates the role of the nurse in community health, gerontology, and geriatrics. The preparation of the professional nurse should include appropriate knowledge and skills to apply the nursing process in the care of older individuals and their families. Knowledge of family theory, the aging process, healthful behaviours, and the nursing care of behaviours associated with chronic confusion in the elderly are relevant content areas. Communication skills can enable the practitioner to elicit the caregiver's perspective on her experience during the process of data collection, to integrate the caregiver's values and beliefs when devising supportive interventions, and to use herself therapeutically in interacting with these clients.

The curriculum should incorporate the necessary content for planning interventions. The concepts of teaching and learning theory can be useful for promoting healthful behaviors. Content relating to small group dynamics and leadership of small groups would prepare the nurse to run a support group for caregiving wives. Decision-making theory can also be useful when planning interventions. Learning experiences could include observation of existing community

resources and the nurse's role in these services. The value of professional development should be imparted to the practitioner. The growing knowledge base in the fields of gerontology and geriatrics dictates that the practitioner keep pace with research developments. The nurse will need to be prepared in the critiquing of nursing research and the application of pertinent findings to nursing practice.

Implications For Research

Much remains to be learned about the impact of caring for an elderly family member with chronic confusion. This study has shown that the impact on the older wife is generally negative. Further research could be carried out with two objectives, to give greater understanding of the impact on the caregiver, and to use this knowledge to increase the support available.

The viability of the concept of burden in the caregiving situation should be explored. What constitutes successful coping with burden? Is it worth the costs to health? Research is needed to determine when burden becomes overwhelming. What are the costs of carrying this burden, in financial, physical, and emotional terms? At what point are caregivers forced to consider alternative placements for their confused dependent relatives? Insight into the impact of caregiving prompts the question whether the caregiver's resolve to cope with the situation is in the best interests of herself, the dependent relative, or the family. Is there

a process of adjustment to the effects of chronic confusion?
Why do caregivers continue to accept a burdensome situation?

Supportive interventions are needed to alleviate the negative impact on the caregiver. Here, the understanding of the negative effects and the variables that influence the impact will serve as the basis for designing interventions. What are the intervening variables that increase or decrease burden? What do caregivers perceive would be the most helpful interventions to enable them to cope with such negative effects as stress and social isolation?

The utilization of supportive community resources needs to be explored. The caregiver's initial reluctance to accept help raises questions about whether she is making optimal use of services, or needs to take a more active role in seeking assistance. The present status of available resources to help families with confused, dependent members could be reviewed. What are society's obligations to the incapacitated elderly and to their volunteer caregivers? How should society, through utilization of nursing services, redress the burden experienced by caregivers?

These caregivers receive little, if any, recognition of their burden or remuneration for preventing the use of costly hospital resources. It appears that public awareness and concern for families coping with chronic disabilities could be increased, but the significance of chronic care is easily overshadowed by the technological advances found in acute care settings. Attention needs to be directed to the management of problems associated with chronic confusion and

other chronic illnesses, especially incontinence and nocturnal restlessness. The alleviation of burden is crucial to improving the quality of life for these families.

These research questions are only initial attempts to identify the problems with high priority in a relatively new field. As more studies are carried out, other questions and issues will emerge. At some point in the study of burden, guidelines will need to be developed to determine when the caregiver should not continue to try to manage the dependent person at home. Nursing research could then focus on how to help caregivers surrender their burden and adjust to the loss of the chronically confused family member.

Recommendations

The extent of the impact on the caregiver discussed in this study brings forth certain recommendations for the nursing profession. Priority should be given to:

1. Devising and testing supportive interventions aimed at relieving the strain, confinement, and isolation of these caregivers.
2. Finding ways to make present community resources for the families of chronically confused elderly persons acceptable and accessible.
3. Increasing the amount of research focussing on the behavioral problems associated with chronic confusion and their management.
4. Repeating this study with larger, random samples of

elderly caregivers to explore the impact of chronic confusion and the implications for nursing.

REFERENCES

- American Psychological Association. (1983). Publication manual (3rd ed.). Washington, DC: Author.
- Archbold, P.G. (1980). The impact of parent caring on middle-aged offspring. Journal of Gerontological Nursing, 6, 78-85.
- Becker, H.S., Geer, B., Hughes, E.C., & Strauss, A.L. (1961). Boys in white: Student culture in medical school. Chicago: The University of Chicago Press.
- Branch, L.G., & Jette, A.M. (1981). The Framingham disability study: I. Social disability among the aging. American Journal of Public Health, 71, 1202-1210.
- Brody, E.M. (1974). Aging and family personality: A developmental view. Family Process, 13, 23-37.
- Brody, J.A. (1982). An epidemiologist views senile dementia: Facts and fragments. American Journal of Epidemiology, 115, 155-162.
- Brody, S.J., Poulshock, W.S., & Masciocchi, C.F. (1978). The family caring unit: A major consideration in the long-term support system. The Gerontologist, 18, 556-561.
- Burnside, I.M., & Moehrlin, B.A. (1980). Health care of the confused elderly at home. Nursing Clinics of North America, 15, 389-402.
- Commission On Chronic Illness. (1957). Chronic illness in the United States. Vol. IV. Chronic illness in a large city: The Baltimore study. Cambridge MA: Harvard University Press.

- Crossman, L., London, C., & Barry, C. (1981). Older women caring for disabled spouses: A model for supportive services. The Gerontologist, 21, 464-470.
- Davis, A.J. (1978). The phenomenological approach in nursing research. In N.L. Chaska, (Ed.), The nursing profession: Views through the mist (pp. 186-196). New York: McGraw-Hill.
- Eggert, G.M., Granger, C.V., Morris, R., & Pendleton, S.F. (1977). Caring for the patient with long-term disability. Geriatrics, 32, (10), 102-114.
- Fengler, A.P., & Goodrich, N. (1979). Wives of elderly disabled men: The hidden patients. The Gerontologist, 19, 175-183.
- Goldstein, V., Regnery, G., & Wellin, E. (1981). Caretaker role fatigue. Nursing Outlook, 29, 24-30.
- Golodetz, A., Evans, R., Heinritz, G., & Gibson, C.D. (1969). The care of chronic illness: The responsor role. Medical Care, 7, 385-394.
- Giorgi, A. (1975). An application of phenomenological method in psychology. In A. Giorgi, C.T. Fischer, & E.L. Murray (Eds.), Duquesne studies in phenomenological psychology: Vol. II (pp. 82-103). Pittsburgh: Duquesne University Press.
- Hayter, J. (1982). Helping families of patients with Alzheimer's disease. Journal of Gerontological Nursing, 8, 81-86.
- Jette, A.M., & Branch, L.G. (1981). The Framingham disability study: II. Physical disability among the aging. American

- Journal of Public Health, 71, 1211-1215.
- Kapust, L.R. (1982). Living with dementia: The ongoing funeral. Social Work in Health Care, 7(4), 79-91.
- Kay, D.W.K. (1972). Epidemiological aspects of organic brain disease in the aged. In C.M. Gaitz (Ed.), Aging and the brain. The Proceedings of the Fifth Annual Symposium held at the Texas Research Institute of Mental Sciences in Houston, October, 1971 (pp. 15-27). New York: Plenum.
- Klein, R.F., Dean, A., & Bogdonoff, M.D. (1967). The impact of illness upon the spouse. Journal of Chronic Diseases, 20, 241-248.
- Lalonde, M. (1974). A new perspective on the health of Canadians: A working document. Ottawa, Canada: Department of National Health & Welfare.
- Litman, T.J. (1974). The family as a basic unit in health and medical care: A social-behavioral overview. Social Science and Medicine, 8, 495-519.
- Lopata, H.Z. (1973). Widowhood in an American city. Cambridge, MA: Schenkman.
- Mechanic, D. (1979). Future issues in health care: Social policy and the rationing of medical services. New York: MacMillan.
- Morycz, R.K. (1980). An exploration of senile dementia and family burden. Clinical Social Work Journal, 8, 16-27.
- Nissel, M., & Bonnerjea, L. (1982). Family care of the handicapped elderly: Who pays? London: Policy Studies Institute.
- Omery, A. (1983). Phenomenology: A method for nursing

- research. Advances In Nursing Science, 6, 49-63.
- Pringle, D.M. (1982). The psychological well-being of elderly patients and their family caregivers and how both perceive their visiting nurses. In G. Zilm, A. Hilton, & M. Richmond (Eds.), Nursing research: A base for practice. Proceedings of the National Nursing Research Conference (pp. 1-11). Vancouver, B.C.: University of British Columbia.
- Sainsbury, P., & Grad de Alarcon, J. (1970). The effects of community care on the family of the geriatric patient. Journal of Geriatric Psychiatry, 4, 23-41.
- Sanford, J.R.A. (1975). Tolerance of debility in elderly dependants by supporters at home: Its significance for hospital practice. British Medical Journal, 3, 471-473.
- Schwartz, H., & Jacobs, J. (1979). Qualitative sociology: A method to the madness. New York: The Free Press.
- Shanas, E. (1979). The family as a social support system in old age. The Gerontologist, 19, 169-174.
- Smallegan, M. (1981). Decision-making for nursing home admission: A preliminary study. Journal of Gerontological Nursing, 7, 280-285.
- Statistics Canada. (1979). Canada's elderly. One of a series from the 1976 Census of Canada. Canada: Ministry of Supply and Services.
- Strauss, A.L. (1975). Chronic illness and the quality of life. St. Louis: Mosby.
- Wolanin, M.O., & Phillips, L.R.F. (1981). Confusion: Prevention and care. St. Louis: Mosby.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980).

Relatives of the impaired elderly: Correlates of feelings
of burden. The Gerontologist, 20, 649-655.

APPENDIX A
INTRODUCTORY LETTER

Dear Mrs. _____,

My name is Karen Larson and I am a registered nurse doing graduate work at the University of British Columbia in the School of Nursing. I am interested in studying long-term care in the home and the experience of the caregiver.

I have found that there is little information written about the wives who are caregivers to husbands who experience chronic confusion. I think it is important for nurses to learn what it is like to be a caregiving wife in the home on a day-to-day basis. I would be very interested to meet with you and to hear your ideas about how being a caregiver has affected your life.

If you are willing to participate in this study, it would involve meeting with me on two or three occasions for a period ranging from thirty minutes to one hour, between March and May. I will arrange a convenient time and place for our meeting, probably in your home. I will tape record the interview rather than write as we talk. The only people who might listen to the tapes will be myself and my faculty advisors. Upon completion of the study, the tapes will be erased. If a topic comes up that you may not wish to discuss, you would be free to not talk about any such areas. You will be free to withdraw from the study at any time.

I hope you will be able to help me with this study. If you can participate, you can contact me by filling in the

APPENDIX B
CONSENT FORM

I, _____, do hereby consent to participate in the study on the impact of long-term caregiving which is being conducted by Karen Larson, a graduate student in the University of British Columbia School of Nursing.

I understand

1. that participation in the study involves no risks or discomforts
2. that my participation is voluntary and that I may withdraw at any time
3. that any information identifying me as a participant in this study will remain strictly confidential
4. that refusal to participate in the study or withdrawal from the study would in no way interfere in any services I now receive
5. that the interviews will be tape recorded and that only the student and her supervisors will listen to the tapes, and the tapes will be erased at the end of the study.

Client

Date

Nurse

Date

APPENDIX C
SAMPLE QUESTIONS

Sample Questions For Initial Interview

1. What is it like to be a caregiving wife?
2. What aspects of your life have been affected by being a caregiver? e.g. daily routine, rest, hobbies.
3. What kind of help do you receive?
4. What kinds of support do you receive from family, friends, and community services?

Questions For Succeeding Interviews

1. The things you have told me lead me to believe that being a caregiver is stressful. Do you find that being a caregiver is stressful?
2. What are the benefits of having your husband at home? or Why would you rather have your husband at home? What do you enjoy doing with your husband?
3. What behaviours are associated with confusion in your husband? How do you know when he is confused?
4. What kinds of help are available that you are able to afford? Do you know about: paying homemakers for extra services; daycare hospitals; swing beds; special interest groups? Has anyone ever discussed these and other possibilities with you?
5. What are specific methods used to cope with the

following effects? (Choose relevant items)

being shut-in

physical hardship and tiredness

social isolation

incontinence

memory loss

falling

social withdrawal of husband

6. How often does a nurse visit you from Long-Term Care?
or What does the nurse do for you when she/he visits?
7. What do you find has been the most difficult problem to
cope with in caring for your husband at home?
8. What has been the most helpful aid or who has helped you
the most in caring for your husband at home?