

**THE NEEDS OF INFORMAL CAREGIVERS**

**By**

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**A Thesis**

**Submitted to the Faculty of Graduate Studies**

**In Partial Fulfillment of the Requirements**

**for the Degree of**

**MASTER OF EDUCATION**

**Department of Curriculum Mathematics and Natural Sciences**

**University of Manitoba**

**Winnipeg, Manitoba**

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**SUZANNE DICK**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
of Manitoba in partial fulfillment of the requirements of the degree  
of  
MASTER OF EDUCATION**

**Suzanne Dick 1997 (c)**

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## **ABSTRACT**

The purpose of this study was to investigate by means of a semi-structured interview questionnaire, the impact that informal caregiving had on a sample of 20 caregivers during the time of caregiving and bereavement. Needs of the caregiver, areas of support, and community services utilized were also identified. The setting for this research was a rural municipality in Manitoba. It was found that caregivers experience needs and concerns similar to those identified in other research on informal caregiving and bereavement. This study is unusual for its retrospective approach as well as its examination of caregiving as a process that extends its impact on the caregiver after the death of the recipient of care into the bereavement period.



## **ACKNOWLEDGMENTS**

I would like to express my sincere gratitude to Dr. Dexter Harvey, advisor, for his counsel, guidance and continuous encouragement over the course of this work. To the other members on my committee: Dr. Dave Curtis and Dr. Karen Chalmers for their time, and thoughtful advice.

Extended thanks to my husband Kris for his words of encouragement, proof-reading skills and his many many deeds during my M.Ed. program. To our children: Graham, Colin and Rebecca for their patience and understanding.

Special thanks to my parent's Irene and Eugene Blank and my mother-in-law Jean Dick who gave up numerous days to provide child care support.

To the Home Care Coordinator and Resource Coordinator, who work in the municipality where this study took place. Without their input, both knowledge and time, this study would not have been possible.

A special mention to my nursing mentor and friend Claudia Tennant. Her work and dedication in caring for human beings has been a source of inspiration.

## TABLE OF CONTENTS

	Page
ABSTRACT.....	i
ACKNOWLEDGMENTS.....	ii
LIST OF FIGURES.....	vi
LIST OF TABLES.....	vii
LIST OF ABBREVIATIONS.....	viii
Chapter I: INTRODUCTION.....	1
Overview.....	1
Statement of the Problem.....	2
Setting.....	3
Definition of Terms.....	6
Chapter II: REVIEW OF THE LITERATURE.....	9
Introduction.....	9
Caregivers.....	9
Physical Issues During Caregiving.....	12
Emotional Issues During Caregiving.....	13
Social Issues During Caregiving.....	13
Bereavement.....	16
Conclusion.....	19
Chapter III: STUDY DESIGN & METHODOLOGY.....	20
Introduction.....	20
Rationale for the Use of A Retrospective Study.....	21
Sampling Procedure.....	21
Methodology.....	22
Subject Selection.....	23
The Research Instrument.....	24
The Interview.....	25
Potential Problems with this Data Source.....	26

## TABLE OF CONTENTS

iv  
Page

Chapter IV: QUESTIONNAIRE RESULTS.....	29
Introduction.....	29
Caregiver Profile.....	30
Recipient of Care Profile.....	32
General Background Information.....	32
Objective 1: Impact of Caregiving on the Respondents Physical, Emotional & Social Well-being.....	33
Caregiving Period.....	34
Bereavement Period.....	47
Objective 2: Support Network.....	60
Caregiving Period.....	60
Bereavement Period.....	61
Objective 3: Community Resources.....	63
Caregiving Period.....	66
Bereavement Period.....	68
Other Identified Needs or Resources.....	68
Chapter V: DISCUSSION.....	70
Introduction.....	70
Impact Related to Physical Needs.....	70
Impact Related to Emotional Needs.....	72
Impact Related to Social Issues / Needs / Supports .....	73
Community Services.....	74
Impact Related to the Rural Setting.....	75
Impact Related to the Bereavement Period.....	77
Intervention Strategies.....	78
Conclusion.....	82
Chapter VI: CONCLUSION.....	83
REFERENCES.....	87

**TABLE OF CONTENTS****Page****APPENDICES**

<b>Appendix A- Overview of Services Offered in the Provincial Municipality Where Respondents for this Study Lived.....</b>	<b>94</b>
<b>Appendix B- Letter Left With Some Study Participants After The Interview.</b>	<b>96</b>
<b>Appendix C- Study Introductory Letter.....</b>	<b>97</b>
<b>Appendix D- Introductory Letter for Community Informants.....</b>	<b>99</b>
<b>Appendix E- Caregiver Questionnaire.....</b>	<b>100</b>
<b>Appendix F- Consent for Study Participation.....</b>	<b>111</b>
<b>Appendix G- Thank you Note Mailed to Participants After The Interview....</b>	<b>112</b>
<b>Appendix H- Study Results.....</b>	<b>113</b>
<b>Appendix I- Caregiver Assessment Guide.....</b>	<b>191</b>

**LIST OF FIGURES**

	<b>Page</b>
Figure 1: Cumulative Plot of Response Values Related to Impact.....	43

**LIST OF TABLES**

	<b>Page</b>
Table 1: Caregiver Responses To Impact Interview Questions.....	39
Table 2: Numerical Values Used to Determine Physical, Emotional and Social Impact of the Caregiving Event.....	41
Table 3: Relationships Between Level of Impact and Other Variables.....	45
Table 4: Supports and / or Strategies Used When Dealing With the Negative Impact During Bereavement.....	47
Table 5: Other Stressors Experienced During the Caregiving Period.....	49
Table 6: Issues Respondents Were Not Prepared For During the Caregiving Period.....	50
Table 7: Relationship Issues Expressed by the Caregivers During the Caregiving Period.....	53
Table 8: Caring Difficulties as Identified by the Respondents During the Caregiving Period.....	54
Table 9: People / Events Identified Which Decreased the Stress Associated with Caregiving, During the Caregiving Period.....	55
Table 10: Rewarding Experiences Related to Caring as Experienced by the Respondents During the Caregiving Period.....	57
Table 11: Advise Caregivers Would Share With Other Caregivers in a Similar Position As They Were In.....	59
Table 12: Support Caregivers Received During the Caregiving Period.....	60
Table 13: Supports Identified by the Caregivers During the Bereavement Period.....	61
Table 14: Community Service Summary.....	64
Table 15: List of Services Respondents Suggested Could Assist With Caregiving Activities.....	69
Table 16: Summary of Needs That Arising From the Analysis of the Data.....	79

## **LIST OF ABBREVIATIONS**

Col. - Column

D. - Don't

NACA- National Advisory Council on Aging

p.- page

% - percent

Q- Question

vs.- versus

## Chapter I

### INTRODUCTION

#### Overview

All societies, in particular industrial countries, are faced with an ever-increasing elderly population. With fiscal restraints and restructuring of various government departments, particularly health departments, federal and provincial governments in Canada, are looking for more creative and sustainable ways to care for people in general, and the aging population, in particular. Data from Manitoba in 1994, suggest that 25 percent of seniors were hospitalized in any given year, and that 5 percent of seniors who were admitted to hospital accounted for 59 percent of the total hospital days for all persons in a one year period (National Advisory Council on Aging (NACA), 1994, Vignette #29). Further, the well elderly in Manitoba make up about 90 percent of the elderly population (Quality Health for Manitobans, 1992).

There is also agreement in the health care literature that family members will continue to be the primary source of support in long term care given to the frail elderly in the community, dispelling the myth that families abandon the elderly (Abel, 1991; Brody, 1990; Jutras & Renaud, 1987; Lovett, 1989; Orodener, 1991; Stephens & Christianson, 1986). As reported by Abel (1991) in a review of American health care, families deliver 70 to 80 percent of long term care. This figure is comparable to the Canadian figures from 1980, 1981, and 1985 data that family members or friends provide between 75 to 85 percent of the help received by seniors needing care in the community (NACA, 1994, Vignette #11).



### **Statement of the Problem**

The purpose of this descriptive study was to determine the physical, emotional, and social impact caregiving had on the respondents during the time of caregiving and following the death of the recipient of care. Further, the data obtained may provide identification of caregiving needs during this time as well as community services that were perceived as useful. Included in the data analysis will be a comparison with other retrospective and prospective caregiver and bereavement studies in order to determine if there are any similarities or differences in the results.

Citing Hasselkus (1988), Chappell (1995) noted that "...informal caregivers are not particularly task oriented as are many paid caregivers, and herein lies the discrepancy in understanding caregivers' needs" (p.28-29). The decisions that are involved in caregiving are described by Chappell as "...invisible work" (p.29), and are considered far more important for caregivers than particular tasks. Further, Chappell cites Bowers (1987) when she finds that "a task definition of caregiving is inconsistent with the experiential world of caregiving..." (p. 29). Chappell feels that if we are to understand and meet the needs of caregiving, then we must try and understand what the caregiver is experiencing from a perspective other than tasks. This will assist us in determining what the invisible work is. This invisible work might include the types of decision making, or how to maintain the self image, and autonomy of the caregiver.

To ensure that need consists of more than tasks, as suggested by Chappell (1995), this study will describe 'need' as a function of what people believe are their ideas, attitudes and preferences (Abbey-Livingston & Abbey, 1982, p. 4). A 'needs assessment' is the

systematic process in which needs are determined (Edmonton Social Planning Council, 1993).

A unique component of this study is that it was done retrospectively. In most studies of informal caregiving, the caregiver is interviewed only during the actual time of caregiving. One of the major purposes of exploring the impact of the caregiving experience from a holistic point of view, was to offer a more encompassing view of caregiving. Also, typical caregiving studies have dramatized the negative aspects of caregiving to the exclusion of some of the more positive memories and experiences. It was hoped that these memories would be more likely to come out in a retrospective approach.

This research interviews the caregiver after the recipient of care has died. Information was obtained about the caregiving and bereavement period. The data obtained includes issues such as support, relationships, social impact, needs and services accessed, duration of illness, and, finances. Bereavement data involved looking at services, present health and finances.

It is the intent of this study to document informal caregiver responses in order to meet the challenge of improving the quality of the caregiving experience.

### **Setting**

To ensure confidentiality, one of the reassurances given to the respondents was that the municipality would not be described by name, therefore, any documents used to obtain data will omit the name in its references. The setting for this study was a rural one.

When reviewing the literature, there was a lack of consistency as to a definition of “rural.” For the purposes of this study, rural was defined as a geographical area of open country / nonfarm or farm setting containing no more than 2500 persons in any settlement within the greater geographical area. The municipality where the research was conducted met this definition.

The 1986 population of the municipality was 18, 300 (Provincial electoral statistical profile, Manitoba Bureau of Statistics January 1990). The Age distribution of the population was:

Age	0-14	years or 24.9%
	15-24	years or 14.9%
	25-54	years or 44.7%
	55-64	years or 8.0%
	65+	years or 7.4%

(Manitoba Bureau of Statistic January 1990)

As indicated by the population breakdown, those over 55 years represent only 15.4 percent of the total population. The majority of study respondents came from this age group. A complete compilation of services offered in this municipality is provided in Appendix A. Residents from this municipality receive their acute care from a regional hospital or go into a nearby city. This holds true for personal care home services as well. The travel factor varies within the municipal boundaries from as close to the city limits as fifteen minutes to as far from the city as one hour driving time. This obviously affects each family differently, but can have a profound affect in an emergency situation or in circumstances where general travel is required to see a physician or other specialists.

Several interesting issues related to rural areas emerged in the literature. One, previously mentioned, is the disparity regarding definitions of “rural” itself. Another is the importance attached to determining the length of time an individual has lived in the rural area where one is conducting research. It is very difficult to make accurate assumptions about rural versus urban variables if a research subject has lived in an urban area all his or her life, but has then retired to a rural setting (Martin Matthews & Vanden Heuvel, 1986). This factor may explain some of the disparities when comparing various rural and urban studies. When one compares rural vs. urban studies related to variables such as well-being, health (mental and physical), and social support there are generally contradictory results, making it difficult to discern any patterns (Martin Matthews & Vanden Heuvel, 1986; Ortega, Metroka, & Johnson, 1993). For example, Ortega, et al. state that “studies generally find that older persons report higher levels in well-being...[and] rural social support advantage may simply buffer or counter-act the rural disadvantage in physical health status” (p.102). Notwithstanding this possibility, however, in another study quoted by Ortega et al. “there is no support for the proposition that the mental health, health, and social support consequences of aging are different for rural and urban residents” (p. 109). Ortega, et al. conclude that the negative social and psychological consequences often associated with a rural environment have been exaggerated. It is true that rural residents are often under served related to medical and transportation services. Most importantly, these authors caution researchers not to treat all rural communities as though they are similar in nature ( p.114-115).

### **Definition of Terms**

1. Primary informal caregiver- "...the friend or family member who provided the greatest amount of assistance to the elderly\* care recipient in terms of taking care of him or her, attending to his or her affairs, performing chores around the house" (Stephens & Christianson, 1986, p. 13).

2. Caregiving- "...care provided to an elderly\* person who has some degree of physical, mental or emotional impairment that limits his or her independence and necessitates ongoing assistance "(Dwyer & Coward, 1992, p. 10 cited by Horowitz, 1985).

\*elderly is deleted from the above definitions for the purposes of this study.

3. Sandwich generation- phrase which defines a group of individuals who are a group of informal caregivers or "...women in the middle; they have assumed the task of caregiving for seniors while not relinquishing other duties" (McKibbin, 1996, p. 39).

4. Adult- Male or female over the age of 18 years.

5. Support- Assist or help, support is the least explicit about the nature of the assistance given (Webster's Ninth New Collegiate Dictionary, 1983, p. 1186).

6. Social support- "...it has the following components: instrumental assistance, emotional sustenance, affirmation, and companionship (House, 1981, Wortman, 1984, cited in Abel 1991, p. 152).

7. Family social support- "...perceived support from friends, relatives and community resources. Supportive interactions with social networks provided resources families draw upon in meeting the needs of their members" (Fink, 1995, p. 139).

8. Well-being- "elements of well-being other than health, such as happiness, morale, and life satisfaction, or successful task performance" (Antonovsky, 1987, pg. xvii).

9. Need- need is described as a function of what people believe are their ideas, attitudes, and preferences. The reasons 'need' is looked at as a research project is to be able to develop long and short range plans, to help define and solve identified problems, to help decision makers, planners and [researchers] set priorities. A needs assessment will provide the background for accountability (Abbey-Livingston & Abbey, 1982, p.4).

A 'needs assessment' is the systematic process in which needs are determined (Edmonton Social Planning Council, 1993).

Further, "Identification of needs occur because persons become aware that resources are unavailable to meet those needs" (Buehler & Lee, 1992, p. 300).

10. Rural setting- defined as a geographical area of open country / nonfarm or farm setting containing no more than 2500 persons in any settlement within the greater geographical area (Researcher's own definition).

11. Grief- "is a normal, dynamic, unique, multidimensional process characterized by pervasive distress for which relief is sought through coping strategies which enable one to face and construct new realities"(Jacob, 1996, p. 284).

12. Bereavement- " the state of having suffered a loss" (Jacob, 1996, p. 281).

## **Chapter II**

### **REVIEW OF THE LITERATURE**

#### **Introduction**

The literature reviewed for this study focused on the broad issues of caregiving and bereavement with particular emphasis on a description of caregivers and the caregiving process. As well, an examination of the physical, emotional and social dimensions of the caregiving and bereavement process were also examined.

#### **Caregivers**

What is meant by the term care or caregiving? For the purposes of this study care is defined, as “...care provided to [a] ... person who has some degree of physical, mental or emotional impairment that limits his or her independence and necessitates ongoing assistance” (Dwyer & Coward, 1992, p.10 cited by Horowitz, 1985). The term primary informal caregiver is used to denote “...the friend or family member who provided the greatest amount of assistance to the ... care recipient in terms of taking care of him or her, attending to his or her affairs, performing chores around the house” (Stephens & Christianson, 1986, p. 13).

The literature abounds in caregiving studies. Some social factors which have contributed to the growing interest in informal caregivers are:

- a) Progressive aging of the population (Gallagher, 1994; Jutras & Renaud, 1987; Lewis & Meredith, 1988; and Orodnenker, 1991). By the turn of the century in Canada, persons 65 years and older will make up 13 percent of the population,



and by the year 2030, this will rise to more than 20 percent (Jutras & Renaud, 1987, p. 2). The “ ‘old old’ constitute the fastest growing segment of the population” (Abel, 1991, p. 6);

b) Desire for alternatives to institutionalization (Orodenker, 1991);

c) Economic factors. For example, the rise in women’s labour force who traditionally were the main resource of caregivers (Abel, 1991; Gallagher, 1994; Lewis & Meredith, 1988; Orodenker, 1991);

d) Canadian health care reform. In Manitoba “with appropriate community-oriented services and supports they [many Manitobans] are now able to retain their independence and continue to live in their own homes with their families in their own communities” (Quality Health for Manitobans, The Action Plan, 1992, p. 13);

e) New family situations (divorce, single parenthood, blended families); geographic mobility; immigration; increasing tendency of young people aged 18-25 to live with their parents; space limitations within the home; presence of two or three generations of family members as a result of greater longevity; and finally increased pressure on an individual family member as the number of children decrease (Jutras & Renaud, 1987, p. 4).

According to Gallagher (1994), the original literature on caregiving focused on the emotional components of caring, obscuring the practical labour families and members of the community contributed in the caregiving experience. More recent caregiving themes seem to concentrate on the instrumental tasks, shifting the focus from the

emotional to “concrete forms of help and support” (p. 4). However, this shift in focus is not satisfactory as it does not contribute to a holistic view of caregiving. Caring is more than work, it is an ‘experience.’ Pearlin & Zarit (1993) view caregiving as a process “... with its surrounding variables in a state of change” ( p.160). Whether the caregiving experience is viewed as positively or negatively it is not necessarily determined exclusively by the number of tasks.

In order to look at the caregiving experience in its totality, other variables require input. For example, the quality of the relationship between the informal caregiver and the recipient of care both before and during the caregiving experience; the affect of the illness on the personality of the recipient of care; the reason why the person agreed to provide care in the first place; the health (emotional and physical) of the caregiver; the social network, financial responsibilities, and other caregiving and family responsibilities.

One of the most common general observations on the well-being of the caregiver is that “caregiving is stressful” (Stephens & Christianson, 1986). An important assessment of the caregiving experience, in the opinion of the author, is determining how the caregiver perceives their caregiving situation. “The degree of negative stress is not always correlated with the amount of tasks, but upon how the “caregiver perceives their responsibilities” (Abel, 1991, p. 62). Caregiver perceptions of needs vary among those who provide care. Some of the common themes identified in the literature are “health, finances, ethical conflicts, family dynamics, and employment (Melillo & Futrell 1995, p. 40). Abel (1991) feels that current research focuses so much on caregiver stress that a better understanding of the caregiver experience is lost or denied. What becomes

extremely clear with this study and in the review of the literature is that every caregiving experience is unique.

The responsibility for caregiving often falls upon one person (Abel 1991; Dwyer & Coward 1992). Married couples first turn to a spouse for help. In some cases the spouse is also disabled, posing an extreme burden on him or her (Abel, 1991). If this is not possible, care usually falls on a family member, (Stephen & Christianson, 1986), more often a daughter or daughter-in-law (Abel, 1991; Gallagher, 1994; Lewis & Meredith, 1988; Orodener, 1991). According to Stephen & Christianson (1986) “A large proportion of caregivers (almost 40 per cent) were themselves elderly (65 years of age or older)...” (p. 25).

### **Physical Issues During Caregiving**

The health of the caregiver and the physical demands related to the tasks of caring cannot be overlooked. This varies for individuals even with similar disease entities. Overall, Stephens & Christianson (1986) felt that physical strain was most associated with women and live- in caregivers, particularly for those who indicated that their own health was poor.

For the primary informal caregiver, it is not assistance from other siblings or family members that often decreased the negative strain, but the very real feeling that she has “the emotional support of other family members-that they have supportive attitudes and can be depended on at times of need” (Brody, 1990 p. 51).

From the author's experience, government services are limited in their range of physical services provided in the home. When discussing the utilization of formal services with families, some areas need to be explored, including the availability of services, the ability of the family to afford services not offered by the government sector, how the recipient of care or the caregiver views outside help, feelings of control and decision making, volunteer services, and geographical location.

### **Emotional Issues During Caregiving**

Emotional issues cause the most severe strain on caregivers. Doty, cited by Dwyer & Coward (1992) describes three motives for caregiving, which the author of this study strongly feels determines how the caregiving experience is perceived by the caregiver: "love and affection [in the relationship between the caregiver and recipient of care], a desire to reciprocate for past assistance, and a more generalized societal norm of spousal or filial responsibility" (p. 11). In addition, the characteristics of the ill person such as "severe disability, mental problems with disruptive behavioural symptoms and certain personality traits" (Brody, 1990, p. 53), may also contribute to this strain. The cumulation of stressors as identified, is cited as one of the main reasons why decisions are made to terminate care in the community (Orodenker, 1991).

### **Social Issues During Caregiving**

Undoubtedly there is a cultural / social influence on how society looks after its frail, ill and elderly. This is an external pressure, but may influence decisions made within

the informal caregiving situation in a negative or positive way. The nuclear family which predominates in our society has promoted the myth of the structural isolation of the elderly. However, according to Brody, as cited by Dwyer & Coward (1992) “adult child caregivers provide more care and more difficult care to more parents over much longer periods of time than they did in the good old days” (p.8).

In addition to the general social attitudes towards caregiving, gender issues also affect the phenomena. “Most of the individuals who care for family members are women” (Mancini, 1989. p. 246). Caregiving both formally (nurses, social workers), and informally (unpaid), is clearly deemed women’s work in our society. Other societal issues which directly impact on the informal caregiver are:

- 1) governments placing more pressure upon the families to provide informal care in order to reduce health care costs related to long term and chronic illnesses;
- 2) social trends such as increased divorce rates; and
- 3) participation of females in the labour force.

These social changes have largely occurred within the last three decades. As a society, we need to reevaluate the role of women in the informal caregiving role. It would be unrealistic to assume that women, in particular, are able to assume the demands associated with the primary caregiving role within a family structure without experiencing considerable consequences from these responsibilities (Dwyer & Coward, 1992).

Despite the fact that there are more women than men providing caregiver support, the fact remains that men do care give. Many studies report that there are differences in

the way that men provide care compared to women. According to Kaye & Applegate (1990), men want to remain in control of a caregiving situation, and are more reluctant to seek help in order to relieve some of their caregiving tasks.

Caregiving is not without cost in such areas as emotional, financial, employment and time. These costs predominantly affect women caregivers.

Emotional difficulties as described earlier are probably the most costly with respect to long term strain. According to Stephens & Christianson (1986) financial difficulties were minor in relation to emotional strain, however, those who lived with the recipient of care did report more financial concerns.

Financial costs might occur from drugs, ambulance, transport to appointments, special diets, some equipment for example oxygen which is not always covered by government services.

Additional financial costs are related to the caregiver giving up some employment hours or promotions to care for their parents (Abel, 1991). Orodener (1991) reports that females who were employed were more likely to experience less stress in the caregiving role as compared to those not employed. There is conflicting data in the literature as to whether employment creates negative or positive stress on the caregiver.

Time is considered a valuable asset in our society. Caregiving functions whether it is raising children or caring for ill or dependent adult relatives, requires an element of time. Developments in technology have changed the housekeeping duties in relation to time. Women frequently use this additional time to work for pay. Caregiving infringes upon this time. It is also elusive in that, *quality time* may not be readily available. The

caregiver may actually decide to suspend valuable family time, employment time, or social time to provide care to a sick or dying family member.

Another issue related to caregiving is social support. Significant helpers identified by Bass, Bowman and Noelker (1991) during the caregiving period were children and spouse and after the recipient's death were children, spouse and parents. Bass, Bowman and Noelker (1991) and Sankar (1991) demonstrate from their studies that social support during the caregiving period plays a vital role as to how relationships are perceived after the death of the recipient of care. For example, if the caregiver felt positively toward the support, then the relationship likely flourished after the death. However, if social support was expected and did not occur or if the support was perceived as negative then after the death of the individual the relationship was not re-established. Interestingly, Sankar (1991) found that those caregivers in a re-marriage situation were likely to be at most risk for receiving inadequate support, due to possible issues related to loyalty. It is important to recognize that social support is a double edged sword, that carries negative attributes as well as positive ones, depending upon how well the support is perceived by the caregiver.

### **Bereavement**

The phenomenon of bereavement was also explored in the health care literature. As this study took a retrospective look at the caregiving event, the primary caregivers were interviewed after the death of the recipient of care. Thus, each research subject was dealing with bereavement issues. The questions during the bereavement period

focused on the caregiver's well-being during that time and tried to identify areas of need or risk as well.

Bereavement is multifaceted. It can occur as anticipatory grief, which is a collection of losses before the actual biological death has occurred. During the caregiving period, the caregiver and recipient of care reflect on the various adjustments required. For example, the loss and change of traditional roles, re-establishing new roles. For the recipient of care, loss of a future and for the caregiver a future without the person being cared for (Humphrey, 1986). There is also bereavement in the traditional sense, that of grief experienced after the death of an individual. In the present study respondents likely experienced some anticipatory grief, however the study focused on bereavement after the death of the recipient of care. In some situations the caregivers reported that death occurred unexpectedly, in the sense that they were not expecting it at the time it did happen, but it was expected eventually given the recipient of care's illness and poor prognosis.

Sankar (1991) feels that a key life transition, akin to that of marriage, occurs when caregiving and bereavement are linked creating a chronic stress context. Both Bass, Bowman and Noelker (1991), and Sankar (1991) look at the experience of caregiving, the death of the individual cared for, and the caregiver's adjustment to the death as interrelated, not separate phenomena, as being of the same chronic stress context. Thus the social support received by the caregiver during the caregiving period "influenced bereavement adjustment as does bereavement support" (Bass, Bowman and Noelker, 1991, p. 33). This is an important finding in the literature as it provides one way of



predicting the post death adjustment for the caregiver. Further, Bass et al. (1991) indicate that the presence of professional help is seen as very important in decreasing the difficult effects of family bereavement.

Some of the effects associated with grief as described by Lund et al. (1986) are “anger, guilt, shock, confusion denial depression and irritability” (p. 314). Further, Lund et al. feel that elders are at particular risk when a spouse dies, as they are more likely to experience anxiety and social isolation. In their study, they concluded that “there were no significant differences between males and females in the selected social and psychosocial bereavement outcomes”(Lund et al., 1986, p. 318). They also question the notion that bereavement goes through well-defined stages. They purport that these so called stages are difficult to identify and separate, and that certainly bereavement has no time table. In fact, their study concluded that “bereavement is a long-term experience that does not end at two years” (Lund et al., 1986, p. 319).

Pearlin and Zarit (1993) have made a link to unresolved or ignored areas of caregiving issues in the past, which can cause longer recovery time for some caregivers. They define recovery during the bereavement period as a “...diminishment of distress and to such things as the establishment or renewal of social ties, occupational life, and/or interests in organizations and leisure activities” (p. 162).

A caregiver goes through more than ordinary bereavement according to Pearlin & Zarit (1993) “after many years of having caregiving as the central organizing activity of their lives, caregivers may find that the inevitable restructuring of their lives is threatening. Beyond adaption to loss is an extended recovery process that includes a social as well as

psychological reintegration” (p. 167). This observation proved to be particularly relevant to this study.

## **Conclusion**

The above variables are documented in the caregiver literature and have been provided here as a rationale for the preparation of the study questionnaire. Depending upon the orientation of a particular study, confirmation of how caregivers adjust to the pressures of their role varies in specifics, but not in generalities. From the review of the literature, (Orodenker, 1991, citing Giele’s study in 1974) the three most influential factors related to the caregiver’s ability to care and maintain dependent elders were: “(1) the individual’s level of impairment [both caregiver and recipient of care], (2) the presence or absence of a willing and / or capable family, and (3) the ability of the formal system to fulfill unmet needs” (p.10).

In summary, caregiving is a complex and very individualized experience. By its nature it is stressful, and it is of an unpredictable duration, which contributes to a variation in expected outcomes. In addition, the dynamics of the caregiver’s own life situation add another dimension to the process. As Abel, 1991 has noted, communities generally, and the formal service sector in particular, need to determine ways in which it can “organize society to make care for the dependent population more just and humane” (p. 66).

## **Chapter III**

### **STUDY DESIGN & METHODOLOGY**

#### **Introduction**

This is an historical retrospective descriptive study which investigated the impact informal caregiving had on caregivers by analyzing the perceptions, feelings, and incidents experienced during the actual caregiving period and following the death of the recipient of care.

Data were acquired by means of in-depth personal interviews using a structured questionnaire. The interview allowed for both quantitative and qualitative responses, which provided a deeper exploration of key issues that would not have been possible in a phone or mail in survey. The ages of the respondents varied as well as the type of illnesses experienced by the recipient's of care. Although each caregiving situation was unique, each interviewee had been the primary informal caregiver whose recipient of care was now deceased.

The data collected during the caregiving and bereavement time frame were compared with prospective and other retrospective research findings to determine if retrospective results from this research were comparable, in determining caregiver impact / needs. If so, this study may contribute to the goal of greater use of retrospective data when studying caregiver issues. "Greater understanding of caring from the carer's point of view—from inside out -- is crucial if support is to be effective" (Lewis & Meredith, 1988 p.13).

### **Rationale for the Use of a Retrospective Study**

Using a retrospective approach when studying caregiver needs is unusual in the research literature. The author used this approach, as it seemed more appropriate for the community involved in the study for several reasons. First, all the participants would have had at least one month's experience as informal caregivers, and would have experienced the process of caring from the actual care to loss. The participants were unlikely to feel threatened for fear that services might be withheld due to their responses, when describing their experience. Participants would have had the opportunity to reflect and to evaluate their experience in terms of how it has impacted on their lives.

### **Sampling Procedure**

The following criteria were used to select subjects for this study:

1. Adults, who were 18 years of age and older.
2. The respondent or recipient of care would have been residents of the rural municipality studied during the study time frame. The death of the recipient of care will have occurred no less than six months and or no more than 5 years from the interview date.
3. The respondent would have cared for the recipient of care for at least one month outside of an institutional setting, with care occurring in the caregiver's or recipient's of care own residence. This ruled out accidental deaths but was not dependent on the actual location of the recipient's death (for example, hospital, home, or nursing home). The age of the person receiving care will not be a selection criterion.

4. The respondent was an informal caregiver as defined in this study.

### **Methodology**

The following procedure was used to obtain potential study participants. The death registry was obtained for the municipality covering the period from January, 1990 to June, 1995. Names identified from the registry that were known to meet the study criteria were submitted to the government home care coordinator of the municipality. In addition, the home care coordinator and resource coordinator reviewed case files to determine primary caregiver contacts. Those people who were aware of the study, were encouraged to discuss it with whom ever they met in the community in hopes to attract, by word of mouth potential respondents. As well, some respondents who participated in the study were given a letter with the researcher's name and asked if they knew of anyone in the community who met the research criteria, and who might be willing to participate (see Appendix B). Potential participants were asked to initiate a phone call to the researcher. One call was received, but did not meet the criteria. The thirty individuals identified as primary caregivers through home care files, were then sent a letter of introduction about the study, under the signature of the Home Care Coordinator. This letter included an explanation and voluntary nature of the study; reassurance about confidentiality; and the researcher's phone number. The information letter also included a stamped, self-returned envelope, with an accompanying form which was to be filled in and returned to the Home Care Coordinator (see Appendix C). This returned form provided a document on file for the home care agency, giving the researcher permission (or not) to

contact the primary caregiver as a possible study participant. This protocol was agreed upon by the Provincial Regional Director, in order for the researcher to have file access to the relative's name only.

In the event that there were community informants, a letter was prepared to explain to them the study's intent. If further phone contact was refused, no further contact would be made (see Appendix D). This form was never used as there were no participants obtained by community informants. The researcher knew of several people who met the criteria from the community and these individuals were approached informally. One person agreed to participate in the study. Another participant heard of the study and volunteered to participate in the study on her own. As replies were returned to the home care office, the home care coordinator or resource coordinator contacted the researcher, providing her with phone numbers of potential respondents. The researcher then made telephone contact to arrange for an interview at the respondent's convenience. Interviews began in May 1996 and ended in July 1996.

### **Subject Selection**

The participant selection was a non-random, convenience sample. The goal was to obtain a minimum of twenty study participants. All those who responded positively to the letter sent out by the home care coordinator were interviewed. Thirty letters were distributed and eighteen responses were received.

Twenty interviews were conducted, eighteen from home care files and two

volunteer participants known to the researcher from the community.

One respondent was found to have poor short term memory recall. However, upon review of the interview notes, it was found that she was able to answer the questions related to the caregiving period, therefore the interview was retained in the study. Four interviews did not meet the death criterion of five years: two were five and one half years, one was six years and one was seven years. The five year cut off was to exclude recall issues, however, these interviews were included as the researcher was satisfied that there were no recall problems during the interview.

The purpose for the interview taking place at least six months after the death of the recipient of care was to increase the respondent's emotional comfort level in order to discuss caregiving issues. However, one of the interviews was conducted, about three months after the death of the recipient of care. After discussing the situation with the caregiver, the researcher determined that the individual wanted to participate and felt that she was emotionally prepared for the interview process.

### **The Research Instrument**

The research instrument was a semi-structured questionnaire. It contained open and closed questions in order to elicit as much information as possible. The questionnaire was used in the interview as a guide to ensure that all subjects were asked all relevant questions.

The questionnaire (Appendix E) was developed by the researcher. Several questions were derived from similar studies measuring the same phenomena, (Lewis &

Meredith; and Stephens & Christianson, 1986).

During the first two interviews, some revisions were made to the 'Community Services and Resources' section of the questionnaire. One change was to combine the aids and adaptations and hospital equipment into one service category, and the other revision was to delete doctor as a category as all respondents were under the care of a physician. The items were then renumbered. As well, there were some minor word changes to make the questions more easily understood. For example, in Question 50 the word 'help' was changed to 'assistance.' Also, in Question number 25, the "professional help" category was deleted, as it was felt it was redundant since the section under community services covered the formal / professional sector network.

### **The Interview**

At the time of the interview, a signature of consent was obtained from all study participants. This included reinforcement about confidentiality, whether or not a taping of the interview was acceptable, and whether the subjects wanted a summary of the study once it was collected. See Appendix F.

Included on this form was an area to check if they agreed to taping the interview. Thirteen interviews were taped. Nineteen respondents wished to receive a summary of the study when it was completed.

The interviews ranged from 45 minutes to over 3 hours. Some of the respondents had known the researcher from actual home care cases. In these instances the interview was viewed as a time to renew acquaintances. All respondents were interviewed in their



own homes. The author of this study was the only interviewer. The semi-structured nature of the interview, allowed respondents to discuss issues at length. The participants, regardless of whether they knew the researcher or not, often divulged very personal and at times emotional accounts of this period in their lives. Many respondents felt it was a positive catharsis of some unresolved issues, when they were given the opportunity to verbalize the caregiving experience. Further, they too were astonished at how many emotions arose during the interview. This intensity of feelings did not have any bearing on how long ago the recipient of care had died.

All participants recall of the caregiving period was sharp, clear, and spontaneous even if the death occurred four, five and sometimes seven years previous.

After completing the interview, a thank you note was sent out to all the participants within a two-week period. See Appendix G.

### **Potential Problems with this Data Source**

Several potential problems with the data source were identified. Selection bias was possible as the majority of the sample came from home care files, and therefore received some type of home care service ranging from supplies only to staff support. Ideally a sample of caregivers who met the study criteria but who were not known to home care, would have been desirable, but no participants came forward from this group.

The community in which the study was conducted is small, and the researcher was familiar with many of the respondent's home situations which could bias responses and influence the way the interviewer probed for further information. To attempt to control

this possibility, the researcher made a conscious effort to be aware of personal bias. Also, since the community is small, confidentiality might have been an issue. Respondents were reassured that their anonymity would be protected. This was done by not revealing names in the taped interviews, or written thesis, and not publicly recording the name of the municipality where the study took place.

One of the major issues was to assess during the analysis of the data, whether some of the respondents did in fact reinterpret their experience. As well, the possibility of the subjects selective memory must be acknowledged. To balance these concerns, the questionnaire repeated some questions from another angle, and probes during the interview raised other issues that required a spontaneous response. Selective memory or memory loss was not obvious to the researcher during the interviews, except in the one case described earlier.

Due to the small size of the sample, statistical analysis and generalizability of results were not possible. However, it will be possible to compare the results from this study with similar studies to increase the validity of the findings.

The type of illness and age of the recipient of care were not selection criteria, therefore a wide variety of ages and types of illnesses were represented. This had a potential of creating problems with respect to comparisons with caregiving studies, which focus on particular illnesses, or on a particular age group. As acknowledged earlier, much of the literature explores caregiving in the context of the elderly. However, it was the researcher's opinion that the caregiving experience, was characterized by many common experiences, and for this reason, the results of this study can reasonably be

compared to studies that focused only on the elderly.

## **Chapter IV**

### **QUESTIONNAIRE RESULTS**

#### **Introduction**

The caregiver does not operate in a vacuum. He or she has multiple influences upon how and when decisions are made throughout the caregiving and bereavement periods. The respondent's and recipient's of care profiles will be introduced initially, followed by the objectives of the study, as outlined below. Objective 4, comparison of the data will be done throughout the discussion. The complete set of interview responses is contained in Appendix H.

The objectives of this investigation were:

1. To determine the physical, emotional and social impact informal caregiving had on the respondents during the time of caregiving and after the death of the recipient of care;
2. To identify areas of support the caregiver used during caregiving and after the death of the recipient of care;
3. To identify community services used, that were found useful and other services that were identified that would have been useful during the caregiving and bereavement periods, and;
4. To compare this study data with other retrospective and prospective studies to identify similarities and differences in their findings as it relates to caregiver impact/needs as identified in this study.

### **Caregiver Profile**

The caregivers ranged in age from thirty-eight to eighty- three years of age. Ten respondents (50%) were over sixty years of age. Two males and eighteen females were interviewed. The gender imbalance would appear to support the findings in previous studies that the majority of caregivers were female. However, the small sample in this study makes this conclusion tentative.

Thirteen (65%) of the subjects were widowed, four (20%) married and one (5%) were single.

Fourteen respondents (70%) were spouses of the recipient of care (two husbands, twelve wives); five were daughters (25%), one was a daughter-in-law (5%). This supports the finding that “Elderly males are most likely to receive care from their spouses and elderly females rely predominantly on children (usually female)...” (Stephens & Christianson, 1986, p. 25) “Wives report the most stress as caregivers” (Orodenker, 1991, p. 47).

One respondent did not have any children, fourteen of the respondents had at least one child living within a day drive from their residence, (excluding the three respondents who had children living with them). Two respondents had children living further than a one-days drive away from their parents.

Twelve respondents (60%) felt that they were currently financially “managing;” one (5%) felt she was poor; while seven respondents (35%) felt that they were comfortable. Finances were one area which cause caregiver stress. As the financial situation dealt with the present, one cannot assume that this financial condition was the

same during the caregiving period. When the financial situation of seniors was examined across Canada, it was found that between 1980 and 1990 the percentage of unattached senior men [over 65 years] below the poverty line dropped from 53 percent to 26 percent and for unattached senior women, the percentage dropped from 60 percent to 38 percent (National Advisory Council on Aging, 1993, Vignette #4). Although the percentages have dropped in both cases, this represents at least one in four for both males and females. This reinforces the evidence that finances can contribute to caregiver stress for both men and women.

Current employment status of the respondents indicate that thirteen (65 %) of respondents were retired or not employed, four (20%) were employed full time and three (15%) of respondents were employed part time.

Sixteen of the respondents (80%) felt their health at the time of the interview was good or fair for their age. Three respondents (15%) felt their current health was excellent, and one respondent (5%) felt that their health was poor. Correspondingly eight respondents (40%) acknowledged some form of disability while twelve (60%) indicated they had no disability as described in the questionnaire. Since this health question is associated with present health, it does not necessarily provide a link with health and the caregiving activity. Orodener (1991) reported in her study that “Women... who rate their own health as fair or poor average significantly higher stress as a group (690) compared with their healthier counterparts (377)” ( p. 47).

Clearly, most of the respondents felt that they were healthy despite the documentation of some disability in forty percent of the respondents.

### **Recipient of Care Profile**

There were thirteen males and seven females receiving care. Their ages ranged from forty seven years to one hundred and five years. Sixteen (80%) of those receiving care were over the age of sixty-one, and four (20%) were between forty-seven and sixty years of age.

There was a wide range of medical problems. These medical problems were divided into three main categories: chronic illnesses which made up of eight cases (40%); eleven cancer cases (50%) and one case (5%) of AIDS.

### **General Background Information**

The time of death occurred less than one year to over six years prior to the time of the interview. In seventy-five percent of cases, death occurred between three months and four years prior to the date of the interview.

The length of caregiving had a range from less than three months to over four years. Ten (50%) people interviewed cared for their loved one for one year or less, while four people (20%) were within two years, another four people (20%) were within three and four years and the remaining two (10%) cases were over four years. The intensity of the care-giving involvement (hours per week) is a strong predictor of stress, especially in the cases where there are more severely dependent elderly (Orodenker, 1991, p. 116). This was not specified in this study, however, one might presume that intensity of care increased prior to the time of death. Duration may affect caregiving positively or negatively. According to Orodenker (1991) citing Giele's study in 1974, if the following

three factors are in place, duration will have less effect on the ability of the caregiver to adjust to long term care. These factors are: “(1) the individual’s level of impairment, (2) the presence or absence of a willing and /or capable family; and (3) the ability of the formal system to fulfill unmet needs” (p. 10). Since this study sample was heterogenous, these factors varied among each case.

Of the cases interviewed, nine persons (45%) died in the home, like wise nine (45%) died in hospital and two (10%) died in a nursing home. The author did not review a study which discussed the impact place of death might have had upon the caregiver during the bereavement period.

In eight cases (40%), the caregiver had cared for someone in a similar way before. This may be because they had cared for another relative in the past; that they had worked as a formal caregiver in the system as a nurse or home care attendant; or that they had cared for a spouse who had also died. Twelve (60%) respondents identified no experience in caregiving before.

### **Objective 1: Impact of Caregiving on the Respondents Physical, Emotional and Social Wellbeing**

The purpose of this study was to focus on the *impact* caregiving had on the physical, emotional, and social well-being of the caregiver. As stated throughout this thesis, caregiving, and subsequently bereavement, do not occur in isolation. In order to get an appreciation of the caregiving experience, and its ensuing impact on the caregiver, all responses need to be looked at in the context of the total experience. Five specific



interview questions 27, 46, 81, 82, and 83, were directly related to this objective.

Impact is not specifically defined and it obviously means different things to different people. In order to quantify impact, this study has used three categories - low, moderate and high impact. The higher the number value the more difficult or distressing the experience was for the caregiver.

### **Caregiving Period-**

Question 27 in the interview schedule dealt with the respondent's perceived feelings about the caregiving role overall. When answering how it made the respondents feel to be the primary caregiver, their responses were qualitative. To determine a quantitative value to this question, the researcher placed a numerical value on the caregiver's response. These values were given a range from one to five, one being that the caregiving experience was felt to have a low impact to five being a high impact experience. These values were predicted by looking at the similarities in answers between each respondent, and then placing a numerical value beside each response. To validate the researcher's numerical value, the author's academic advisor, independently using a four point scale also placed values on the responses. These values were compared with the researcher's and it was found that the extreme highs and lows used in the four point scale were the same as the investigator's high and low values.

Some examples of responses that were given a value of one or two (low impact):

- “I felt well enough to look after him.”
- “Felt comfortable with the role...”
- “Felt comfortable.”
- “I felt comfortable...”

There were eight respondents who were given a value of one or two.

Some examples of responses that were given a value of three (moderate impact):

- “You just do it, no time to think, jump in...”
- “Initially difficult...wasn’t overwhelming...”
- “I wanted to do it...”

There were four respondents who were given a value of three.

Examples of responses that were given a value of four or five (high impact)”

- “Quite stressful...”
- “Overwhelming at times...”
- “I felt helpless....”

There were eight respondents who were given a value of four or five.

Questions 81, 82, and 83, asked the same question as number 27, but broke some of the caregiving areas down into three sub groups: physical, emotional and social impact of the caregiving experience. The respondents also had specific categories to choose from. Values were placed beside each response. These values were a:

- “Yes” response in the physical, emotional or social area would yield a numerical value of 3.0;
- “No” response in the physical, emotional or social would yield a numerical value of 1.0, and;
- “Don’t know” response, yielded a numerical value of 2.0.

Question 46 also looked at the respondent's response to family and / or personal impact of caregiving. A category was chosen and a number value was assigned to each category. These values were:

- "No" impact response yielded a numerical value of 1.0;
- "Some impact" yielded a numerical value of 2.0;
- "Fair bit of impact" yielded a 3.0 and;
- "Large impact" yields a numerical value of 4.0.

As questions 46 and 83 both looked at the social aspect of caregiving, each respondent's values to these two questions were added together to get a total social impact score.

#### Discussion of Table 1-

Table 1 provides a tabulation of the numerical scores for the five questions discussed earlier. The last column provides the total social impact score, a combination of questions 46 and 83.

In terms of the total impact that caregiving had on their lives eight respondents (40%) perceived their overall caregiving experience as having a low impact on their lives. Although a low impact was obtained, it is important to note that this does not equate with an inconsequential experience. Another four (20%) respondents rated their caregiving experience as having a moderate impact and eight (40%) felt the caregiving period was a high impact experience.

With regard to the physical effects of caregiving, fifteen of the respondents (75%)

felt that there was no impact, four (20%) felt that there was some physical impact and one person (5%) indicated that they didn't know. Physical impact implies some physical illness or injury, for example a back injury which can directly be related to caregiving. From the responses, physical concerns were not a major issue for most caregivers during the caregiving period.

With regard to the emotional effects of caregiving, ten respondents (50%) felt there was an emotional impact associated with caregiving, and ten (50%) felt that there was not. There was no middle of the road response to this question. Stephens & Christianson (1986) reported almost half of their study respondents had more emotional strain due to caregiving than other types of strain. This certainly is confirmed by the data shown in Table 1. In general, in comparing the physical and emotional impact scores, emotional impact scores were more frequent and rated higher. Brody (1990) reported that emotional strain was by far the most generally reported than any other type of stress, causing the greatest negative impact.

With regard to the social effects of caregiving, eleven (55%) felt there was no social impact and nine (45%) indicated that there was some. One might speculate that this result is due to a high degree of social support within the sample. This will be discussed shortly.

Question 46 (column 6), discusses social impact as well, with a specific focus which addressed the caregiver's own family and personal life. There were more specific categories to choose from in this question as compared to question 83. One would expect that similar percentages would be obtained for both questions from the total sample.

Seven (35%) felt that there was no impact as compared to 9 (45%) in question 83. If one added the 'no' and 'some' impact categories, one would get a response of twelve (60%). Five (25%) felt there was a fair bit of impact and three (15%) indicated that the caregiving period affected their family and personal life to a large degree.

The total social impact score is the sum of the responses to questions 46 and 83. Scores ranged from a low of two to a high of seven. The total social impact scores were then classified as : Low (1-3); Moderate (4) and High (5-7). From these scores, eight respondents (40%) were rated as low social impact, five (20%) were rated as moderate social impact and seven (35%) felt that caregiving affected their social life to a large degree, or impact. The two respondents who scored a value of seven, when totalling the two questions (Q46 & 83) also scored high in the total general impact question (Q27) score, as well as in the physical (Q81) and emotional (Q82) areas, indicating that all levels of care physical , emotional and social were deemed difficult for these caregivers. It also validates their responses.

Melillo & Futrell (1995) indicate that caregiving responsibilities interfere with the caregiver's social, emotional and family needs at least some of the time. This was clearly shown from the data obtained in Table 1, columns 4, 5, 6, and 7.

**Table 1: CAREGIVER RESPONSES TO IMPACT INTERVIEW QUESTIONS**

Subject	General Impact	Physical Impact	Emotional Impact	Social Impact	Family/Personal	Total Social Impact
Number	Value (Q=27)	(Q 81)	(Q82)	(Q83)	Impact (Q=46)	(Q=46 &83)
Columns:						
Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7
1	2	1	1	1	2	3
2	5	1	3	3	2	5
3	3	3	3	1	1	2
4	4	3	3	3	4	7
5	3	1	3	1	2	3
6	2	1	1	3	2	5
7	4	1	3	3	1	4
8	1	1	1	1	1	2
9	1	1	1	1	1	2
10	1	1	1	3	1	4
11	5	1	3	1	1	2
12	2	3	3	3	3	6
13	3	1	1	3	3	6
14	5	1	3	1	4	5
15	4	1	1	1	3	4
16	4	2	3	3	2	5
17	3	1	1	1	3	4
18	5	3	3	3	4	7
19	2	1	1	1	1	2
20	2	1	1	1	3	4

**RESULTS:**

Low		No=15	No= 10	No=11	5=Some Impact	8=Low Social Impact
Impact=	8	Yes= 4	Yes=10	Yes=9	5=Fair Bit Impact	5=Moderate Social Impact
Moderate		Don't know=1			3=Large Impact	7=High Social Impact
Impact=	4				7=No Impact	
High						
Impact=	8					

**ABBREVIATIONS:**

Q= Question number

D.=Don't

Col.= Column

**VALUES:**

Low=1-2	No=1	No=1	No=1	No Impact=1	Low=1-2-3
Moderate=4	D. know=2	D. know=2	D.know=2	Some Impact=2	Moderate=4
High=3-4	Yes=3	Yes=3	Yes=3	Fair Bit Impact=3	High=5-6-7
				Large Impact=4	

### Discussion of Table 2-

Table 2 compares the outcome of three main areas.

1. the subjective response to the overall caregiving experience,
2. question 27, the more quantifiable response for questions 81,82, and
3. the combined scores of questions 46 and 83.

Total impact scores are given three times. The second column represents the researcher's rating of the respondent's verbal replies. The third column represents the total numerical values when columns two, three, four and six from Table 1 are added together, for a total impact score. The fourth column in Table 2, includes the outcome values of questions 81,82,83, and 46 (columns 3, 4, and 7 from Table 1) excluding question number 27 (column two, Table 1).

When examining the results of Table 2, one would expect that all three results would mirror each other. The low impact scores were consistent for all questions within a number or two.

The discrepancy is when you compared moderate and high impact scores, especially between the general impact question 27 and the other two results. There is less of a discrepancy between columns 3 and 4.

When given a subjective value to their response, more respondents overall felt that their caregiving experience had a large impact, 8 as compared to 3, when the question was broken down into several areas.

**Table 2: NUMERICAL VALUES USED TO DETERMINE PHYSICAL, EMOTIONAL AND SOCIAL IMPACT OF THE CAREGIVING EVENT:**

Subject Number	Total for General Qualitative Impact (Q=27)	Total Impact All Questions	Total Impact Q=81,82, and (83 & 46 combined)
Columns: Col. 1	Col. 2	Col. 3	Col. 4
1	2	8	5
2	5	14	9
3	3	11	8
4	4	17	13
5	3	10	7
6	2	9	7
7	4	12	8
8	1	5	4
9	1	5	4
10	1	7	6
11	5	11	6
12	2	14	12
13	3	11	8
14	5	14	9
15	4	10	6
16	4	14	10
17	3	10	6
18	5	18	13
19	2	6	4
20	2	8	6

**RESULTS:**

Low Impact=8  
Moderate Impact=4  
High Impact=8

Low Impact=7  
Moderate Impact=11  
High Impact=2

Low Impact=9  
Moderate Impact=8  
High Impact=3

**ABBREVIATIONS:**

Q=Question number  
Col.= Column

**VALUES:**

Low= 1 - 2  
Moderate=3  
High= 4 - 5

Low= 5 - 9  
Moderate= 10 - 14  
High= 15 - 19

Low= 4 - 6  
Moderate= 7 - 10  
High= 11 - 13

**DISCUSSION:**

Total Impact Score, column 2 reflects responses to qualitative question number 27.

Total Impact Score, column 3 reflects a value which includes ALL the impact questions added up together.

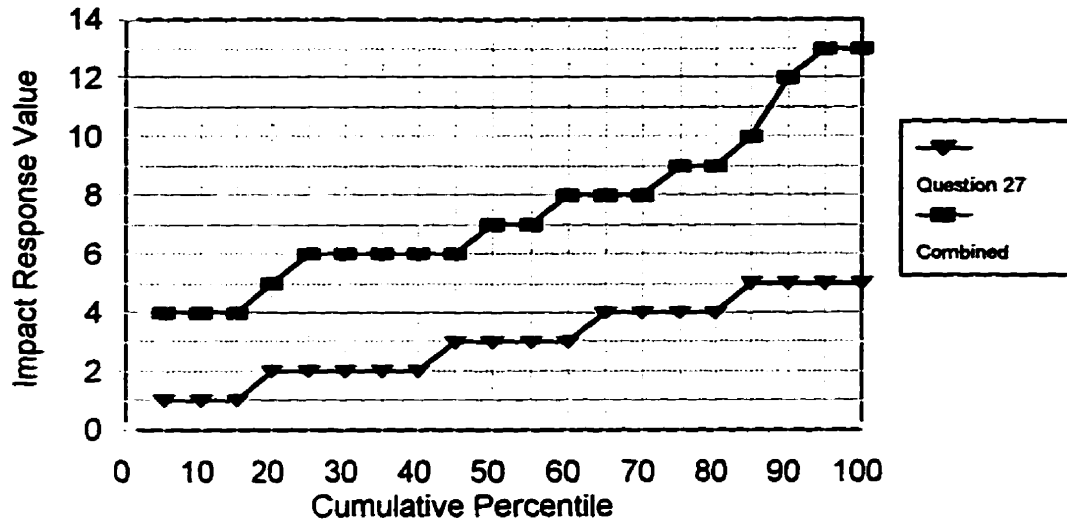
Total Impact Score, column 4 reflects questions: 81, 82, and combined 46 & 83. Question 27 has been deleted.



Figure 1 provides a graphical representation of the responses related to question 27 and combined questions 81, 82, and (83 & 46). These values have been plotted as a cumulative percentage plot. The rationale for including this plot was to reinforce that the perception of impact appears to vary when it relates to the type and number of questions asked. Below the 50th percentile the data trend appears very similar, that is, the shape of the two lines mimic each other. This seems to imply that if the experience was generally considered as low impact the respondent's answers reflected this feeling regardless of whether one or a number of questions were asked. Above the 70th percentile a slight variation occurs. In these cases, where the impact was moderate to high it suggests that asking the same question in a number of ways is important for improved clarity.

A possible explanation for variance would be the numbering system. Some of the respondents numerical values bordered between impact categories. Subject numbers 6, 11, 15 and 17, (Table 2) are examples of this. A variance of one number could place them into a higher or lower category. This does not explain one anomaly, namely subject 12, where the numbers do not borderline between categories. This subject has three distinct impacts: low, moderate and high.

The results of comparing Q-27 with the other four questions reinforces the need for researchers to ask similar questions in different ways in order to validate responses.



*Note:*

1. Question 27
2. Combined value equals summation of values for Questions 81, 82, (83 & 46)

**Fig. 1: Cumulative Plot of Response Values Related to Impact**

#### Discussion of Table 3-

Table 3 presents other factors which affected caregiving. These data were used to determine if there was a relationship between the total impact and four specific variables: age, relationship of the caregiver to the recipient of care, duration of illness, and type of illness. Total impact scores from column four of Table 2 were used. It was felt to be a more detailed response to impact, since it does not include question 27, which asks the same question in a different way. This comparison was done in order to compare these factors to get a better understanding of why impact varied among the respondents as it did.

### High Impact respondents-

When comparing the three high impact subjects with respect to relationship to the recipient of care, two were wives and one a daughter. With respect to age, two were in their 40's, and one over 80 years of age. Both younger women had families to look after, in addition to the recipient of care.

It was not surprising that a caregiving spouse whose husband was diagnosed with AIDS was one of the high impact respondents. "The tragedy of the epidemic is intensified by the young age of the victims, the lack of proven treatment, the cost of treatment, and the prolonged, debilitating, often fatal illnesses that occur...devastating impact for the individual [and family]...age, physical distance from family of origin, social stigma, employment disruption with resulting financial destitution, and potential alienation from significant others" (Tiblier, 1987, p. 257, 259). Although the treatments for AIDS have improved in recent years, the social stigma and alienation felt by the patient and family still remains.

The other two high impact cases were chronic conditions, which often signifies a longer duration of caring, however, both younger caregivers had similar durations, that being over one year. From the author's knowledge of two of these cases, the last six months of life for both recipients of care involved very complex and highly individualized physical care. When the interview with the older respondent was reviewed, the effect of the illness was both mentally and physically challenging. The caregiver indicated that it was not so much the physical demands, but the constant emotional changes which were particularly difficult for her.

**Table 3: RELATIONSHIPS BETWEEN LEVEL OF IMPACT & OTHER VARIABLES:**

Subject Number	Age (Caregiver)	Relationship	Duration	Type of Illness	TOTAL IMPACT Without question 27:
Columns: Col. 1	Col. 2	Col. 3	Col. 4	Col.5	Col. 6
4	40	Wife	1+ years	AIDS	High
12	82	Wife	1+ years	Chronic	High
18	42	Daughter	3+ years	Chronic	High
2	59	Husband	3-6 months	Cancer	Mod
3	73	Wife	>5 years	Chronic	Mod
5	53	Wife	7-11 months	Cancer	Mod
6	58	Wife	3-6 months	Cancer	Mod
7	75	Husband	2+ years	Cancer	Mod
13	59	Wife	1+ years	Cancer	Mod
14	45	Daughter	< 3 months	Cancer	Mod
16	83	Wife	> 5 years	Chronic	Mod
1	76	Wife	3-6 months	Cancer	Low
8	86	Wife	2+ years	Cancer	Low
9	82	Daughter	3+ years	Chronic	Low
10	53	Wife	<3 months	Cancer	Low
11	81	Wife	2+ years	Cancer	Low
15	60	Daughter	2+ years	Chronic	Low
17	73	Daughter in Law	4+ years	Chronic	Low
19	74	Wife	3+ years	Chronic	Low
20	38	Daughter	3-6 months	Cancer	Low

**ABBREVIATIONS:**

Col. = columns

### Moderate Impact Respondents-

There were eight subjects in this range, six cancer and two chronic cases. The age range was from 45 years to 83 years. The relationship to the recipient of care was five wives, two husbands, and one daughter. Jutras & Veilleux (1991) found that age and male spouses were two factors in increasing caregiver burden. These factors were not found to be as significant in this study.

Duration of illness ranged from four cases of less than one year, (all cancer cases), one case over one year, also cancer, one case over two years, cancer, and two cases over five years, both chronic conditions. The duration and the illness resulted in similar findings, otherwise there did not appear to be any other significant relationships detected.

### Low Impact Respondents-

Looking at the nine cases here, the only similarities which could be made is that the chronic cases were consistently of higher caregiving duration, and all the respondents were female. Other than that, due to the variability in responses, there does not appear to be any correlation related to level of impact. The respondents ages varied from 38-86 years. Medical conditions fell into two areas. There were five cases of cancer, and four chronic cases. The duration was similar in that all the cancer patients, except one were under one year, and the chronic illnesses were over two years.

### **Bereavement Period**

Probably the two words that came up the most, related to impact on caregivers after the death of the recipient of care, were feelings of “loneliness” and a “sense of relief.” In the study conducted by Jacob, 1996, “loneliness stood out as the major cause of emotional distress...loneliness was a major complaint of all these widows...”(p. 282). Other responses of note were the need to adjust to change, and the possibility of financial insecurity. As mentioned previously, only one respondent indicated that her financial situation was “poor” at the time of the interview. Certainly, the feelings of possible future financial insecurity were clearly an issue for some of the respondents.

How the respondents dealt with the negative impact of caregiving varied. Some of the supports and/or strategies used are tabulated in Table 4.

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**Table 4: SUPPORTS AND/ OR STRATEGIES USED WHEN DEALING WITH THE NEGATIVE IMPACT DURING BEREAVEMENT**

<u>Supports / Strategies</u>	<u># of Responses</u>	<u>Percentage of Sample (n=20)</u>
-Family and friends helped	6	30
-Went on living the best they could	6	30
-Coping not well	1	5
-Religious faith	1	5
-On my own	1	5
-Extra help costs money,	1	5
-No negative impact	1	5
-Bereavement person or group	3	15

---

Bedell (1979) indicates that "...the normal survivor does not forever disengage himself from his social and physical surroundings"(p. 51). As indicated in Table 4, many of the strategies involved other members of society. As well, according to Bedell knowing that death will occur should cushion the damaging effects after death. In all cases the prognosis was poor, and death was anticipated, however the actual time when the death might occur or how difficult it was, was not always predictable.

Other events which contributed to the total caregiving experience will now be addressed. The following information deals with additional potential stressors.

#### Perceived Caregiver Burden-

This category attempts to identify other factors which might contribute to a feeling of extra pressure or responsibility during the caregiving time.

Eight of the respondents (40%) indicated that they were responsible for the care of other people including: children, four (50%); parents, one (12.5%); and other relatives, two (25%). There was one (12.5%) 'no response.' Orodener (1991) in her study indicated that there was virtually no difference in the mean level of stress when comparing caregiving women who had a spouse and children and the remainder of her sample, which included single parents and women with spouses only (p. 59).

According to eighteen (90%) of the respondents, being male or female had no influence on their decision to be a caregiver. In two instances of a 'somewhat influential' response, both respondents were female. One indicated that it was her own idea, and the

other was a nurse so it was “expected of her” to be the caregiver. Other responses expressed were that it was an assumed obligation, as they were the spouse or it was unavoidable as they lived near by.

There is a reported difference in caregiving perception between men and women (Dwyer & Coward, 1992). “Gender of the caregiver, his or her relationship to the care recipient and his or her living arrangements were all significantly correlated with reported emotional strain”(Stephens & Christianson, 1986, p. 91). Dwyer & Coward generalize that gender plays an important part in caregiving from the point of view that families continue to be the primary source of long term care, women for the most part provide this care and that most people who receive long term care are also women. Sixteen respondents identified other stress experiences during the time of caregiving. Some of those stressors are tabulated in Table 5.

---

**Table 5: OTHER STRESSORS EXPERIENCED DURING THE CAREGIVING PERIOD:**

<u>Stressor / Concern</u>	<u># of Responses</u>	<u>Percentage of Sample (n=20)</u>
-Job related	3	15
-A move away from the family home	2	10
- Family issues for example troubled or dependent children	3	15
-Death of a close spouse or relative	4	20
-Financial	1	5
-Personal illness	2	10
-Family members ill health	1	5

---



These results confirm Pearlman & Zarit (1993) findings that “secondary stressors” are those stressors which do not directly involve caregiver tasks, but affect the caregiver in some way. These include: “...family conflicts, economic hardships, occupational cross-pressures, and the constriction of social and leisure life”( p. 166).

During the interview, caregiving responsibilities that the respondents were not prepared for were discussed. Although seven respondents felt that they were prepared for most everything, the others expressed a variety of concerns, as shown in Table 6.

**Table 6: ISSUES RESPONDENTS WERE NOT PREPARED FOR DURING THE CAREGIVING PERIOD:**

<u>Concern</u>	<u># of Responses</u>	<u>Percentage of Sample (n=13)</u>
-More complex care that a nurse might do, for example, injections, medications, testing for blood sugar	3	22
-The emotional aspects of care	2	16
-How gruesome it was	1	8
-The occurrence of a sudden death	1	8
-Difficulty seeing a wound that wouldn't heal	1	8
-The physical demands	3	22
-The driving, phoning, and responding to emergency situations	1	8
-The unknown factor	1	8

“The well being of the primary caregiver is more likely to be the pivotal variable” [in relation to whether the recipient of care is institutionalized or not] (Orodenker, 1991, p. 11). This is extremely important, in that it is not possible to compare one situation to another by the number of tasks alone. Table 6 describes areas in which the caregiver was not prepared for. Not all the circumstances described were task related. If these caregivers perceived that their situation was untenable, then this subjective measure is an

extremely important indicator as to whether the caregiver would be able to continue providing care.

#### Employment during the time of Caregiving-

During the caregiving period, eleven respondents (55%) were not employed or retired, four respondents (20%) were employed full time. One respondent (5%) was employed part time. Four respondents (20%) indicated that they had to give up employment due to their caregiving activities. This was discussed in Orodnenker's 1991 study when she describes the positive buffering effect multiple roles may have on the caregiving experience, however, "...stress will increase if working women disrupt job routines to accommodate caregiving" (p. 85).

#### Living Arrangements-

Seventy-five percent of the caregivers lived with the recipient of care in the same residence. Fourteen caregivers were spouses of the recipient of care. One was a daughter who lived with her mother. Stephens & Christianson (1986) mention that live in caregivers were more likely to provide financial assistance. This was not identified as a caregiving issue in this study, as only one respondent lived with her mother, the other live ins were spouses, in which sharing of finances is common in this culture. Brody (1990) mentions that every caregiving study she looked at showed that strain is much greater on the caregiver when the recipient of care lives with the caregiver. If family members live nearby the ill relative they are more likely to be designated as the primary caregiver.

Conversely, if family members live further away and are unable to provide daily physical contact, this causes different types of strain and may also contribute to negative stress related to feelings of lack of control related to their family members declining health and the need to make more trips (Brody, 1990).

“Proximity is the single strongest antecedent of the frequency of interaction between parents and their children”(according to Krout and Lee as cited by Coward et al., 1993, p. 221). This frequent interaction by children does not necessarily improve the psychosocial well-being of the parents ( according to Coward et al.’s literature review, 1993, p. 223-224).

Of the five (25%) respondents who lived in separate dwellings, two lived less than a fifteen minute drive away, and three lived within a thirty minute drive from the recipient of care.

#### Quality of the Relationship with the Recipient of Care-

Overall, eighteen (90%) of the respondents felt they had a good or excellent relationship with the recipient of care before and after their illness. Two (10%) felt that they had a satisfactory or fair relationship before the illness. None of the respondents indicated a poor relationship before or after the illness. Some of the relationship issues expressed by the respondents are summarized in Table 7.

To summarize, ten (50%) felt that caregiving had a positive affect on their relationship. Four (20%) felt it affected their relationship negatively and six (30%) felt that caregiving had no effect on their relationship.

**Table 7: RELATIONSHIP ISSUES EXPRESSED BY THE CAREGIVERS DURING THE CAREGIVING PERIOD:**

<u>Relationship Issue</u>	<u># of Responses</u>	<u>Percentage of Sample (n=20)</u>
-The sexual aspect was gone..."	1	5
-Personality changes for the worse related to the disease	4	20
-The recipient of care would hardly ever say that they appreciated the care	2	10
-Dependency issues related to the expectation on the part of the recipient of care that the caregiver could be relied upon	2	10

#### Caregiving Tasks-

Tasks were divided into three time frames, tasks early in the illness trajectory, changing responsibilities as the illness progressed and tasks done at the end of the caregiving period.

Initially, the tasks were often seen as accompanying the ill person to doctor's appointments, making meals, housework, assistance with ambulation, laundry, general household administration, perhaps some assistance with dressing, grocery shopping, medication assistance, companionship, and emotional support. For many of the caregivers, these tasks were done even when the receiver of care was well.

As expected, when the illness progressed the complexity of care changed as well as the demands upon the caregiver. There were more complicated and frequent changes in medication to look after, including injections and oxygen use. Intravenous drugs were used in one case. There were demands related to the increasing physical weakness of the recipients of care such as more falls, personal care related to dressing, feeding, bathing,

incontinence, wound dressing changes and the general emotional issues which escalated as the responsibility increased.

Except for one respondent who did not provide an answer, there were numerous and varied responses to what the caregivers felt was most difficult about caring.

Generally, the perception was that emotional aspects related to caring were identified most strongly as being the most difficult. The physical tasks seemed to be taken in stride by most caregivers as what was expected of them. This concurred with the literature reviewed. Brody (1990) states "mental disabilities--whether functional or organic--are especially stressful and difficult to deal with (p. 44). Some of the responses related to caring difficulties are provided in Table 8.

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**Table 8: CARING DIFFICULTIES AS IDENTIFIED BY THE RESPONDENTS DURING THE CAREGIVING PERIOD:**

<u>Caring Difficulties</u>	<u># of Responses</u>	<u>Percentage of Sample (n=20)</u>
-Seeing someone you cared about progressing toward an eventual terminal end	7	35
-The need for dependency and the psychological issues surrounding being dependent	6	30
-Trying to carry on with normal activities	1	5
- Dealing with past relationship issues	1	5
- Uncooperativeness of the recipient of care	1	5
- Constant demands	1	5

---

Three respondents reported that there was no difficulty in caring.

Only six respondents felt that there were caregiving skills that they could not do at least initially. An example of these skills were: mending or sewing; taking blood tests for

sugar; personal care; lifting; complex medication issues; and tube feeding. One respondent felt that everything involving caregiving skills was new!

During the interview the caregivers were asked to identify circumstances which could potentially have an effect upon relieving some of the identified stressors they described earlier. This will now be discussed.

#### Perceived Burden Relief-

When asked if other life events occurred to decrease the stress in their lives, eleven (55%) stated that there were while nine (45%) indicated no event occurred to decrease their level of stress. Some of these events are identified in Table 9.

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**Table 9: PEOPLE / EVENTS IDENTIFIED WHICH DECREASED THE STRESS ASSOCIATED WITH CAREGIVING, DURING THE CAREGIVING PERIOD:**

<u>Event</u>	<u># of Responses</u>	<u>Percentage of Responses</u>
- Family	6	38
- Friends	1	6
- Home care	3	19
- Life Line	1	6
- Volunteers	1	6
- Senior Resource Centre	1	6
- Going on vacation	2	13
- Work	1	6

---

When the respondents were asked to identify those areas of caregiving which they felt they were prepared for, there were two 'no' responses. A surprising fourteen indicated they were more or less prepared for what happened. Four stated that they were

not prepared for any of the caregiving tasks. Bull, Maruyama & Luo (1995) cite Archbold et al. (1990) that “preparedness for caregiving was associated with less burden”(p. 133).

Of those identified by the respondents who were most helpful about caregiving issues, many respondents answered more than one category. Of the responses, nurses came out on top with eleven (55%) response. Of those who indicated nurses, three also identified doctors, and one identified family as well as their doctor.

Of the 25 percent that answered doctor, they also identified druggist and oxygen supplier as being most helpful regarding caregiving issues.

A family member was identified by two respondents, while two participants stated no one. Of the ‘no one’ response, one stated that she was a nurse, and the other was the same respondent who indicated no family, and no community services (aside from equipment) were accessed.

#### Perceived Level of Satisfaction-

When asked if the caregiver felt that overall the recipient of care appreciated the care they had given an overwhelming one hundred percent said yes. According to Orodener (1991) “The caregiver is likely to feel more stress if other family members are unhappy about her caregiving role, or if other aspects of her life are unfulfilling” (p. 59). In the study conducted by Montgomery & Kamo (1989) they found that a pattern for predicting subjective burden is influenced by the relationship to the caregiver’s health, the level of affection and the level of objective burden. Those caregivers who felt a greater affection to the recipient of care often felt less burdened (p. 218).

The enjoyable or rewarding things about caring were generally stated in terms of what they did or how they felt toward the experience. Some examples are shown in Table 10.

**Table 10: REWARDING EXPERIENCES RELATED TO CARING AS EXPRESSED BY THE RESPONDENTS DURING THE CAREGIVING PERIOD:**

<u>Rewarding Experiences</u>	<u># of Responses</u>	<u>Percentage of Sample (n=20)</u>
- Able to make the receiver of care comfortable	4	20
- Able to have the receiver of care at home	3	15
-That they could do it [care give]	3	15
-They felt good knowing that the recipient of care affirmed positively the care they provided	3	15
- They felt they had done all they could do for the receiver of care	3	15

Two respondents could not find any rewarding or positive experiences about caring. One of the respondents who indicated nothing enjoyable was a wife, while the other was a daughter-in-law. Abel (1991) indicates that “Most women identified at least some gratification from caregiving” ( p.96).

Where there are unresolved or poor earlier relationship issues for example from childhood with respect to a daughter and mother, or daughter in law to mother in law or spouse to spouse, this could have a negative effect on the caregiving experience. This was true in both cases where the respondents did not perceive any rewarding events about caring. Familial relationships (Brody, 1990) can complicate caregiving issues. Obviously poor past relationships between the caregiver and recipient of care result in emotional strain. Abel (1991) further reflects that when “adult children are the caregivers,



...services are rendered within the context of relationships that already are characterized by deep ambivalence” (p. 112). Caring for someone is not always a ‘labour of love.’

When asked to place a value on their level of satisfaction about the care they provided, thirteen (65%) stated “very satisfied” and seven (35%) were “satisfied” with the care they provided. These statements of perceived positive feelings related to the care they provided, and the feelings in turn that the recipient of care did appreciate the care they gave are extremely important according to Bass et al. (1991) with respect to the bereavement adjustment. They further state “Findings show that spouse and adult-child caregivers’ perceptions of support given to their impaired elderly relative before death have a significant impact on their subsequent bereavement adjustment. Moreover, perceptions of their relative’s care are more important for surviving spouses’ and child’s adjustment than support given directly to them during bereavement” (p.38).

Variable responses were given when the respondents were asked about advice they would share with others in a similar situation. Table 11 summarizes these responses. Two respondents did not offer any advice.

When asked if the caregivers would change anything if they could, five indicated that they would. There was one no answer, due to interview error, as the question was not asked.

**Table 11: ADVISE CAREGIVERS WOULD SHARE WITH OTHER CAREGIVERS IN A SIMILAR POSITION AS THEY WERE IN:**

<u>Advise</u>	<u># of Responses</u>	<u>Percentage of Sample (n=20)</u>
-Providing the best care possible, to do it if you can, you would not regret it and give all the help and love you can	9	45
-Accept help	1	5
-Try and get family support	1	5
-Share responsibilities early, as there is a role reversal	1	5
-People would rather be at home	1	5
-Get all the information you can	1	5
-Take one day at a time	1	5
-Take frequent breaks	1	5
-Feel good about yourself	1	5
-You have given the final gift	1	5

A sample of the responses given with respect to ‘changing anything if they could’ are as follows:

- “Yes, one. Time of death was difficult related to choking.”
- “Yes, try and get her into a home sooner--but she wouldn’t agree to this.”
- “Yes, I was forced into a situation ... where I was a nurse [she was not trained as such.]. Its a combination-no place to turn to- home care said no to lots of things...”
- “Yes, I probably could have been more persistent with the doctor. I felt he could have been looked after better, in respect to his cancer in the last three years.”
- “Yes, I would have liked her to stay at home if she could, but circumstances didn’t allow.”

## Objective 2- Support Networks

This area looks at the support network the caregivers used, during the caregiving and bereavement period. It has the potential for being a stress buffer.

### Caregiving Period

Early in the interview, respondents were asked if their children provided them with caregiving support. For those nineteen respondents who indicated that they had children, seventy five percent indicated that they did provide help. Of the four who indicated the children did not, two explanations are possible.

1. there were two respondents who indicated that their children lived further away than a one day drive,
2. six respondents mentioned that they had children living with them. Of these six, some of these children could be dependents and may not have been capable of offering assistance to the respondent.

The respondents were asked if the caregiving responsibilities were shared with anyone else. This question does not address the issue of formal supports. In response to this question, ten (50%) stated yes, while another ten (50%) stated no. Table 12 provides a summary of those people identified as having provided the caregivers with support.

**Table 12: SUPPORT CAREGIVERS RECEIVED DURING THE CAREGIVING PERIOD**

<u>Support</u>	<u># of Responses</u>	<u>Percentage of Sample (n=10)</u>
-Spouse	1	5
-Daughter	5	25
-Daughter in law	1	5
-Friend	1	5
-Sister	2	10

Of those who offered help all were female except for one spouse. The friend's gender was not specified.

Of the ten respondents who stated that they received no help, six indicated in an earlier question that children were a source of support. When reviewing the two questions, the children were more often viewed as providing emotional support, rather than personal care.

Further, eight cases of the 'no' help response did identify later that some sort of community service was accessed. Only one of the total sample indicated they had no social support or community services (other than equipment) support. She stated "I could manage on my own." Her total impact score was valued at eight or Low Impact. This would indicate that she did manage the caregiving experience as she said.

### **Bereavement Period**

Fifty percent of persons identified children as providing the most support during this time. Other supports were also related. Table 13 provides a summary of the supports utilized by the caregivers.

**Table 13: SUPPORTS IDENTIFIED BY THE CAREGIVERS DURING THE BEREAVEMENT PERIOD**

<u>Supports</u>	<u># of Responses</u>	<u>Percentage of Sample (n=20)</u>
-Children	10	50
-Spouse	3	15
-Other family	4	20
-Home care attendants	2	10
-Self	1	5

Jacobs (1996) cites several authors' conclusions in that "Social supports have been documented as having a positive impact on the outcome of bereavement" ( p. 283).

Eighteen (90%) respondents indicated that they were not receiving any professional help. Of the two respondents who were, this came from the Bereavement Support Group, available in the municipality. Of those who were not receiving help, four indicated that they might benefit from some sort of help. Three had a " don't know " response.

Of the nineteen respondents who indicated they had children, fifteen (80%) stated yes the children provided some support and four (20%) indicated no, their children did not provide any support.

Of the four who stated no support from their children, two of their children were dependents. The other two respondents who had children, but didn't receive any assistance from them gave no reason. From the interviews, it is known that one child was a step son and the other respondent did have two children, both living within a days drive from where she lived.

According to the literature, social supports are associated with lower morbidity and enhances ones sense of control (Wallerstein, 1992). Although the myth that the elderly are not abandoned, their social support network does shrink (Gallagher, 1991). According to Abel (1991), "social support does appear to increase well-being, the extent to which it protects individuals against the harmful effects of stress is by no means clear" (p. 149). Social networks in and of themselves can create their own stressors. Social

support can offer “emotional sustenance, affirmation, and companionship” (Abel , 1991, p. 151). Sankar (1991) and Bass, Bowman and Noelker (1991) demonstrate from their studies that social support during the caregiving period plays a vital role as to how relationships are perceived after the death of the recipient of care. For example, if the caregiver felt positively toward the support, then the relationship likely flourished after the death. However, if the social support was expected and did not occur or if the support was perceived as negative then after the death of the receiver of care, the relationship did not likely continue. Interestingly, Sankar (1991) found that those caregivers in a re-marriage situation were likely to be at most risk for receiving inadequate support, due to possible issues related to loyalty. It is important to recognize that social support is a double edge sword and carries with it negative attributes as well as positive ones, depending upon how the support is perceived by the caregiver.

Very important helpers identified by Bass, Bowman and Noelker (1991) during the caregiver period were children and spouse and after the recipients death were children, spouse and parents. This study concurs with this, the respondents identified immediate kin as the most predominant social support, both during and after the caregiving experience.

### **Objective 3: Community Resources**

In this section community resources related to the caregiving and bereavement period are discussed. A summary of community services is provided in Table 14.

Table 14: COMMUNITY SERVICE SUMMARY:

Variable	Type of Service Homemaker	Home Health Aid	Friendly Visitor	Telephone Reassurance	Life Line	Transportation	Mens	Senior Resource
Did you receive this service?								
YES	13	13	0	0	3	3	6	4
NO	7	7	20	20	17	17	14	16
When during the care period?								
BEGINNING	1	1	--	--	0	2	3	2
MIDDLE	4	4	--	--	1	0	1	1
END	8	8	--	--	2	0	2	1
Who Paid?								
GOVERNMENT	13	13	--	--	--	2	--	4
RECIPIENT OF CARE								
					3	--	6	--
Who told you about the service?								
FAMILY	1	2	--	--	--	1	2	1
FRIEND	1	2	--	--	--	--	2	1
PROFESSIONAL	11	9	--	--	2	2	2	2
OTHER					1	--	--	--
Usefulness of the service								
VERY USEFUL	11	12	--	--	2	3	2	2
SOMEWHAT USEFUL	0	1	--	--	0	--	2	1
USEFUL	2				1	--	2	1
NOT USEFUL								
Is the service available?								
YES	20	20	20	0	20	20	20	20
NO				20	0	--	--	--
If not available would it be useful?								
YES				8				
NO				8				
N/A as is available	20	20	20	0	20	20	20	20
No response				4				

**Table 14:** Community Service Summary Continued: 65

Variable	Type of Service										Other:*	
	Adult Day Care	Counselling	Physical Therapy	Home Care Nurse	Respite	Nursing Home	Equipment					
Did you receive this service?												
YES	0	1	2	13	2	3	20					5
NO	20	19	18	7	18	17	0					15
When during the care period?												
BEGINNING	--	--	1	6	2	0	9					2
MIDDLE	--	1	6	2	0	0	7					1
END				4	0	3	4					2
Who Paid?												
GOVERNMENT	--	1	2	13	0	2	19					3
RECIPIENT OF CARE	--	0	0	0	2	2	1					1
NO CHARGE												1
Who told you about the service?												
FAMILY	--	0	0	1	0	0	1					1
FRIEND	--	0	0	1	0	0	0					0
PROFESSIONAL	--	1	2	11	2	3	18					3
OTHER	--	--	--	--	--	--	1					1
Usefulness of the service?												
VERY USEFUL	--	1	1	11	1	3	18					4
SOMEWHAT USEFUL	--	0	1	2	0	0	0					1
USEFUL	--	0	0	0	1	0	1					0
NOT USEFUL	--	0	0	0	0	0	1					0
Is the service available?												
YES	2	20	20	20	20	20	20					--
NO	18	0	0	0	0	0	0					--
If not available would it be useful?												
YES	0											
NO	2											
N/A as is available	18	20	20	20	20	20	20					--
No response												

Other = Minister, Foster Home, Social Assistance, Hairdresser



### **Caregiving Period**

All respondents indicated that they received some type of community service. Two received equipment support only. The most common service used was that of the homemaker, home care attendant and home nursing service of which thirteen respondents (65%) used each of these services.

Of services accessed, except for equipment, meal preparation, use of the Senior Resource Person and transportation, the majority of other services were introduced toward the middle or the end of the caregiving period. When looking at offering services Abel (1991) suggests that they should be "...offered at an earlier stage in the caregiving process"( p. 172). Abel (1991) concluded that despite the availability of government services, family members were not anxious to give up their caregiving responsibilities. Too often caregivers would wait until things got difficult before seeking help, especially outside of the family or peer group for assistance.

In general, of those eighteen respondents who received services (excluding those who accessed equipment only), nine (50%) were very satisfied with the services. One (5.5%) respondent was somewhat satisfied, seven (39%) indicated they were satisfied and one ( 5.5%) stated that she was dissatisfied with the services. This respondent was receiving home care attendant assistance at the time of the interview and expressed to the researcher that her dissatisfaction was with the present services, not those which occurred during the time her husband was alive.

All but two services were available in the municipality where the study was being conducted. The services not offered were adult day care and telephone reassurance. Two

of the recipients of care lived in a city. It also must be noted that there was no nursing home within the municipal boundaries at the time of conducting this research, however access to a nursing home as it would be to a hospital is not any more difficult than other residents of the province, except for the fact that the nursing home chosen would not be near their home or in their own municipality.

Professionals were the predominant means of informing the respondents of services.

The government paid for most of the services accessed except for respite, meals on wheels, Lifeline, nursing home, and some equipment not specified.

Kaye and Applegate (1990) found that feelings of burden increased with outside assistance. This may be attributed to the lack of control the caregivers felt by this assistance. This was an important element of well being associated when males were the primary informal caregiver (p. 143). There is conflicting data as to whether formal services help decrease or increase stress in the caregivers (Orodenker, 1991). This study did not identify any caregiving problems associated with the services used within the home during the caregiving period. One case as stated earlier commented that there wasn't enough service offered for her needs.

**Bereavement Period**

Eighteen respondents (90%) indicated that they were not receiving any professional help. Of the two respondents who were, this came from the Bereavement Support Group, located within the municipality. Of those who were not receiving help four indicated that they might benefit from some sort of help. Three had a “ don’t know ” response.

**Other Identified Needs or Resources**

When the respondents were asked if they had any other comments to make twelve (60%) stated yes. Table 15 provides a list of these remarks. Some respondents provided more than one suggestion.

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**Table 15: LIST OF SERVICES RESPONDENTS SUGGESTED COULD ASSIST WITH CAREGIVING ACTIVITIES**

<u>Service</u>	<u># of Responses</u>	<u>Percentage of Responses</u>
<b>1. General:</b>		
-24 hour support line	3	12
-Transportation in area, more than a car but less than an ambulance	1	4
-Visitor service especially for people who don't have families	1	4
-Personal care home in the municipality	1	4
-Counselling service	2	8
-More senior housing	1	4
<b>2. Workshop Topics:</b>		
-Eating/cooking	1	4
-Drugs use	2	8
-Care of the bed-ridden patient	1	4
-What to expect	1	4
-Transferring/lifting	3	12
-Personal care	3	12
-Identification of what services are available	1	4
<b>3. Support groups for:</b>		
-Widows / Singles club	2	8
-A group beyond bereavement group, not labelled as such	1	4
-Caregiver support group	1	4

## **Chapter V**

### **DISCUSSION**

#### **Introduction**

This study has examined the impact caregiving has had on a sample of primary caregivers during two life transition periods caregiving and bereavement. The following discussion presents an analysis of the main findings of this research. The impact on caregivers was considered from the physical, emotional and social perspective. Implications for social support and community services are also considered.

#### **Impact Related to Physical Needs**

Physical impact on the caregiver, relating to the caregiving experience was not shown to be a problem for most of the respondents in this study.

The use of the formal service sector, primarily home care staff for housekeeping, personal care and registered nurses, seemed to have met the physical needs of the recipients of care. Most of the caregivers interviewed seemed to have managed well in this area. There was only one exception in which it was felt that services were not adequate to meet the caregiver's needs. There was no indication, however, that the recipient of care suffered from this perceived lack of services. This was due to the fact that the caregiver provided the additional needed support, although this clearly was very stressful for her.

Duration of the recipient's of care illness was commonly cited in the literature as one area which impacts upon caregiver's needs. Bass et al (1991) suggest that the

presence of professional support during the caregiving period will decrease bereavement difficulties later. In this study, duration did not appear to have a negative impact on the caregiving experience. This could be a consequence of the study design in that the caregiving experience was over, the caregivers had gone through the complete illness trajectory, therefore duration became a non-issue in their minds at the time of the interview. Duration may have been an issue if the interviews had been conducted at some point during the caregiving experience.

At the end of a life threatening illness, there is an expectation that the recipients of care would require some level of increase in physical care, requiring an increase in services. This was illustrated by the fact that most formal services were accessed during the middle or end stage of the illness trajectory.

In order to provide physical care, caregivers require certain skills and information. Buehler & Lee (1992) citing Mor et al. confirm that a common feature of all cancer patients and their caregivers was a need for more information. This was not supported in this study. Respondents expressed various levels of comfort at providing physical care. When asked if additional information would have been helpful, there were seven workshop suggestions. The workshop topics focused around nursing care for the ill person, discussion on 'what to expect,' cooking classes and identification of services available. KcKibbon (1996) suggests that "Educational and support programs help caregivers to increase their knowledge in areas such as normal aging, skill development, time management and community resources" (p. 39). Some possible reasons why workshops were not perceived as being a high priority might be that in some instances there was a

quick illness trajectory, a lack of time and or energy, there were other family members knowledgeable in this area, or that many of the respondents saw the nurse or doctor as a source of information. Hagen & Gallagher (1996 ) concur that expecting caregiver participation and involvement in support groups or educational sessions may be unrealistic. Alternative ways in which to disseminate information needs to be sought out. Another view with regard to teaching caregiving skills is that it might in the eyes of the formal system, place unrealistic expectations and responsibilities upon the caregivers, when the issue should be owned and resolved by the community, (Wright & Murphy, 1993, p.2).

### **Impact Related to Emotional Needs**

Emotional needs were clearly of paramount concern both during and after the caregiving experience. Buehler and Lee (1992) state that “Particularly anguishing to caregivers was watching the person with cancer experience symptoms and deteriorate” (p. 300). This study found a similar pattern of experience, across several types of illnesses.

The intensity of emotions which surfaced during the interview came as a surprise to the researcher. This was not an isolated event. As described earlier in this thesis, many of the respondents, when describing their caregiving experience, spent considerable time going into very detailed accounts of events. For the most part the respondents felt that this catharsis was positive, and they often reflected that they hadn’t realized how much this life event had impacted on their lives. Jacob (1996) suggests “that reminiscence is a

key factor in the grief experience ...Painful images of the illnesses are difficult to erase” (p. 285). This may provide the reason why all the caregivers could recall so vividly their experience, despite in some cases many years having elapsed.

### **Impact Related to Social Issues/Needs/Supports**

All of the respondents except one, received people support from either the formal or informal sector or both. Primarily in the informal sector it was family who offered this support. This study did not specifically differentiate whether the support was aimed at the receiver of care or the caregiver. Presumably if there was a reciprocal relationship, both would benefit no matter who received the support, if this support was perceived as positive. When reviewing the question asked when discussing support, it was biased toward a response expecting that support to be of benefit. Thus any support received that might have been negative, was not mentioned by the respondents. Sankar (1991) takes the view that support received or not received during the caregiving period is equally important from the point of view that it will affect subsequent relationships after the receiver of care has died. Further, social supports should be aimed at the caregiver as this will “facilitate the care of the dying person” (p. 50).

Respondents indicated that during the caregiving period five were employed, four full time. Of the total sample, twenty percent had actually given up their job due to the responsibilities associated with caregiving. Given the small sample, this appears to be a large proportion of people.

Costs related to providing care did not emerge as an issue with nineteen out of



twenty respondents. All respondents except one indicated that they were managing or were comfortable financially when interviewed. Anecdotally there was an expressed concern about future financial prospects, particularly voiced among those women who lost partners.

### **Community Services**

The decision to use community service is often associated with two attitudes. One attitude is directed toward the acceptability of the service. This implies feelings related to societal expectations. Often families feel more comfortable providing the service, rather than accessing the formal system. The second attitude is related to the perceived quality of the services (Collins et al, 1991).

It is not surprising in this study that all the respondents had accessed community services, as this sample was primarily obtained from home care files. It would be of benefit for a better understanding of the total experience to look at caregivers who provided similar care to their families, but who did not access any formal services. It is not clear from this study if the community services received by the respondents actually mediated some of the caregiver burden. Jutras & Veilleux (1991) cite various studies which describe caregiver burden increasing when they had to deal with professionals from formal service networks. In this study, the interview discussions and the level of satisfaction that those services provided lead one to assume that these services did offer some level of relief for both the caregiver and the recipient of care. Fink (1995) acknowledged in her study that when families have adequate resources, any strain within

the family may not have a negative effect on the well-being of the family, however conversely if there is a high level of family responsibility in the care, this did affect the well-being of the family (p. 144). This example was seen clearly with the one respondent who did receive services, but her level of involvement in the care was also extremely high. Home care services do have a general overall benefit to the recipient of care in that they may halt or even reverse some of the loss of independence (Jutras & Renaud, 1987, p. 19). This factor alone would benefit both the receiver of care and the caregiver during the early illness trajectory.

Twelve (60%) respondents stated that they had no previous experience in caregiving and thirteen (65%) were not prepared for some caregiving problems. One could speculate that information / knowledge would be an important part of the formal services offered to this target group, but as mentioned earlier, this was not an expressed need during the interview by most respondents.

### **Impact Related to the Rural Setting**

It has been suggested in the literature, that the rural environment is more supportive than that of a city (Ortega, et al, 1993). If this is true from a social support perspective then the respondents in this study would be well off. As indicated earlier there are many factors associated with social support and its availability. The individual plays an important part in his or her willingness to access this support. The respondents in this study received the majority of their support from their children, and / or other family members. This support was in the form of physical and emotional support. One would

assume that if the respondents were members of the community for a number of years, they would be more likely to have a better established support system, which might buffer any rural disadvantage with respect to formal resources. This was not found to be the case during the interviews as a result of a lack of formal resources. Families, rather than neighbours or friends, consistently were the main source of support, then came the formal service network.

A few respondents suggested that a 24 hour help line and a transportation service would of been helpful in their situation. Undeniably the more rural one is the less available are the services.

The 24 hour help line was felt to be important so that individuals could easily access advice and perhaps assistance within their community. Those patients in the municipality who were registered with a palliative care program located in a hospital had access to their 24 hour service line. In general, patient's illness trajectory and duration varies tremendously. Some of these informal caregivers were looking after their spouse or family for many years before death. A 24 hour phone line would at the very least provide some sort of comfort in the knowledge that a voice was available for advice. This is particularly important for those families who do not have other supports, for instance, friends or relatives living nearby.

Transportation was the other service which came up during the interviews. An ambulance service is available in the community. As this municipality borders on a city, many of the patient's physicians were located there. When the illness is on a downward slope, it is particularly difficult for families to drive their ill relatives into the city for

appointments. A handivan or stretcher service is not currently available. Often it is women who must try and manage the transfer of men who are often larger than themselves. For those residents who live nearer to the city, this service might be accessed through a city service.

### **Impact Related to the Bereavement Period**

According to the research results, most of the sample were managing the bereavement period reasonably well. This observation may be attributed to the high level of satisfaction all respondents felt about the caregiving they provided. As well all respondents except one, identified at least one person who provided them with some support. This emphasizes the importance the before death situation has on the outcome adjustment during the bereavement period.

During the bereavement period loneliness was a consistent emotion that was expressed. For emotional well-being among the elderly, Wisner and Strain (1986) cite Larson as indicating three important indices: "health, marital status and social interaction" (p. 207). Many respondents in this study have lost their marital status, some for a second time, and some have precarious health or disability needs. The one area which could theoretically ameliorate the loneliness reported by the caregivers is social interaction.

Four respondents did indicate that they might benefit from some type of professional help. When one compares the level of impact experienced during the caregiving time, two of these four respondents rated their caregiving experience as high impact, one was low and one was moderate. It is not surprising that the two high impact

experiences would likely view their situation as being at risk, however, an explanation for the other two respondents wasn't as obvious.

Table 16 provides a compilation of the needs that arose from the analysis of the data provided by the respondents of this study. These needs form part of an intervention strategy discussed in the next section.

### **Intervention Strategies**

It is the belief of this author that a thorough and accurate assessment of the family situation during the hospitalization of the receiver of care could prevent many care problems in the home after discharge, possibly preventing what is known as a revolving-door syndrome, that is, the frequent re-admissions of ill persons. This assessment would determine who would be the primary caregiver and realistically assess their capacity to fulfill this demanding role. Thus the assessment would be focused on the recipient of care's emotional and physical needs as well as that of the primary caregiver.

Appendix I provides an example of an assessment tool used to assess both caregivers and recipients of care developed by Melillo, Futrell, & Esposito (1995). Bull, Maruyama & Luo (1995) concur that "The health of the patient and coping by the caregiver before [hospital] discharge had significant direct links to caregiver response two weeks post discharge" (p. 137). A working team relationship, between the formal and informal sector is often less threatening for the family, and they are more likely to agree to some assistance from the formal network. Smith et al, 1991, p. 20 state that "counsellors...most difficult task was to convince clients to give up some control over

caring for their elder.”

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**Table 16: SUMMARY OF NEEDS ARISING FROM THE ANALYSIS OF THE DATA:**

**PHYSICAL Need for:**

-formal services in a rural area to be accessible and flexible in their ability to respond quickly to crisis emerging from caregiving issues.

-access to some type of formal service for advice and assistance on a 24 hour basis.

-formal services to identify changes in the illness trajectory which will require changes in services needs related to both skills, alternative community services, and personnel input.

-adequate transportation services.

**EMOTIONAL Need for:**

-information related to the illness process and the availability of community services.

-positive caregiver reinforcement for the work that they are doing from both the receiver of care's significant others, as well as community and formal services.

-ongoing assessment by the community and / or formal services of family dynamics in order to identify relationship issues associated with difficult behaviours.

-a non threatening environment from community formal services, support groups, or community volunteers to allow caregivers an outlet to discuss their feelings during and after the caregiving experience.

**SOCIAL Need for:**

-community support groups during the caregiving period.

-community support groups/services to identify and deal with the profound loneliness many caregivers experienced (in particular spouses), after the recipient of care died.

-formal services to recognize that caregivers have a life which extends beyond the caregiving role, and that this life may have additional stressors, or potential stress relievers, which must be identified, when services are implemented.

-a method of identifying those caregivers who have no previous experience related to caregiving, ensuring that they are distinguished as needing more attention related to skills and support.

-the community to identify those caregivers who do not have an extended social network to call upon, both during and after the caregiving experience.

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Providing workshops for caregivers and ensuring that all municipal residents in general are familiar with community services available are practical and feasible projects. The ensuring of the well-being of the caregiver, in particular those widowed, would be more difficult and expensive to assume. Once more, a voluntary service of calling and visiting people would help defer costs. This is already done to some degree by the Senior Resource Person in the municipality. This study reinforces this need, as spousal loss is deemed a major crisis by Vezina et al. (1988) and adjustment is often dependent upon accumulated difficulties after the death.

Support groups were identified as another need by some respondents in this study. It is suggested by Lund et al. (1986) that if support groups are established during bereavement that these groups include both sexes as their study did not find any substantial gender difference in adjustment during this time.

Grandine (1995) has suggested a Family System's Nursing Theory to look at the family unit as its focus of care. This encourages viewing the individual and family simultaneously rather than in the traditional way of looking at the individual within a family context. This could be one method where the primary caregiver would be identified early in the assessment, as suggested earlier.

Numerous studies recommend a combination of services, to reduce the inherent limitations of any community network. Some of these examples fulfil the needs identified within this study, Table 16. (Taken from: Hagen, & Gallagher, 1996, p.28, 31; Jutras & Renaud, 1987, p. 8, 23, 24; McKibbin, 1996, p. 40 and the NACA position on Community Services in Health Care For Seniors, 1990, p. 7,8,12).

**Direct Help Measures-**

- Trained professional support conveniently located in a community
- Day programs
- Respite care
- Transportation services
- Personal support services- Homemaking / meal service, personal care
- Financial aid
- Adaptive devices
- Physical changes in the home
- Remote supervision techniques for example Lifeline

**Complementary measures-**

- Establish information workshops, including information about services available.

Workshops could be held within the place of employment. Consider the formation of a caregiver association.

- Social support services to maintain a sense of connectedness to the community.

For example, friendly visitors, telephone assurance, neighbourhood watch, clubs and groups for support.

- Companies supporting their workers when time off is needed to provide caregiving services. This study and others demonstrate that caregivers, specifically women, have given up jobs and decreased working hours in order to accommodate their role as caregivers.

- Develop a community partnership network.



-Non institutional supported-living residential arrangements, which might involve seniors housing, home sharing.

-Health promotion and prevention. For example self-care or personal health practices, group fitness activities, personal development and health education programs.

-Political action for change in recognizing the plight of the frail and ill in communities and the demand placed upon informal caregivers.

Many of the above services are already available to residents to some degree within the study setting. Some services are located outside of the municipality, but are directed to residents within this area.

## **Conclusion**

Caregiver needs, in this study, were focused on the emotional aspect of seeing someone they cared about, progress to a known terminal end. Other expressed needs were associated with the increasing dependency of the recipient of care, as physical and psychological demands escalated as the illness progressed. Often new skills had to be learned especially during the last few months of illness.

During the bereavement period, emotional needs, primarily related to loneliness again surfaced, with accompanying uncertainties corresponding to the respondent's personal health, financial situation and role adjustments.

## **Chapter VI**

### **CONCLUSION**

Whether one agrees or not with the strategy, governments are looking toward families to assume many care giving responsibilities for ill and frail family members, as one answer to escalating health care costs (Davies, 1995). This study assessed the impact caregiving had on caregivers during the caregiving and bereavement period.

Compared to the majority of research on caregiving, this study is unique in several ways. First, it is a retrospective study, examining the caregiving experience after the receiver of care has died. This research has demonstrated that this is a feasible way in which to collect data. Recall is often suggested as one reason for not collecting retrospective data. Recall was not a problem with this sample. Many of the descriptions provided by the respondents obviously coincide with previous research on this subject, inferring that the sample's reporting is consistent with previously known data. Secondly, the rural environment from which the sample was obtained, is uncommon. Thirdly, the study incorporates two life transitions namely caregiving and bereavement. Finally, the study encompasses an heterogeneous sample, in terms of age, medical conditions, duration, and complexity of care. This hopefully has contributed to an enriching amount and variety of information.

Melillo & Futrell (1995) describe caregivers as the "hidden patients" (p. 43). Certainly professional service providers assessing each family would be well advised to keep this in mind. The needs of caregivers are often overlooked, especially when patient demands are complex and frequently changing. This is true especially for the eventual

caregivers who are not living in the same home at the time of assessment. These members are often overlooked because assessments are done during working hours when many of these caregivers are not in the actual home or hospital when the formal service assessment is done.

The experience of the caregiver during the bereavement period is likely to take on greater implications. Adjustment is more involved during the bereavement period for a caregiver. These individuals have to make decisions during the caregiving period which ultimately impact on the recipient of care. After their death, the caregiver reviews the caregiving period and has to come to terms with what has gone on before. Pearlin and Zarit (1993) summarize this particularly well, "After many years of having caregiving as the central organizing activity of their lives, caregivers, may find that the inevitable restructuring of their lives is threatening. Beyond adaptations to loss is an extended recovery process that includes a social as well as psychological reintegration" (p. 167).

Successful programs offered during the caregiving and bereavement period require flexible and diverse interventions. Promoting healthy strategies during the bereavement period, might well be one cost-effective means to ensure the successful life transition for the caregiver. Jacob (1996) reminds us that older widows in particular "are not assertive in seeking support and their needs often go unnoticed" (p. 285).

The concluding statements offered by this study's respondents indicated a need for some type of social support group in both the caregiving period and for those who are left widowed. The support provided by family during the caregiving period is not sustained during the bereavement time, due to other commitments. This fact holds true for

community services as well. Arnet Connidis & McMullin (1994) clearly emphasize the need for formal services, given the trend toward more at risk groups such as single, divorced and childless individuals and groups. Thus, in a community there is a group of lonely, isolated people, with specialized needs, that are often missed. The tragedy is that often community services are well aware of these people, having placed services in the home during the caregiving period, but due to costs are unable to follow through with health promotion seeking strategies and risk prevention. The key according to Zarit & Pearlin (1993) is to "...find a proper balance of assistance that interfaces in supportive and mutually compatible ways" (p.304).

This study has initiated this link between caregiving and bereavement, demonstrating that recall as a potential barrier to a retrospective caregiving study is not a factor if the respondent is cognitively competent during the interview. Such individuals will and have recalled past events clearly.

Further, this research has found in many instances, similar outcomes when comparing other caregiving and bereavement studies. This suggests that the caregiving impact is similar regardless of whether caregivers are interviewed during or after the event. It is also felt that a longitudinal study with a heterogeneous population of caregivers would be of benefit for the collection of data. Further, formal interventions should not stop after the caregiving period is over. The community as a whole has a responsibility to identify those persons at particular risk.

By not limiting the discussion of caregiving to stress, burden and tasks, it is felt that this broadened scope of exploration of the caregiving experience will allow service

providers an opportunity to examine their programs and discuss a wide range of creative services at the community and formal government levels. Abel (1991) sums it up well “the critical question for evaluators is not whether various programs make caregivers feel better about themselves but whether the programs can improve the quality of caregivers’ lives and minimize the sacrifices caregiving requires” (p. 66).

Caregiving, without doubt, places a heavy responsibility upon the informal caregiver. The overall experience despite its intensity and duration can, however, have long term positive effects. This is especially true with respect to satisfaction experienced when there are flexible formal services available within a community which can be easily accessed to provide a buffer when needs arise.

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**APPENDIX A****Overview of Services Offered In The Provincial Municipality Where Respondents of This Study Lived****Health Services-**

- 24 hour volunteer ambulance service,
- One fee for service physician with specific clinic hours,
- Four seniors housing located in four of the six higher populated settlements,
- One retail pharmacy with specific hours,
- Lifeline,
- Volunteer firefighters,
- Foot care clinics, limited hours, home visits in special circumstances,
- Senior Resource Centre: coordinates congregate meals, bereavement support, volunteer drivers etc.
- Senior Drop In Centres in three of the six denser populated communities,
- Self help groups include: AA groups, Adult Children of Alcoholics, Weight Watchers, LaLeche League, Teens Against Drunk Drivers, Moms and Tots, Youth Groups, TAB, Block Parents, Teenage Parenting Program, Recreation Programs, Private Personal Counselling,
- Government Public health services, no office in the area,
- Government Home care services, no office in area ,
- Child and Family services, including children's foster homes,
- One full time and one part time dentist,
- Lab & Imaging- Blood letting through physician clinic, no x-rays,
- Privately owned physio therapy clinic,
- Equipment loans regionally or in the city,
- Canadian Cancer Society has local volunteers.

Other services:

- RCMP local detachment,
- Taxi in the largest populated community,
- Justice Committee,
- Nite Life: Adult Education Program,
- Private Hearing Testing Service - regional service,
- Psychologist offered through the school division,
- Speech therapy offered through the school division,
- Guidance councillors offered through the school division,
- Agricultural home economist,
- Hearing Conservation & Speech Therapy-regional based,
- Mental health-regional based,
- Emergency social services- regional based,
- Various churches,
- Variety of service clubs.

Note: all regional services have not been listed.

(Summary of Services Available within ....Health Association Boundaries, December, 1994).

**APPENDIX B****Letter Left With Some Study Participants After The Interview**

Dear study participant:

If you should know of others in the community who might be interested in being interviewed, as you have been for this study and meet the criteria as described below, please feel free to give them my name and have them contact me at:

*Suzanne Dick*      *Phone Number:* \_\_\_\_\_

1. Adult over the age of 18 years.
2. Primary informal caregiver. Provided care for at least one month in the recipient of care's home, and was the main caregiver. You could be the recipient of care's spouse, relative, or friend.
3. You or the recipient of care would be a resident of \_\_\_\_\_ Municipality.
4. The recipient of care would have died, not less than 6 months ago, but not more than 5 years ago.

Thank you,

Suzanne Dick

**APPENDIX C**  
**Study Introductory Letter**

Dear \_\_\_\_\_ Date: \_\_\_\_\_

This is to request your participation in a study being conducted in the \_\_\_\_\_ Municipality by one of our Home Care Nurses, Suzanne Dick.

This study is being conducted as a Master's of Education thesis requirement. It has been reviewed and approved by the Research and Ethics Committee of the Faculty of Education, University of Manitoba, and has the support of the Regional Director of Manitoba Health, \_\_\_\_\_ Region.

The purposes of the study are to:

- a) provide a better understanding of caregiver needs within a rural environment, and
- b) enable our community and care agencies to look at how they presently provide support and how to improve their support from ideas and information obtained from your responses.

Suzanne is interested in learning about how caregiving has affected your life. From your experiences, we can learn how community services, such as Home Care, can best assist the caregiver, not only during the time of care but also after the death of the recipient of care. As each caregiving experience is unique, it is important that she talk with as many people as she can, including yourself.

If you agree to be contacted, I will be giving Suzanne only your name. There will be no information given from the home care files. Further, any information you give to her during the interview will not be shared with me or other staff. Each interview is completely confidential, which means your name or the municipality from which the interview has taken place will not appear on any report or publication that may subsequently be written after the interview. As stated earlier, home care staff will not have access to any personal data you provide, but only to information in final reports.

The interview will take about 1 to 1 ½ hours. Your decision to participate is purely voluntary and you may withdraw from the study at any time. As a respondent in the study you are entitled to receive a copy of the study summary, if you wish.

As a study respondent you must have been the main caregiver (the one who spent the most time and had the responsibility for making decisions about care) for your \_\_\_\_\_. You or your \_\_\_\_\_ must have been a resident of \_\_\_\_\_ Municipality.

Please take time to consider participating in this study, as your knowledge about caregiving is very valuable. If you require further information, please do not hesitate to call me, or Suzanne Dick at \_\_\_\_\_). Whatever decision you make, we would appreciate it if you would fill in the attached form and place it in the self-addressed envelope provided.

We look forward to hearing from you. Thank you for your time.

Sincerely,

Name:  
Position: Home Care Coordinator  
Phone number:



**PLEASE FILL IN AND PLACE IN THE SELF ADDRESSED ENVELOPE. THANK YOU FOR YOUR TIME AND ASSISTANCE. THE INFORMATION BELOW PERTAINS TO THE CAREGIVER STUDY DESCRIBED IN THE INTRODUCTORY LETTER ONLY.**

**PLEASE CHECK ONE:**

Yes I would be willing to participate in the caregiver study, as described in the introductory letter I received from \_\_\_\_\_. Please have Suzanne Dick call me to set up an interview time. I understand that any information I give is strictly confidential, and that I may withdraw from the study at any time. My phone number is: \_\_\_\_\_.

I require further information before I can make a decision. Please have Suzanne Dick call me in order that I may obtain more information. My phone number is: \_\_\_\_\_.

No, I do not wish to participate in this study at this time.

I do not meet your definition of a primary caregiver, however \_\_\_\_\_ at this phone number \_\_\_\_\_ better meets your criteria and is willing to be contacted about this study.

Other:

Print Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## APPENDIX D

### Introductory Letter For Community Informants

Date: \_\_\_\_\_

Dear: \_\_\_\_\_

Thank you for speaking with us concerning the study entitled "Needs of Informal Caregivers."

I am interested in learning how caregiving has affected your life, and how community services, such as Home Care, can best assist the caregiver, not only during the time of care but also after the death of the recipient of care.

As each caregiving experience is unique, it is important that I talk with as many people as I can, including yourself. Each interview is completely confidential, which means that your name or the municipality from which the interviews will take place will not appear on any subsequent report or publication.

The interview will take about 1 to 1 1/2 hours. Your decision to participate is purely voluntary, therefore you may withdraw from the study at any time. As a respondent in the study you are entitled to receive a copy of the study summary, if you desire.

The potential benefits of this research will be:

- a) to provide a better understanding of caregiver needs within a rural environment; and
- b) to enable our community and care agencies to look at how they presently provide support and how they might improve their support from ideas and information obtained from your responses.

As a study respondent you must be the main caregiver (the one who spent the most time and had the responsibility for making decisions about care) for your \_\_\_\_\_. You or your \_\_\_\_\_ will have been a resident of \_\_\_\_\_ Municipality.

This study is being conducted as a Master's of Education degree thesis requirement. It has been reviewed and approved by the Research and Ethics Committee of the Faculty of Education, University of Manitoba.

If you are willing to participate, I will be in touch with you within the next few weeks to arrange for an interview time.

In the meantime if you have any questions, please feel free to call me at my home number: \_\_\_\_\_, or my research advisor, Dr. D. Harvey at 1-204-474-9223. Dr. Harvey can also be reached at the Department of Curriculum: Mathematics and Natural Sciences, Faculty of Education, University of Manitoba, R3T 2N2. Thank you.

Sincerely,

Suzanne Dick RN,BN.

**APPENDIX E**  
**Caregiver Questionnaire**

No.

Date:

Time started:

Time completed:

PREAMBLE: [Identify yourself, purpose of the study, reinforce confidentiality, obtain signature of the respondent on consent letter.]

**A. CAREGIVER'S BIOGRAPHY:**

**Caregiver/ Respondent:**

1. Gender:        a. Female        b. Male

2. Age in years: \_\_\_\_\_ years. No answer: \_\_\_\_\_.

3. Marital status        a. Single        b. Married        c. Widowed        d. Divorced

4. a. Number of living children: \_\_\_\_\_ b. No children or no living children

5. Do any of these children live with you now? a. Yes    b. No    c. N/A

6.     If yes: how many: \_\_\_\_\_

7. Did any of your children live with you during the caregiving period?

    a. Yes    b. No    c. Yes, during the last stages of caregiving only    d. N/A

    e. Other:

8. Did your children provide you with caregiving support?        a. Yes    b. No    c. N/A

9. Do any of your children live within a days drive from where you live? a. Yes    b. No

    c. N/A

10.    If yes: How many? a. \_\_\_\_\_. B. N/A

11. What is your relationship to the recipient of care we are discussing today?

    a. Husband    b. Wife    ~~c. Daughter/Son~~    d. Daughter/Son in law

    e. Relative    f. Friend    f. Other:

12. Employment status during caregiving period: a. Not employed    b. Part time

    c. Full time    d. Initially employed, but had to give up employment due to

    caregiver responsibilities    e. Retired    f. Other:

**Recipient of Care:**

13. Age: \_\_\_\_\_.

14. Sex:        a. Female        b. Male

15. What was the medical problem?

16. How long ago did \_\_\_\_\_ die? \_\_\_\_\_ (years).

17. Where did \_\_\_\_\_ die? a. Home        b. Hospital        c. Nursing home        d. Other:

THE CAREGIVING PERIOD:

18. During your caregiving time did you live in the same residence?  
a. Yes b. Separate homes
19. If in separate dwellings: How long did it take you to get to \_\_\_\_\_ residence?  
a. < 15 minutes b. 15 minutes c. 30 minutes d. 45 minutes f. 1-2 hour  
g. 3 hours g. 4 hours h. >4 hours i. Other:
20. What was the length of the caregiving time? (The time you could say you began to actually give care to the time you stopped caregiving? \_\_\_\_\_(years)
21. Were you the primary caregiver for anyone else during the time you were caring for \_\_\_\_\_?  
a. Yes b. No
22. If yes, Who?  
a. Children b. Mother c. Father d. Other
23. Had you ever cared for anyone in a similar way before? a. Yes b. No
24. Were the caregiving responsibilities shared with anyone else? (does not include formal service)  
a. Yes b. No
25. If yes: With whom else: a. Spouse b. Son c. Daughter d. In-laws e. Friend  
f. Neighbour g. Other:
26. If no: Can you explain why/why not?
27. How did it make you feel to be the primary caregiver, e.g. the one who was primarily responsible for the care of \_\_\_\_\_?
28. Did being: female or male have any influence on your decision to be a caregiver?  
a. No influence b. Somewhat influential c. Not much influence  
Explain: [Probe: Society often emphasises caring/ caregiving as a female role.]
29. What were your caregiving responsibilities at the beginning of the caring period?
30. How did these responsibilities change as time went on?  
Probe: describe various turning points in the care

31. At the time when you stopped caregiving for \_\_\_\_\_ what caregiving responsibilities were you doing?
32. What areas of caregiving tasks were particularly difficult?
33. Were there any tasks you felt you were not capable of doing because of a lack of skill, time etc.?
34. What was most difficult about caring?
35. What was most enjoyable/rewarding about caring?
36. During the period of caregiving, did other things happen to add to the stress you were experiencing as a caregiver? [Probe: If yes, how did the respondent cope with the additional stressors as described?] 1=Yes 2=No
37. During the period of caregiving, did other life events occur which decreased the stress in your life? [Probe: details as to what helped relieve the stressors] 1=Yes 2=No
38. What responsibilities of caring did you find you were prepared for?
39. What responsibilities of caring did you find you were not prepared for?
40. Who did you find was most helpful about caregiving issues? For example: diet, feeding, pain management, drugs etc?
- a. Family member      b. Doctor      c. Nurse      d. Friend      e. Other:

41. How would you describe your relationship with \_\_\_ BEFORE she/he got sick?  
 a. Excellent    b. Good    c. Satisfactory    d. Fair    e. Poor
42. How would you describe your relationship with \_\_\_ DURING the time of caregiving?  
 a. Excellent    b. Good    c. Satisfactory    d. Fair    e. Poor
43. Overall, did you feel that caregiving affected your relationship?  
 a. Positively    b. Negatively    c. No effect  
 Please explain:
44. Overall, did you feel that \_\_\_ appreciated the care you gave him/her?  
 a. Yes    b. No
45. Overall, what level of satisfaction did you feel about the level of care you gave \_\_\_?  
 1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_  
 Very satisfied    Satisfied    Somewhat satisfied    not satisfied  
 Explain:
46. What impact did your caregiving role have on other family members/ your personal life?  
 1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_  
 a. No impact    b. Some impact    c. Impacted a fair bit    d. Large impact  
 Explain: [Probe: Time, Financial, Jealousy, Broke the family apart etc.]
47. Looking back, did you feel you were prepared for the caregiving role placed upon you?    a. Yes  
 b. Most of the time    c. Sometimes    d. Never  
 Please explain:
48. What advice would you give someone finding themselves in a similar situation as yours?
49. Would you change anything if you could? 1= Yes 2= No  
 Explain:

COMMUNITY SERVICES & RESOURCES:

50. Did you receive any assistance from a public or private agency to help you in your caregiving task?

- a. Yes                      b. No

51. If yes: What type of services did you access from the community?

If no: Skip to question 69

Probe: For each service mentioned by the respondent determine if:

Code: i) At what point in time during caregiving?

- a. Beginning      b. Middle      c. Toward the end

ii) Who paid?      a. Caregiver      b. Recipient of care      c. Government service  
d. Insurance      e. Other:

iii) How did the respondent find out about the service?

- a. Family      b. Friends      c. Professionals      d. Other:

iv) How useful was the service?

- a. Very useful      b. Somewhat useful      c. Useful      d. Not useful

v) Was this service available:      a. Yes      b. No

vi) If service not available would it have been useful to have: a. Yes                      b. No

Example of services:

52. -Homemaker service/laundry/ meals/ sitter: a. Yes      b. No

i) a. Beginning      b. Middle                      c. Toward the end

ii) a. Caregiver                      b. Recipient of Care      c. Government service  
d. Insurance                      e. Other:

iii) a. Family                      b. Friends                      c. Professionals      d. Other:

iv) a. Very useful      b. Somewhat useful      c. Useful                      d. Not useful

v) Service available:      a. Yes      b. No

vi) Service not available would it be useful to have: a. Yes                      b. No      c. N/A

53. -Home health aides: a. Yes      b. No

i) a. Beginning      b. Middle                      c. Toward the end

ii) a. Caregiver                      b. Recipient of Care      c. Government service  
d. Insurance                      e. Other:

iii) a. Family                      b. Friends                      c. Professionals      d. Other:

iv) a. Very useful      b. Somewhat useful      c. Useful                      d. Not useful

v) Service available:      a. Yes      b. No

vi) Service not available would it be useful to have: a. Yes                      b. No      c. N/A

54. -Friendly visitor: a. Yes      b. No

i) a. Beginning      b. Middle                      c. Toward the end

ii) a. Caregiver                      b. Recipient of Care      c. Government service  
d. Insurance                      e. Other:

iii) a. Family                      b. Friends                      c. Professionals      d. Other:

iv) a. Very useful      b. Somewhat useful      c. Useful                      d. Not useful

v) Service available:      a. Yes      b. No

vi) Service not available would it be useful to have: a. Yes                      b. No      c. N/A

- Code:**
- i) At what point in time during caregiving?
    - a. Beginning    b. Middle    c. Toward the end
  - ii) Who paid?
    - a. Caregiver    b. Recipient of care    c. Government service
    - d. Insurance    e. Other:
  - iii) How did the respondent find out about the service?
    - a. Family    b. Friends    c. Professionals    d. Other:
  - iv) How useful was the service?
    - a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
- 55. -Telephone reassurance:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
- 56. -Lifeline:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
- 57. -Transportation/volunteer service:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
- 58. -Home delivered meals or prepared meals:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A



- Code:**
- i) At what point in time during caregiving?
    - a. Beginning    b. Middle    c. Toward the end
  - ii) Who paid?
    - a. Caregiver    b. Recipient of care    c. Government service
    - d. Insurance    e. Other:
  - iii) How did the respondent find out about the service?
    - a. Family    b. Friends    c. Professionals    d. Other:
  - iv) How useful was the service?
    - a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
59. **-Senior citizen resource person:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
60. **-Adult day-care service:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
61. **-Counselling services:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
62. **-Physical therapy services:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A

- Code:**
- i) At what point in time during caregiving?
    - a. Beginning    b. Middle    c. Toward the end
  - ii) Who paid?
    - a. Caregiver    b. Recipient of care    c. Government service
    - d. Insurance    e. Other:
  - iii) How did the respondent find out about the service?
    - a. Family    b. Friends    c. Professionals    d. Other:
  - iv) How useful was the service?
    - a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
63. **-Home care nurse service:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
64. **-Respite care :** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
65. **-Nursing home:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A
66. **-Aides/Adaptions/Hospital Equipment:** a. Yes    b. No
- i) a. Beginning    b. Middle    c. Toward the end
  - ii) a. Caregiver    b. Recipient of Care    c. Government service
  - d. Insurance    e. Other:
  - iii) a. Family    b. Friends    c. Professionals    d. Other:
  - iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
  - v) Service available:
    - a. Yes    b. No
  - vi) Service not available would it be useful to have:
    - a. Yes    b. No    c. N/A

67. -Other: \_\_\_\_\_

- i) a. Beginning    b. Middle    c. Toward the end
- ii) a. Caregiver    b. Recipient of Care    c. Government service  
     d. Insurance    e. Other:
- iii) a. Family    b. Friends    c. Professionals    d. Other:
- iv) a. Very useful    b. Somewhat useful    c. Useful    d. Not useful
- v) Service available:    a. Yes    b. No
- vi) Service not available would it be useful to have: a. Yes    b. No    c. N/A

68. If you received outside care, how satisfied were you with this service?

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_  
 Very satisfied    Somewhat satisfied    Satisfied    Dissatisfied    Very dissatisfied

Please explain your answer.

[Probe: Did the service you accessed:

- Increase your level of stress?
- Decrease your level of stress?
  - Provided you with some relaxation time?
  - Improve your with your knowledge of caregiving
  - Increase/Decrease your confidence
  - Other:

**CURRENT LIFE:**

I would like to ask you a few questions about your life now.

69. What is your employment status now?

- a. Not employed      b. Part time      c. Full time      d. Retired

70. How would you describe your financial situation?

- |         |          |             |          |
|---------|----------|-------------|----------|
| 1 _____ | 2 _____  | 3 _____     | 4 _____  |
| Poor    | Managing | Comfortable | Well off |

71. What impact did \_\_\_\_\_'s death have on your life?

Probe: routines, work, family, friends, loneliness, feelings re: guilt, relief, loss, etc.

72. How have you managed to deal with the negative impacts?

73. Who would you say provided you with the most support during this time?

- a. Spouse      b. Children      c. Minister/ church representative      d. Other:

74. Had you or are you receiving any professional help (includes support group) in dealing with the loss?

- a. Yes      b. No

75. If yes: who:

76. If no: Do you feel that you would benefit from some help in this matter?

- a. Yes      b. No      c. Don't know      d. N/A      e. Other:

GENERAL HEALTH/ WELL-BEING:

77. Compared to other people your own age, would you say that your general health is:

- a. Excellent    b. Good    c. Fair    d. Poor

78. Because of health or disability, do you have any problem preparing meals, doing housework, laundry, or shopping, walking distances, managing your money, or using the telephone?

- a. Yes, problem with at least one    b. No problem

79. Because of health or disability, do you have any problem

- |                                  |     |    |
|----------------------------------|-----|----|
| - eating/preparing meals,        | Yes | No |
| - getting out of bed or a chair, | Yes | No |
| - dressing,                      | Yes | No |
| - bathing or                     | Yes | No |
| - using the toilet?              | Yes | No |

- a. Yes, at least one    b. No problem

80. Within the last 6 months how often have you visited the doctor?

- a. 0-1    b. Two to four times    c. Five or six times    d. Over 6 times

Do you feel that your caregiving experience has affected your:

81. I) physical health:    a. Yes    b. No    c. Don't know    Explain.

82. II) mental health:    a. Yes    b. No    c. Don't know    Explain

83. III) social wellbeing:    a. Yes    b. No    c. Don't know    Explain.  
(Relating to financial, friends, social activities you enjoyed etc.)

84. Is there anything else you would like to add to our discussion regarding your caregiving experience?    a. Yes    b. No    Probe: Other services for example:

- 24 hour crisis call line
- educational workshops
- support groups etc.

If yes:

**TIME COMPLETED:** \_\_\_\_\_.

**APPENDIX F**  
**Consent For Study Participation**

The purpose of this study is to look at the physical, social and emotional impact caregiving has had on your life. The results of the study will be the basis for a Master of Education degree thesis requirement.

The possible benefits from this research will be:

- a) to provide a better understanding of caregiver needs within a rural environment
- b) to enable our community, friends/relatives and care agencies to look at how they presently provide support and may in fact improve their support from ideas obtained from your responses, and
- c) to determine if a caregiver support group, educational workshops or other programs would be helpful or practical to set up in our municipality.

As a voluntary participant, you will be asked a variety of questions relating to your caregiving experience. If you agree to do so, the interview will be tape-recorded and transcribed later. If you do not agree to taping, your responses will be written down during the interview. You have a right to refuse to answer any questions, or to withdraw from the interview at any time. Once the information has been analysed by the researcher, the tape recordings will be erased. In addition to the researcher's analysis a sample of the notes will be given to two or three other researchers to see if the original interpretations are similar. No names will appear on any of the tapes or transcripts. The final information from all the interviews will be grouped together so that a single interview does not stand out. To further ensure confidentiality your name or the municipality will not appear on any subsequent report or publication. A code number will be used to identify participants.

I, the undersigned, have read the preceding or it has been read to me. I understand its contents, and that any questions that I have pertaining to the research will be answered by Suzanne M. Dick. My permission is freely given.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of Researcher

a) Interview with tape-recording- Yes / No

b) I would like to receive a written summary of the information obtained from the study data:  
Yes / No

If yes, Address: \_\_\_\_\_

\_\_\_\_\_

**APPENDIX G**

**Thank you Note Mailed To Participants After The Interview**

Date:

Dear:

I would like to take this opportunity to thank you for volunteering your time to be interviewed for the study entitled: 'Needs of Informal Caregivers.'

The information that you have provided will have the potential to benefit other individuals and families who are presently experiencing the caregiving role in our community.

Thank you again,

Sincerely,

Suzanne Dick RN, BN

## APPENDIX H

### Study Results

The following provides a summary of how Chapter 4 and this Appendix is laid out. The question and data results follow the sub headings in the chapter, the results form the basis of this Appendix in the following order.

Caregiver Profile- Questions: 1,2,3,4,5,6,9,11,69,70,77,78,79,80 (Includes some questions from 'Current Life' Section of the Questionnaire).

Recipient of Care Profile- Questions: 13,14,15,16

General Background Information- Questions: 17, 20, 23

Objective 1- Impact of Caregiving on the Respondents Physical, Emotional and Social Wellbeing:

Caregiving Period-Questions: 27,46,81,82,83

Bereavement Period-Questions: 71,72

Other potential stressors as identified in the literature-

Perceived Caregiver Burden-Questions: 7,21,22,28,36,39,47

Employment During the Time of Caregiving- Question: 12

Living Arrangements-Question: 18

Quality of the Relationship to the Recipient of Care- Questions: 41,42,43,44

Caregiving Tasks- Questions: 29,30,31,32,33,34

Other potential stress buffers as identified in the literature-

Perceived Burden Relief- Questions: 37,38,40

Perceived Level of Satisfaction- Questions: 4,35,45,48,49

Objective 2- Support Networks:

Caregiving Period- Questions: 8, 24, 25,26

Bereavement Period- Questions: 73,74

Objective 3- Community Resources: Questions 50 to 68 inclusive

Other Resources- Question: 84



**Caregiver Profile: n=20 (unless otherwise stated)**

<b>Characteristic</b>	<b>Number</b>	<b>Percent</b>	<b>Characteristic</b>	<b>Number</b>	<b>Percent</b>
<u>1. Gender:</u>			<u>3. Marital Status (now)</u>		
Female	18	90	Single	1	5
Male	2	10	Married	4	20
			Widowed	15	75
			Divorced	0	
<u>2. Age: (Mean = )</u>			<u>69. Employment: (now)</u>		
18-40	2	10	Not employed	5	25
40-50	2	10	Part time	3	15
51-60	6	30	Full time	4	20
61-70	0	0	Retired	8	40
71-80	5	25			
81-90	5	25			
<u>70. Financial Situation:(now)</u>			<u>11. Relationship to Recipient of Care:</u>		
Poor	1	5	Husband	2	10
Managing	12	60	Wife	12	60
Comfortable	7	35	Daughter/Son	5	25
Well off	0	0	Daughter/Son in law	1	5
			Relative	0	0
			Friend	0	0
<u>4. Number of Living Children:</u>					
-Zero	1	5			
-One	4	20			
-Two	4	20			
-Three	4	20			
-Four	4	20			
-Five and over	3	15			
<u>5. Do any of these [your]children live with you now?</u>					
-Yes			6	30	
-No children living with respondent-			13	65	
-Childless-			1	5	
<u>6. If yes: How many? (n=6)</u>					
-1 child =	2	33.3			
-2 children=	3	50.0			
->3 children=	1	16.7			

**Caregiver Profile Continued;**

<b>Characteristic</b>	<b>Number</b>	<b>Percent</b>	<b>Characteristic</b>	<b>Number</b>	<b>Percent</b>
<u>9. Number of children living within 1 days drive from you:</u>					
Yes (Includes those residing in same residence)				17	85
No				2	10
Childless				1	5

77. Caregiver's health: (now)

-Excellent	3	15
-Good	10	50
-Fair	6	30
-Poor	1	5

78 & 79. Disabilities (now)

Yes	8	40
No	12	60

80. Within the last six months how often have you visited the doctor?

0-1 times	10	50
2-4 times	7	35
5-6 times	1	5
Over 6 times	2	10

**Recipient of Care Profile:**

<b>Characteristic</b>	<b>Number</b>	<b>Percent</b>
<u>13. Age:</u>		
18-40	0	0
41-50	2	10
51-60	2	10
61-70	5	25
71-80	6	30
Over 80	5	25

(20 percent of care recipients under 60 years)

15. Medical Problem:

Chronic illness/s- (Heart/lung/stroke)	8	40
Cancer-	11	55
AIDS-	1	5

See attached for qualitative response to this question.

<b>Characteristic</b>	<b>Number</b>	<b>Percent</b>
<u>14. Gender:</u>		
Female	7	35
Male	13	65

16. How long before interview date did s/he die?

Less than 1 year	1	5
1 years +	7	35
2 years +	2	10
3 years +	3	15
4 years +	2	10
5 years +	3	15
Over 6 years	2	10

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATE ENTRY:****Question # 15. What was the medical problem?****Subject #:**

- #1 -Leukemia
- #2 -Cancer -unspecified
- #3 -Diabetes, Congested Heart Failure
- #4 -AIDS
- #5 -Cancer due to asbestos
- #6 -Cancer: myodysplasia, enlarged spleen emphysema
- #7 -Cancer- unspecified
- #8 -Shingles, cancer-unspecified
- #9 -Chest trouble (lungs), poor hearing
- #10 -Cancer-unspecified
- #11 -Prostate and stomach cancer treated successfully, lung cancer, getting weaker
- #12 -Heart failure
- #13 -Cancer-unspecified

**Subject #:**

**#14 -Breast cancer**

**#15 -Deterioration of Congested heart failure, pneumonia, diabetes,**

**#16 -Diabetes, heart, stroke**

**#17 -Heart problems, general deterioration, pneumonia at time of death**

**#18 -Heart and diabetes, numerous other little things**

**#19 -Stroke, prostate cancer**

**#20 -Cancer-not specified**

**General Background Information:**

<b>Variable</b>	<b>Number</b>	<b>Percent</b>	<b>Variable</b>	<b>Number</b>	<b>Percent</b>
<b>20. <u>Length of caregiving</u></b>			<b>17. <u>Where did death occur-</u></b>		
Time- <3 months	2	10	-Home	9	45
-3-6 months	4	20	-Hospital	9	45
-7-11 months	1	5	-Nursing home	2	10
-1 +years	3	15			
-2 +years	4	20			
-3 +years	3	15			
-4 +years	1	5			
->5 years	2	10			

23. Had you cared for anyone in a similar way before?

Yes	8	40
No	12	60

**OBJECTIVE 1- Impact of Caregiving on the Respondents Physical, Emotional & Social Wellbeing:**

**Caregiving Period-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>27. How did it make you feel to be the primary caregiver, e.g. the one who was primarily responsible for the care of...?</u>		

See attached for the qualitative response to this question.

46. What Impact did caregiving role have on other family members/personal life?

-No impact	7	35
-Some impact	5	25
-Impacted a fair bit	5	25
-Large impact	3	15

Do you feel that your caregiving experience has affected your:

81. Physical Health:

Yes	4	20
No	15	75
Don't know	1	5

82. Mental Health:

-Yes	10	50
-No	10	50
-Don't know	0	0

83. Social Wellbeing:

Yes	9	45
No	11	55
Don't know	0	0

See attached for qualitative response to this question.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:**

**Question #27: How did it make you feel to be the primary caregiver, e.g. the one who was primarily responsible for the care of \_\_\_\_\_?**

To quantify this question the researcher placed a numerical value from 1 to 5 beside each response. These values represent the following: 1-2= Low impact experience

3 = Moderate impact

4-5 = High impact

These values were predicted by looking at the similarities in answers between each respondent.

<u>Subject #:</u> Value		Impact
#1	I felt well enough to look after him.	2
#2	Very much overwhelmed.	5
#3	I wanted to do it, didn't want anyone else to do it.	3
#4	Overwhelming at times, also a good feeling the fact that you are needed.	4
#5	You just do it, no time to think, jump in.	3
#6	Felt comfortable with the role, more I was with him I was doing what I could do for him.	2
#7	Was a responsibility.	4
#8	Felt comfortable.	1
#9	Not really stressful, felt comfortable.	1
#10	I felt comfortable, it was a conscious decision and he wanted to be at home. Daughter also involved in every decision.	1
#11	I felt helpless, hands were tied, couldn't...	5
#12	Took it in stride.	2



<u>Subject #:</u>		<u>Impact Value:</u>
#13	Initially difficult, living in past regarding previous husband's death and knew what was laying ahead. Wasn't overwhelming as had gone before and with support less difficult.	3
#14	Quite stressful, home care looked after, I would go at night, took supper.	5
#15	I didn't mind doing the work, but felt I wasn't getting a lot of thanks from my sister, always heard about good things sister did (from my mother) and not about what I did. And not heard from sister what good I was doing. Heard more negative things (from my mother).	4
#16	Became more difficult as time went on. Didn't realize how a stroke would change personality as it did.	4
#17	I used to worry a lot in case she fell, and when she couldn't answer the phone, alone and wouldn't accept any help for a long time. I would phone a friend as she lived closer.	3
#18	Awful, really big responsibility, really hard.	5
#19	No problem with this, an obligation related to marriage.	2
#20	Easier to care for my mother, you knew there was an end.	2

Total Impact Scores:

1-2= 8

3= 4

4-5= 8

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question: Do you feel that your caregiving experience has affected your:****81. A=physical health 1=yes 2=No 3=Don't know****82. B=mental health 1=yes 2=No 3=Don't know****83. C=social wellbeing 1=yes 2=no 3=Don't know**

This question has a possible explanation attached to it, therefore it falls within some qualitative data. Its purpose is to again determine possible effect of the caregiving experience in general on all three categories.

**Subject #:**

- #1 A=2  
B=2  
C=2: Use to both go out together, now because you don't have a partner you don't go out much.
- #2 A=2  
B=1: Maybe.  
C=1
- #3 A=1: Initially profound fatigue, draining.  
B=1: As above.  
C=2
- #4 A=1: Lifting and carrying pinched nerves--I see chiropractor for back now.  
B=1: Still very draining, rehash, can't come up with any answers.  
C=1: Some social activities have been reestablished in the community.
- #5 A=2  
B=1: To help me grow, learned from it, more prepared for next time a problem occurs. Didn't make me weird. Strengthens you.  
C=2
- #6 A=2  
B=2  
C=1: Getting back involved with \_\_\_\_\_.
- #7 A=2  
B=1: Because its a different world we live in, cope with different things now.  
C=1: To an extent you find you are excluded from couples, not the same. Wife always the centre of everything, I'm not as \_\_\_ and she was --different.

Subject #:

- #8 A=2  
B=2  
C=2: No immediate relatives, home-body, all my friends have died off, friends in the city.
- #9 A=2  
B=2  
C=2
- #10 A=2  
B=2  
C=1: Affected friends, social activities. Had to be careful not to become a home body.
- #11 A=2  
B=1: Many times you are upset, seeing someone so helpless, can't do anything.  
C=2
- #12 A=1: May have for a while tired, temporary. Hip problem, took therapy, may be due to transferring.  
B=1: Temporarily, not permanent, during the time, you worry.  
C=1: Most friends died.
- #13 A=2  
B=2  
C=1: Social activity, not to extent of before last illness.
- #14 A=2  
B=1: In a way, I look after myself.  
C=2: No, because it was so short a time and home care relatively quickly, main concern by herself at night and her sister lives \_\_\_\_, once home care service accessed it helped.
- #15 A=2  
B=2: No permanent. Emotional at the time.  
C=2
- #16 A=3  
B=1: A little bit, depression, might of happened anyway. On medication at night since husband's death. Questionable [whether drug is helping].

Subject #:

#17 A=2  
B=2  
C=2

#18 A=1: **Back injury**  
B=1: **Stress has put me over the edge**  
C=1: **Used to have a big circle of friends, now I would rather stay at home**

#19 A=2  
B=2  
C=2

#20 A=2  
B=2  
C=2

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:**

**Question 46. What impact did your caregiving role have on other family member/ your personal life? 1-No impact 2-Some impact 3-Impacted a fair bit 4-Large impact**

This questions measures a perceived sense of burden, related to social support. An explanation is sought after.

**Subject #:**

- #1 2
- #2 2-Never been a social animal, at home type of person. Because of drugs, transportation, financial burden, extended family stopped coming.
- #3 1
- #4 2-Financial major strain. His family, not included by his choice. Totally absorbed my life for about 6 months, there was no opportunity to get away from it.
- #5 2-Financial impact (had to give up employment). Any doubts in family (his) about my relationship, dispelled these doubts. Respite days/evenings, dad died and couldn't help mom, sister had to do it all, supportive.
- #6 2-Family understood the need to spend time with husband.
- #7 1
- #8 1
- #9 1
- #10 1
- #11 1
- #12 3-Stopped playing bridge, didn't have the energy, not with friends [didn't go out with her friends] as he would feel it.
- #13 3-Son spent time, daughter spent time, sister, family all conscious...
- #14 4-Hard on them [own immediate family], away and under stress.

**Subject #:**

- #15 3-Stress of caregiving, sometimes I would leave mom and be down[emotionally] on way home and couldn't respond the way I should, answer questions abruptly, stress...
- #16 2-Family away anyway, less time for friends, many friends would come and see us. Didn't go out much.
- #17 3- Time, mostly on my time.
- #18 4-At first I thought there was no impact and let me do things, but now when mom is dead they have taken on more things--when Mom passed away, my family now helps to take care of my dad as I can't.
- #19 1-I still managed to do what I needed to do, I was a 'social life person', I had horses, hens, dogs, cats.
- #20 3- Time, financial related to work, because of distance daughter left our house {went to look after mom at her house}.

**Bereavement Period-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>71. What impact did ___'s death have on your life?</u> See attached for qualitative response to this question.		
<u>72. How have you managed to deal with the negative impacts?</u> See attached for qualitative response to this question.		

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question 71. What impact did ....'s death have on your life?**

Purpose of this question was to look at the physical and emotional impact death had on the caregivers.

**Subject #:**

- #1 Lonesome life, family helped with outside work, take care of home.
- #2 Big loss, it's upset my life to no end, still has a bearing on my life, I still haven't remarried...definitely remarry .
- #3 Devastating at first. Learning, trying to adjust--mostly missing 'him'. Did every thing together so decrease in going out and decrease socializing...
- #4 Tougher existence, do the job of two people, financially as 2 income family, [now one] emotionally stand alone, 60 or 70 less people I have to deal with [related to husbands relatives].
- #5 Personal loss, felt gipped, only 10 years...that was the impact, had been on own before so used to that, 10 years married. Terrific loss, was my whole life never stopped loving or missing him, financial uncertainty, he was a wonderful manager, could fix anything, must pay for all maintenance.
- #6 A lot of changes, you have no one to talk to, support you used to have , anything that broke down he fixed, problems we could talk, kids help, not like having him.
- #7 Part of life taken away, about all you can say, his person dies, bills stay the same, financial difference (less).
- #8 Nothing to live for.
- #9 No real effect, upset to certain extent, to see her like that a relief in a way.
- #10 Biggest thing was support [emotional] for children, \_\_\_ got married year later, big yard--no idea what husband did--yard and vehicle, biggest impact, changed my social life people stopped phoning you.



**Subject #:**

- #11 I feel lonesome and afraid. Had moved to different home from country to \_\_\_\_, afraid to sleep at night, hear lots of noises, after he left, every thing was placed on my back-moving . Never told children "I was not happy." A lot of things to get adjusted.
- #12 Mentally and physically tired, lonesome, children nearby helped, friends.
- #13 Whole life turns around, will not take the risk again, making that commitment again, 4 years ago since he died, not happy with being single, I don't see myself ready to do that again.
- #14 Fairly hard to deal with, seeing what she had gone through, grieving and missing her, relief, anger as felt she could have seen about cancer earlier.
- #15 Relief, I miss her, I haven't settled to the fact she isn't there, a big relief knowing I don't have to go now, not saying it like I don't care, with love of family you can get through anything.
- #16 Not glad that he is gone, things that you thought were important before, is not so important for example worldly things, not as much company as before, family is good to you. I miss the car.
- #17 Relieved, she wanted to die. Nursing home made a difference, if anything happened they would look after her.
- #18 I miss her terrible, only positive, the feeling of relief I didn't have to do it [care]like stone being lifted.
- #19 Feeling of relief. More sleep, didn't sleep well even when he was at home, he would always call in the night, only with one ear, anxious for possible phone call, I was upset for awhile and felt he could have done more...
- #20 I lost work during process, some relief due to signs of symptoms of illness, brought family together, wrote all her friends letters, feelings of loneliness.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question 72. How have you managed to deal with the negative impact?**

Question relates to NEEDS and coping for the present day.

**Subject #:**

- #1 Bereavement person. Once every 2-3 weeks during winter.
- #2 Coping not very well, whether my own health is going down...not looking after health very well, part stress related...job stressed before laid off...no job comradeship, I don't socialize.
- #3 Going to church 'faith', bereavement group, very important to me, joined \_\_\_\_\_group of ladies , cards, carpet bowl, mostly ladies can be men.
- #4 Primarily on own, can't afford 'psycho therapy', outside activity, winter time I shovel now.
- #5 Kept busy, large yard, home, family, friends, sought nurse in community 's help, walk the malls for hours after work, sought counselling in city, stated 'too early' , okay after 6 months for counselling .
- #6 Nothing really, bereavement group.
- #7 Went on living, did the things one discussed before she passed away.
- #8 Crying helps, used to talk with dog, talking with son and daughter- in- law now.
- #9 Realized it was a blessing --hate to see anyone suffering.
- #10 Extra help costs money, Trying to live off own salary, had to do some stuff learned \_\_\_\_\_, equipment breaking down, you don't have someone to share good and bad things about the children, neighbour a 'gem.'
- #11 Manage every day. Shop for myself, look after bills, hydro and water, cable, moved after 1 year after husband died.
- #12 Carrying on, no special effort, day to day.
- #13 I am not looking for situation, not getting out.
- #14 Counselling once after death, sister was home for a week.

**Subject #:**

- #15 Love of my family: spouse and children.
- #16 Visiting children has helped, cope as you have, able to talk to other people about their loss, living in a communal residence has been helpful, related to cutting grass etc., and you are not alone.
- #17 No negative impacts.
- #18 Made myself not think about it, month and a half felt better.
- #19 Cried and grieved at loss at time of stroke diagnosis, I am not negative person, try different ways to solve things, very difficult for children when he had the stroke.
- #20 I do a lot of talking and hang around with mother's sisters and that helps keep part of her there.

**Other Potential stressors as identified in the Literature:****Perceived Caregiver Burden-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>7. Did any of your children live with you during the caregiving period?</u>		
-Yes	6	30
-No	13	65
-No children	1	5
<u>21. Were you the primary caregiver for anyone else during the time you were caring for ?</u>		
-Yes	8	40
- No	12	60
<u>22. If yes who: (n=8)</u>		
Child	4	50
Parent	1	12.5
Other	2	25
No response	1	12.5
<u>28. Did being female or male have any influence on your decision to be a caregiver?</u>		
-No influence	18	90
-Somewhat influential	2	10
-Not much influence	0	
See attached for qualitative response to this question.		
<u>36. During the period of caregiving, did other things happen to add to the stress you were experiencing as a caregiver?</u>		
-Yes	16	80
-No	4	40
See attached for qualitative response to this question.		
<u>39. What responsibilities of caring did you find you were not prepared for?</u>		
See attached for qualitative response to this question.		
<u>47. Looking back, did you feel you were prepared for the caregiving role placed upon you?</u>		
-Yes	9	45
-Most of the time	4	20
-Sometimes	3	15
-Never	4	20
See attached for qualitative responses to this question.		

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question #36 -A=During the period of caregiving, did other things happen to add to the stress you were experiencing as a caregiver? Yes /Explain or No**

The purpose is to determine other stressors which might have impacted on the caregiving experience.

**Subject #:**

- #1 -No
- #2 -Yes-job with lay off increased stress, transportation to go to doctor, needed time off work, waiting at doctor office, mortgage payments, my family not close, her family stopped coming around.
- #3 -Yes- selling the farm and moving. Moving decreased number of friends calling as further away.
- #4 -Yes-troubled \_\_\_\_\_, an \_\_\_\_\_.
- #5 -Yes- my father died suddenly, aunt died as well, his sister died 3 days after him.
- #6 -Yes-Money problems, went to social services and given rough time, needed \_\_\_\_\_ difficult to get, the ramp for wheel chair was okayed the day before he died.
- #7 -Yes-Dependent daughter has chronic illness, wife's illness day and night never knowing when she was going to be sick.
- #8 -Yes-\_\_\_ broke out.
- #9 -Yes-Death of husband very sudden, we lived together for 10 years before moving to \_\_\_, died within months after we lived here.
- #10 -Yes-I was \_\_\_\_\_ and didn't know how long [illness would be], no pressure from employment. I had some guilt --my own.
- #11 -No-when he was sick I didn't go any place, except when daughter, was in house there I brought groceries. Didn't go any other place was stressful.

Subject #:

- #12 -Yes-husband's brother died, brother came to visit and he wasn't well. Friends death. Little things-favourite dog had to be put down, daughter with \_\_\_ problems, fire \_\_\_\_\_.
- #13 -No
- #14 -Yes-children/husband. Had home care councillor during and after mother's death.
- #15 -Yes-\_\_\_ added stress, didn't feel like going, but still had to go. \_\_\_ problem, but I still went. Times when we would have liked to go on holidays, husband's sister would help out, she would check in on her [mother], at times had to put holidays off.
- #16 -Selling house stressful , trip to \_\_, when he was moody, once he started using walker, we didn't do trips.
- #17 -Yes, my husband died and I was solely responsible for her care [mother- in-law].
- #18 -Yes, husband was in between jobs, my son and \_\_\_\_\_ and this turned life upside down, manage with burden of all these requirements.
- #19 -No
- #20 -Yes, father had \_\_\_\_\_, not too bad to care for, husband had lump and surgery, it was benign.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question #39-What responsibilities of caring did you find you were not prepared for?**

The purpose is to identify concerns and these could be anticipated by the professionals and dealt with through various ways for example education workshops etc.

**Subject #-**

- #1 -No
- #2- -The unknown was always there.
- #3 -Not prepared to do what nurses would do for example, taking blood, fluctuations in \_\_\_\_, trying to get him to eat, \_\_\_\_ menu, difficult in eating.
- #4 -Everything, physical-you don't know how demanding it is until you are in the middle of it. Emotionally...
- #5 -How gruesome it was, never let it get him down, never complained, just how...
- #6 -None
- #7 -Other than administering morphine by needle, other than that could do almost anything.
- #8 -No
- #9 -Event of husband [sudden through night] ..
- #10 -I was not prepared for the emotional part.
- #11 -No, difficult time swallowing pills--tried many things.
- #12 -No
- #13 -Every once in a while chest would drain fluid and for no reason it would "flood." Never did heal up.
- #14 -If she was quite bedridden, it would be difficult
- #15 -Couldn't of handled them him in the tub I wasn't strong enough for that
- #16 -Had to learn as the need arose

**Subject #:**

- #17 -Not prepared for anything, would adjust to do what I had to do.
- #18 -All the heavy duty medication, driving, phoning, calling him with emergency situations.
- #19 -No
- #20 -Prepared for all.



**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:**

**Question 47. Looking back, did you feel you were prepared for the caregiving role placed upon you?** a= Yes b=Most of the time c=Sometimes d=Never

This question is similar to questions 38/39, again to determine if there are things which can be done pro-actively to help caregivers.

**Subject #:**

- #1 a
- #2 d-I wasn't prepared.
- #3 b-If incidence arose I soon learnt.
- #4 b
- #5 d-Not prepared through knowledge and emotional.
- #6 b-Prepared for the tasks , not prepared for emotional, what was at the end.
- #7 a-In my mind I knew it was there [illness] and had to be prepared for it when it came.
- #8 b
- #9 a
- #10 c
- #11 a
- #12 a-Once a person becomes ill, you don't think about it.
- #13 a-Because had previous experience, first husband experience a lot of learning took place here. Used palliative care team..., someone you could phone--there 24 hours.
- #14 c
- #15 d-Not really prepared, it just comes you do what you have to do...
- #16 c

**Subject #:****#17 a****#18 d-Because in a million years I never thought people would need long term care. In our family they often died quickly and was healthy before they died.****#19 a-At the beginning, I wondered, but there was no support in country, you had to find your own support****#20 a**

**Employment During the Time of Caregiving-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>12. Employment status during caregiving event:</u>		
-Not Employed	5	25
-Part time	1	5
-Full time	4	20
-Employment had to give up due to caregiving.....	4	20
-Retired	6	30

**Living Arrangements-**18. During your caregiving time did you live in the same residence?

-Lived with caregiver	15	75
-Lived in separate residence	5	25
 -If lived in separate dwelling, how long did it take to get to-(n=5)		
-<15 minutes	2	40
-15 minutes	0	0
-30 minutes	3	60
-45 minutes	0	0
-1-2 hours	0	0
-2-3 hours	0	0
-3-4 hours	0	0
->4 hours	0	0

**Quality of the Relationship to the Recipient of Care-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>41. How would you describe your relationship with <u>BEFORE</u> she/he got sick?</u>		
-Excellent	13	65
-Good	5	25
-Satisfactory	1	5
-Fair	1	5
-Poor	0	0
<u>42. How would you describe your relationship with <u>DURING</u> the time of caregiving?</u>		
-Excellent	9	45
-Good	9	45
-Satisfactory	2	10
-Fair	0	0
-Poor	0	0
<u>43. Overall, did you feel that caregiving affected your relationship?</u>		
-Positively	10	50
-Negatively	4	20
-No effect	6	30
See attached for qualitative responses to this question.		
<u>44. Overall, did you feel that <u>appreciated</u> the care you ave him/her?</u>		
-Yes	20	100
-No	--	---
See attached for qualitative responses to this question.		

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question 43. Overall, did you feel that caregiving affected your relationship?**

**A. Positively (P)    b. Negatively (N)    c. No effect (-)**

There is an explanation part to the question, which sometimes was filled in. Due to the stress caregiving has on a relationship, this question is part of question 41 and 42 when it asks about the relationship before and after illness, and is a continuation on the relationship related to caregiving issues.

**Subject #:**

- #1    P
- #2    N-Sexual aspect was gone, she was sleeping in one bedroom and I was in another bedroom. Tough days with arguments. She was testie--due to stress of illness...
- #3    P
- #4    P
- #5    P-I think you care for them that much more, under strain. Occasional "frazzle."
- #6    -
- #7    P-After she accepted the fact she was terminal relationship was better then before, closer and able to talk.
- #8    -
- #9    -
- #10    P-as described earlier.
- #11    -
- #12    N-As he got more oxygen affected him, became very impatient, unreasonable at times, personality changed.
- #13    P
- #14    -

**Subject #:**

- #15 - I would become frustrated, questioned whether due to my mother, but felt due to myself.
- #16 N-Hard to please, which he wasn't before, ...
- #17 P-She came to depend on me and once in awhile she would say " wouldn't get along without you.
- #18 P-Because she knew she could rely on me, and she would rely on me so much she was embarrassed having her daughter clean her personally.
- #19 N-More a burden/responsibility than a love affair. Very frustrated, couldn't do what he wanted to do, threw things, angry at me.
- #20 P-It continued as it was, nothing bad about it.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:**

**Question 44. Overall, did you feel that.....appreciated the care you gave him/her?**

- a. Yes (Y)                      b. No (N)**

This question has a possible explanation to it. The purpose of this question is to get a sense of the many variables associated with the level of satisfaction the caregiver felt during the caregiving period.

Subject #:

Note: all responses were a 'yes'.

Only 2 responders gave an explanation. These were:

#15-Y=She never told me...My spouse would get me to see my mom, when I didn't want to go.

#16-Y=When he didn't appreciate it was times he wasn't feeling good.

**Caregiving Tasks-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
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29. What were your caregiving responsibilities at the beginning of the caring period?

See attached for qualitative response to this question.

30. How did these responsibilities change as time went on?

See attached for qualitative response to this question.

31. At the time when you stopped caregiving for \_\_ what caregiving responsibilities were you doing?

See attached for qualitative response to this question.

32. What areas of caregiving tasks were particularly difficult?

See attached for qualitative response to this question.

33. Were there any tasks you felt you were not capable of doing because of a lack of skill, time etc?

-Yes	6	30
-No	14	70

-Yes	6	30
-No	14	70

See attached for qualitative response to this question.

34. What was most difficult about caring?

See attached for qualitative response to this question.



**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:**

**Question#29: What were your caregiving responsibilities at the beginning of the caring period?**

**Question#30: How did these responsibilities change?**

**Question#31: At the time when you stopped caregiving for \_\_\_\_\_ what caregiving responsibilities were you doing?**

Note: These questions were asked to determine if the demand became more with respect to time/complexity/amount.

A= Question 29 B=Question 30 and C= Question 31.

**Subject #:**

- #1 A=Making meals, looking after his personal care.  
B=No change, if he became sicker, he went into hospital.  
C=Same.
- #2 A=Housework (Normally she would have done); occasional meals; I always did outside work, she couldn't physically vacuum.  
B=No change, at time of death was unexpected.  
C=More weakened; death unexpected when it did occur.
- #3 A=Everything; treatments; appointments; medication; housework (I always did); bathing; meals; home when he needed.  
B=Care became more complicated related to decision related to medication, making whether to be seen by a doctor, didn't always know.  
C=All care (personal care) in the home, in hospital 2 weeks before he died.
- #4 A=Trained in \_\_\_\_, would administer medication through that.  
B=Physical health decreased, more demands on personal care, increase stress mentally, his needs demanding, frustration.  
C=Total personal care-feeding, cleaning.
- #5 A=Weak, couldn't do things, bought riding mower , able to eat, feet , walk, still went shipping, got less and less.  
B=Transportation to hospital in \_\_\_\_, daughter helped.  
Bathing; eventually getting out of bed, medication, confused as decreased oxygen; would have increased hospital stays.  
C=Total care; last 2-3 weeks before death, quit work , he was totally bedridden.

Subject #:

- #6 A=Difficult to walk, would walk with him; help on washroom toilet, off balance.  
B=  
C=Wash him, Complete am care; did not have to feed him; dress him.
- #7 A=Help her when she got sick; at times she needed no help; laundry; meals;  
housekeeping did in between times.  
B=More helping as sickness in personal care; did laundry and meals.  
C=Generally helping if needed, housework.
- #8 A=  
B=Bath him, couldn't walk.  
C=
- #9 A=Assisted with bath.  
B=Couldn't bath as too heavy to get out of tub; liquids ; hard to feed, had home care to help.  
C=
- #10 A=Support, changing dressing.  
B=Couldn't eat, \_\_\_\_\_, eventual pump for pain.  
C=Never had pain-pain controlled-no quality of life.
- #11 A=Meals; help to undress and dress; he was tired wanted to stay home; walked a little bit, sat in chair awake; out much care.  
B=Assisted in walking; bathing; difficult making stairs; had home care assistance.  
C=as above.
- #12 A=-on oxygen ...before death, many medial appointments.  
B=breathing became more laboured, last 3 years, illness more progressive.  
C=All oxygen equipment; bathing; clothing help to dress; not able to look after lawn for quite a while.
- #13 A=Care for chest drain, did driving.  
B=Couldn't hold things down, felt it was time to die, as he became weaker assistance in washing, didn't loose physical control.  
C=Cognizant, all decisions shared.

Subject #:

- #14 A=I would go at night and take supper to her.  
B=Sister stayed with mother; ...home care to stay for the night.  
C=Last month 24 hour care (home care); emotional/moral support; physical care done by home care staff (bath, meals, medication).
- #15 A=10 years in total for bath, business, shopping, doctor's appointment.  
B=As above.  
C=Laundry, meals, fell at times.
- #16 A=More little things for him. Toilet downstairs, he refused to have toilet built into house, so we had outhouse built, so he wouldn't have to go downstairs.  
B=Actual move ...access to bathroom on one floor.  
C=Take him to doctors; medication by me and nurse; incontinent, bathing by home care staff; watch his diet; attend \_\_\_ meetings.
- #17 A=Visit weekly to see that she is alright, grocery shopping; porto-potty bought and would empty it; housework and laundry; she refused personal care .  
B=Home care helped out with laundry; toilet emptying and meals on wheels; she refused help with personal care.  
C=Had bad fall at home, hospitalized and then went into personal care home.
- #18 A=To doctor appointments 2-3 weeks then every week, helped with pills.  
B=\_\_\_feeding; medication; bathing; dressings; up at night if problem with \_\_\_ feeding.  
C=As Mom got sicker, more responsibility to Dad; meals for Dad; grocery shopping; arranged outings; bill payer; as well as care for mom.
- #19 A=Difficult attitude with me he couldn't do anything, but had young man stay overnight and my husband made meals and was able to more things for him.  
B=Mostly bathing, had no use of Right hand; prepared meals.  
C=He would fall more often; incontinent ; more depressed; couldn't sit in chair; sent to hospital then transferred to nursing home.
- #20 A=More companionship/emotional.  
B=Progressed to physical care and emotional; help to bathroom washing, dressing, meal preparation, transportation to doctor, hospital stays increased as time went on, household chores, father required assistance as well.  
C=As above

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question #32: What areas of caregiving tasks were particularly difficult? (A)****Question #33: Were there any task you felt you were not capable of doing because of a lack of skill, time etc.?(B)****Subject #:**

- #1 A=He wanted to see his animals and he was too weak and we both fell in the doorway.  
B=No.
- #2 A=Doing things I never did before like preparing meals, I did no personal tasks.  
B=Couldn't do mending or sewing.
- #3 A=Watch him suffer, no control of...  
B=Taking \_\_ tests ...learn as you go.
- #4 A=Need for rapid response to needs for example, diarrhea vomiting, demands especially at night, very difficult for time changes; physical needs for example, he couldn't move on own.  
B=Personal care-got a lot of tips from workers who helped , made some of the care easier.
- #5 A=Cleaning the \_\_\_\_, I hated doing the most.  
B=Never involved with illness before, everything was new.
- #6 A=None.  
B=No.
- #7 A=I didn't find it too difficult, difficult to get her to accept doing things for her. Doing things in a 'diplomatic way'. She didn't feel I should be doing these things for her.  
B=No, not really.
- #8 A=Transferring because he couldn't walk.  
B=No.
- #9 A=Received help, things were okay.  
B=No.
- #10 A=None.  
B=No, because I am a \_\_.

Subject:

- #11 A=Hard time putting diaper, couldn't lift himself up, difficult with stomach flu, had so much gas, bathroom upstairs, used commode-not difficult.  
B=No.
- #12 A=No.  
B= No.
- #13 A=No.  
B=No.
- #14 A= No direct answer.  
B=No.
- #15 A=In a least 2 times a week, depends on time of year.  
B=No, I was limited in what I could do because of my back and legs because of \_\_\_ for lifting.
- #16 A=Keeping him in bed, fell out several times, too big to carry, getting him up, couldn't sleep well as he wouldn't walk to bathroom, used urinal, incontinent in bed sometimes.  
B=When he fell, difficult to lift.
- #17 A=Trying to get her to go to the doctor when needed; getting her to take medication right, making her understand she had to eat.  
B= No.
- #18 A= \_\_\_ feeding, not difficult , but only difficult because it was my mother.  
B=Times when the \_\_\_ popped out, I felt the doctor was asking more than I could give, it was messing with her innards, medication given at first it wasn't much but then I made mistake and felt bad about it, they were asking too much of me.
- #19 A=Bathing in bathroom, transfer/lift, ended up with a sponge bath.  
B=No.
- #20 A=No.  
B= No, that she would go ultimately.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question #34- What was most difficult about caring?****Subject #:**

- #1 -Two weeks before \_\_\_ started bleeding through mouth and nose at home, phoned ambulance, died with in 1 week.
- #2 -That it would end, knew it was a terminal illness, I refused to accept it.
- #3 -Emotionally.
- #4 -Knowing you are going through this and the person is going to die.
- #5 -Watching him disintegrate, watching him suffer couldn't eat, dreaded time he couldn't control thing, the humiliation, psychological suffering.
- #6 -Didn't find it hard. Liked that kind of work, seeing him not dealing with the dependency he was having a very sufficient man, didn't like someone taking care of him.
- #7 -Watching her die.
- #8 -Attitude you take.
- #9 -Good person, didn't fuss, did a lot of knitting.
- #10 -Trying to keep on with the every day activities of life, daughter... her activities- 3 hours in am to look after him.
- #11 -Nothing, wasn't demanding when he was in pain and needed rubbing.
- #12 -Emotionally the hardest, oxygen is a drug and does eventually affect their thinking a very independent person...emotionally up and down of his illness and how it affected him...
- #13 -I felt the sense of having to be aware of and where he was at all times. This is what had to be. Sister was present and she pressed for someone to come for the night hours, I would let go.
- #14 -See the downward slide with child/job/mom got to be quite a bit.

Subject #:

- #15 -I wasn't treated well when I as a child and to throw aside these feelings, it became a burden. Caring more strong an 'obligation', would still do it even with choices.
- #16 -In hospital at the end, he would push hand away at times don't know why he did this personality changes, he would cooperate with staff better than me, worst when he stopped talking... to staff or me.
- #17 -Trying to get her to understand that she needed help--she was uncooperative with regard to her care.
- #18 -Constant demands, I had to be there all the time.
- #19 -Seeing a person who was always capable , happy and outgoing, deteriorate to depression, anger and unforgivable, anger addressed toward me.
- #20 -Knowing that she would go ultimately.

**Other potential stress buffers as identified in the Literature-**

**Perceived Burden Relief-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>37. During the period of caregiving did other did other life events occur which decreased the stress in your life?</u>		

-Yes	13	65
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-No	7	35
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See attached for qualitative response to this question.

38. What responsibilities of caring did you find you were prepared for?

See attached for qualitative response to this question.

40. Who did you find was most helpful about caregiving issues?

-Family member	1	5
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-Doctor	5	25
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-Nurse	11	55
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-Friend	0	0
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-Other	3	15
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**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question #37- During the period of caregiving, did other life events occur which decreased the stress in your life? Yes/Explain or No**

The purpose is to determine other stressors which might have impacted on the caregiving experience.

**Subject #:**

- #1 -No
- #2 -No
- #3 -Yes-Family / friends would visit, going for drives.
- #4 -No
- #5 -No
- #6 -Yes-Lifeline, community services helped to decrease stress, for example the Senior Resource Person, home care, volunteers.
- #7 -Yes-when we went away \_\_\_\_.
- #8 -Yes-home care decreased stress, didn't feel any stress with caregiving.
- #9 -Yes-Brother and wife helped and sister and niece in \_\_.
- #10 -No
- #11 -Yes-especially during time home care attendant provided shower for husband twice a week for about 1 year.
- #12 -No
- #13 -Yes-people support-children, sister, husband himself, when he wasn't feeling well, apologize that he needed to lie down, put further effort to see what I was doing.
- #14 -No
- #15 -No
- #16 -Last trip to \_\_\_\_.

**Subject #:**

- #17 -Grandchildren were something to look forward to.
- #18 -No
- #19 -Yes, went to hockey game with grandson playing too, husband with me, enjoyed my work, then I could cope with being at home in the evenings with husband.
- #20 -My daughter ...stayed at my parents house and mother's sisters came to relieve her. My mother didn't want to be alone.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question #38-What responsibilities of caring did you find you were prepared for?**

The purpose is to identify concerns and these could be anticipated by the professionals and dealt with through various ways for example education workshops etc.

**Subject #-**

- #1 -Yes.
- #2 -No response.
- #3 -Took responsibilities in strike, handled situation as they came up, people would help, family helped, support home care to phone.
- #4 -Not prepared for any.
- #5 -Not prepared for any of them. Worked side by side things fill more to her happened gradually always together.
- #6 -I knew what to do, related to my job.
- #7 -Yes, because I was the one in my family who took responsibility for mom and dad when they were sick.
- #8 -I foresaw it coming [getting sicker].
- #9 -Yes.
- #10 -Yes.
- #11 -I was prepared with gas in the car, prepared to take him to doctors or hospital.
- #12 -Yes, never questioned it.
- #13 -I had gone through it before, I felt more prepared.
- #14 -No response.
- #15 -All.
- #16 -Wasn't too prepared for anything, when he first became sick, I didn't think that it would last long, had never done any nursing.

**Subject #:**

#17 -None really

#18 -Things I knew, I had to take over, just happened.

#19 -I was prepared for almost any kind of caregiving, through my younger years at home with my mom and dad. I spent time with people who were ill and dying in their own homes.

#20 -All

**Perceived Level of Satisfaction-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>4. Overall, did you feel that appreciated the care you gave him/her?</u>		
-Yes	20	100
-No	0	0
 <u>35. What was most enjoyable/rewarding about caring?</u> See attached for qualitative response to this question.		
 <u>45. Overall, what level of satisfaction did you feel about the level of care you gave ___?</u>		
-Very satisfied	13	65
-Satisfied	7	35
-Somewhat satisfied	0	--
-Not satisfied	0	--
See attached for qualitative response to this question.	8	
 <u>48. What advice would you give someone finding themselves in a similar situation as yours?</u> See attached for qualitative response to this question.		
 <u>49. Would you change anything if you could?</u>		
-Yes	5	25
-No	14	75
See attached for qualitative response to this question		

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question #35-What was most enjoyable/rewarding about caring?****Subject #:**

- #1 -That you had him at home.
- #2 -I don't if there was anything at all.
- #3 -When he would smile.
- #4 -I was able to comply with his wishes.
- #5 -Knowing he cares, drew us and family closer together.
- #6 -Know that I was make him comfortable, helping him, 'I was there for him.'
- #7 -That you were able to do it.
- #8 -All good, just being able to care for him at home.
- #9 -She enjoyed reading and working with her hands, tried to keep her as happy as possible and to take her out.
- #10 -To give him decency, allowing him respect ability, I know he was comfortable with me doing the tasks.
- #11 -I was happy he was able to enjoy his meal. If I cooked I knew he would like it.
- #12 -You knew you did all you could do.
- #13 -Made me feel good to make him feel better.
- #14 -Being able to do things for her, having her at home was really good.
- #15 -To be able to look after them as my health wasn't always good and I still had to go.
- #16 -When he wasn't in his moods, he had some compassion he realized what it was like to be sick. It makes you feel you are doing what you can. I enjoyed doing it.
- #17 -No rewards, once in a while she would say "I wouldn't know what I would do without you."

**Subject #:**

- #18 -The love, it made her feel so good, if she was feeling crappy, I would cheer her up, she had a good mind but her body fell apart.**
- #19 -God gave you enough health to be able to care for my husband at home, do what needed to be done for him.**
- #20 -Toward the end lots of times there would be increase bonding and stories with mother's sisters and may family. Undivided attention to my mother often.**

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:**

**Question 45. Overall, what level of satisfaction did you feel about the level of care you gave.....?**      **1=very satisfied      2=satisfied      3=somewhat satisfied**  
**4=not satisfied**

This question looks at the caregivers own feelings toward the care they gave in order to determine their sense of satisfaction with the caregiving period.

**Subject #:**

- #1      2
- #2      2-I think I did my best...
- #3      1-Felt "I did my best...gave my all."
- #4      1
- #5      2-Begin the first time, wondered whether I could do more, I did best I knew how. Ignorance is bliss.
- #6      1-Always had the feeling I could have done more. Do what you can.
- #7      2
- #8      1
- #9      1
- #10     1
- #11     1-Felt quite happy about care I gave.
- #12     1- I did the best I could.
- #13     1-I did not want to be left with " I wish I had."
- #14     2
- #15     1-I gave the care I could give.



Subject #:

- #16 2-A person feels that you always feel if you did all you could, if you could do more.
- #17 1-I did the best I could.
- #18 1
- #19 1
- #20 2-Because both she and I felt we could of halted procedure--guilt, she had all the cheap tests first, if had done the cat scan first...I felt 'what would have been?'

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question 48. What advice would you give someone finding themselves in a similar situation as yours?**

This question seeks information from the respondents to determine if there are any advice which might be helpful for programming for this target group.

- #1 To do the best you can.
- #2 Be better prepared for every day common chores, what ever the other person did, you are have to do, big thing to have to if man don't normally do women's chores and men equally do men's things. Share responsibilities in the home.
- #3 Give all help and love you can. Do what I did, keep them happy, look on positive side.
- #4 Total emersion, if that is what the person wants, it's worth it. Feel good about yourself to have given that --a final gift.
- #5 Do the best you can, and love them with all you got.
- #6 To get all information and not get things held back. Someone saying he could live for along time and then dies, rather of been told and been prepared could have talked more to him, asked him how he really feels.
- #7 Do things to the best of your ability, home versus hospital death no difference, her wish.
- #8 Not really.
- #9 If possible help relatives or who ever my experience was good.
- #10 Each one is separate, you have to do what you have to do, give what you can and he appreciates it, some one was a nurse.
- #11 People would rather stay home to care give at home. Any patient would appreciate that, if someone to look after them.
- #12 No.
- #13 Take one day at a time, reminded myself daily of this.
- #14 To accept whatever help, to try and deal with it all, would have been too much.

Subject #:

- #15 Do what you have to do, you know yourself what you have to do, when the situation arises. You have to prepared to talk to parent in a grown up fashion, role has changed--talking parents as an equal.
- #16 Be prepared for the unexpected, such as a change of personality and not take what they say seriously and not take it to heart, as it would put you down. Take frequent breaks. Get a way as often as you could.
- #17 Do the best you can, try and get doctors cooperation, found doctors cooperation as essential--her doctor did house calls.
- #18 Try and get lots of family support, I did try to get family support they said no, support groups "I really felt alone."
- #19 To be patient, kind and understanding and let remarks just go over your head.
- #20 If they can financially handle it, go with it, you wouldn't regret it. Finances related to time it took to care give, if I worked full time I wouldn't be able to do it, a 'family thing' more difficult to do it.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question 49. Would you change anything if you could?**

This question is a general overview of the caregiving experience and hopes to identify concerns related to the experience which could be improved. It also identifies how the experience has been looked at emotionally as well as physically by the caregiver.

**Subject #:**

- #1 No.
- #2 Didn't ask.
- #3 No, I feel I did my best.
- #4 No.
- #5 Not really.
- #6 No related to caregiving. Do more maybe..tried to talk to him so he wouldn't be so hurt related to physician's not being honest.
- #7 I wouldn't change anything, how you are able to accept things yourself.
- #8 No.
- #9 I don't think so.
- #10 As far as his care no. If the diagnosis was sooner--outcome would be different. Children robbed of him.
- #11 No.
- #12 I would get out on own more.
- #13 Yes, no cancer. NO, I wasn't left with "I wish I had" Yes one, time of death was difficult related to \_\_\_\_.
- #14 No.
- #15 No.
- #16 No.

Subject #:

- #17 Try and get her into a home sooner--but she wouldn't agree to this.
- #18 I was forced into a situation in the predicament where I was a nurse, but not trained as one. Its a combination-no place to turn to--home care said no to lots of things... nurses would only come in the mornings.
- #19 I probably could have been more persistent with the doctor, I felt he could have been looked after better, in respect to his cancer in last 3 years.
- #20 I would have liked her to stay at home if she could, but circumstances didn't allow.

**OBJECTIVE 2- Support Networks:****Caregiving Period-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b>8. <u>Did your children provide you with caregiving support?</u></b>		
-Yes	15	75
-No	4	20
-No children	1	5

**24 & 25. Were the caregiving responsibilities shared with anyone else? (Does not include formal network)**

-Yes	10	50
- No	10	50
-If yes, who: -Spouse	1	10
(n= 10) -Son	0	0
-Daughter	5	50
-In-Law	1	10
-Friend	1	10
-Neighbour	0	0
-Other	2	20

**26. If no, please explain.**

See attached for qualitative response.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question # 24: Were the caregiving responsibilities shared with anyone else?****# 25: , with who else?****# 26: if no: Can you explain why/why not?**

Both yes and no responses are recorded here.

The purpose of this question is to identify social support. Formal support services are addressed later, therefore this question DOES NOT include formal or paid services.

**Subject #:**

- #1 No-I could manage on my own.
- #2 No-
- #3 No-Family support was there, more emotional support than personal care.
- #4 No-my husband wanted me only.
- #5 Yes-Daughter helped.
- #6 Yes-Daughter is a nurse, other family helped with transport, general house and yard maintenance.
- #7 Yes-Daughter primary support also identified son.
- #8 Yes-Daughter in law.
- #9 Yes-Sister-support and company.
- #10 No-He was in and out of hospitalization for stabilization often.
- #11 No-
- #12 No-Each hospital discharge they asked if I needed care, and we never had it.
- #13 No-I was the caregiver.
- #14 No-
- #15 Yes, my spouse.
- #16 No-
- #17 Yes, a friend (relative to my step-mother).
- #18 Yes, sister
- #19- Yes-Daughter was main helper, son also helped.
- #20- Yes-Oldest daughter.

**Bereavement Period-**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>73. Who would you say provided you with the most support during this time?</u></b>		
-Spouse	3	15
-Children	10	50
-Church representative	0	0
-Other:	7	35
Home care attendant and doctor		
Sister, and best friend		
Home care worker		
Own attitude		
My family		
My mother's sister		
Sister		

See attached for qualitative response to this question.

<b><u>74. Had you or are you receiving any professional help in dealing with the loss?</u></b>		
-Yes	2	10
-No	18	90
If yes who?(n=2)		
-Bereavement Support Group	2	100
If no: (n= 18 ) Do you feel that you would benefit from some help in this matter?		
Yes	4	22.2
No	11	61.1
Don't Know	3	16.7



**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question 73. Who would you say provided you with the most support during this time?**

This question reflects the 'Other' category response only.  
The purpose is to determine social support received.

**Subject #:**

#1

#2 Home care attendant and doctor.

#3 Home care worker.

#4 Sister, best friend.

#5

#6

#7

#8 Own attitude, must look at it in a sensible manner.

#9 Sister.

#10 My family: mother, brothers and neighbours, as well as daughter.

#11

#12

#13

#14

#15

#16

#17

#18

#19

#20 My mother's sister.

**OBJECTIVE 3- Community Services:**

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>50. Did you receive any assistance from a public or private agency to help you I your caregiving task?</u></b>		
-Yes	20	100
-No		
If yes, what type of service? (n=20)		
 <b><u>52. Homemaker service/laundry/meals:</u></b>		
-Yes	13	72.2
-No	7	27.8
If yes:(n=13)		
At what point in time during caregiving?		
-Beginning	3	23.0
-Middle	2	15.4
-Toward the end	8	61.6
Who paid?-Caregiver	0	--
-Recipient of care	0	--
-Government service	13	100.0
-Insurance		
Note: In a spousal relationship, the designated payer is the recipient of care.		
How did respondent find out about the service?		
-Family	1	2.0
-Friend	1	2.0
-Professionals	11	84.0
-Other		
How useful was the service?		
-Very useful	11	85.0
-Somewhat useful	0	--
-Useful	2	15.0
-Not useful	0	--
Service available?(n=20)		
- Yes	20	100.0
- No	0	--
If service not available would it be useful to have?		
-Yes	0	
-No	0	
-N/A as is available	20	100.0
-No response	0	

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>53. Home Health aides:</u></b>		
-Yes	13	65
-No	7	35
<b>If yes: (n=13)</b>		
<b>At what point in time during caregiving?</b>		
-Beginning	1	8.0
-Middle	4	21.0
-Toward the end	8	61.0
<b>Who paid?-Caregiver</b>		
-Recipient of care	0	--
-Government service	13	100.0
-Insurance		
<b>How did respondent find out about the service?</b>		
-Family	2	15.0
-Friend	2	15.0
-Professionals	9	70.0
-Other	0	--
<b>How useful was the service?</b>		
-Very useful	12	92.0
-Somewhat useful	1	8.0
-Useful	0	--
-Not useful	0	--
<b>Service available:(n=20)</b>		
-Yes	20	100.0
- No	0	--
<b>If service not available would it be useful to have</b>		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
173		
<b>54. Friendly Visitor:</b>		
-Yes	0	--
-No	20	100.0
If yes: (n=0)		
At what point in time during caregiving?		
-Beginning		
-Middle		
-Toward the end		
Who paid?-Caregiver		
-Recipient of care		
-Government service		
-Insurance		
How did respondent find out about the service?		
-Family		
-Friend		
-Professionals		
-Other		
How useful was the service?		
-Very useful		
-Somewhat useful		
-Useful		
-Not useful		
Service available:(n=20)		
-Yes	20	100.0
-No	0	--
If service not available would it be useful to have		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>55. Telephone Reassurance-</u></b>		
-Yes	0	--
-No	20	100.0
If yes:		
At what point in time during caregiving?		
-Beginning		
-Middle		
-Toward the end		
Who paid?-Caregiver		
-Recipient of care		
-Government service		
-Insurance		
How did respondent find out about the service?		
-Family		
-Friend		
-Professionals		
-Other		
How useful was the service?		
-Very useful		
-Somewhat useful		
-Useful		
-Not useful		
Service available:(n=20)		
-Yes	0	--
-No	20	100.0
If service not available would it be useful to have		
-Yes	8	40.0
-No	8	40.0
-N/A as is available	0	--
-No response	4	20.0

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>56. Lifeline-</u>		
-Yes	3	15.0
-No	17	85.0
If yes: (n=3)		
At what point in time during caregiving?		
-Beginning	0	--
-Middle	1	33.0
-Toward the end	2	67.0
Who paid?-Caregiver	0	--
-Recipient of care	3	100.0
-Government service	0	--
-Insurance	0	--
How did respondent find out about the service?		
-Family	0	--
-Friend	0	--
-Professionals	2	67.0
-Other	1	33.0
How useful was the service?		
-Very useful	2	67.0
-Somewhat useful	0	--
-Useful	1	33.0
-Not useful		
Service available:(n=20)		
-Yes	20	100.0
-No	0	--
If service not available would it be useful to have?		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>57. Transportation/volunteer service-</u>		
-Yes	3	15.0
-No	17	85.0
 If yes: (n=3)		
At what point in time during caregiving?		
-Beginning	2	67.0
-Middle	0	--
-Toward the end	1	33.0
Who paid?-Caregiver	0	--
-Recipient of care	2	67.0
-Government service	0	--
-Insurance	0	--
-No response	1	33.0
How did respondent find out about the service?		
-Family	1	33.0
-Friend	0	--
-Professionals	2	67.0
-Other	0	--
How useful was the service?		
-Very useful	3	100.0
-Somewhat useful	0	--
-Useful	0	--
-Not useful	0	--
Service available:(n=20)		
-Yes	20	100.0
- No	0	--
If service not available would it be useful to have		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>58. Home delivered meals or prepared meals-</u></b>		
-Yes	6	30.0
-No	14	70.0
<b>If yes:(n=6)</b>		
<b>At what point in time during caregiving?</b>		
-Beginning	3	50.0
-Middle	1	16.0
-Toward the end	2	34.0
<b>Who paid?-Caregiver</b>	0	--
-Recipient of care	6	100.0
-Government service	0	--
-Insurance	0	--
<b>How did respondent find out about the service?</b>		
-Family	2	33.5
-Friend	2	33.5
-Professionals	2	33.0
-Other	0	--
<b>How useful was the service?</b>		
-Very useful	2	33.5
-Somewhat useful	2	33.5
-Useful	2	33.0
-Not useful	0	--
<b>Service available:(n=20)</b>		
-Yes	20	100.0
-No	0	--
<b>If service not available would it be useful to have?</b>		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--



<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>59. Senior Citizen Resource Person-</u></b>		
-Yes	4	20.0
-No	16	80.0
<b>If yes:(n=4)</b>		
<b>At what point in time during caregiving?</b>		
-Beginning	2	50.0
-Middle	1	25.0
-Toward the end	1	25.0
<b>Who paid?-Caregiver</b>	0	--
-Recipient of care	0	--
-Government service	4	100.0
-Insurance	0	--
<b>How did respondent find out about the service?</b>		
-Family	1	25.0
-Friend	1	25.0
-Professionals	2	50.0
-Other	0	--
<b>How useful was the service?</b>		
-Very useful	2	50.0
-Somewhat useful	1	25.0
-Useful	1	25.0
-Not useful	0	--
<b>Service available:(n=20)</b>		
-Yes	20	100.0
- No	0	--
<b>If service not available would it be useful to have</b>		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b>60. Adult day-care service-</b>		
-Yes	0	--
-No	20	100.0
If yes: (n=0)		
At what point in time during caregiving?		
-Beginning		
-Middle		
-Toward the end		
Who paid?-Caregiver		
-Recipient of care		
-Government service		
-Insurance		
How did respondent find out about the service?		
-Family		
-Friend		
-Professionals		
-Other		
How useful was the service?		
-Very useful		
-Somewhat useful		
-Useful		
-Not useful		
Service available:(n=20)		
-Yes	2	10.0
- No	18	90.0
If service not available would it be useful to have?		
-Yes	0	--
-No	18	90.0
-N/A as is available	2	10.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>61. Counselling services-</u></b>		
-Yes	1	5.0
-No	19	95.0
<b>If yes:(n=1)</b>		
<b>At what point in time during caregiving?</b>		
-Beginning	1	100.0
-Middle	0	--
-Toward the end	0	--
<b>Who paid?-Caregiver</b>	0	--
-Recipient of care	0	--
-Government service	1	100.0
-Insurance	0	--
<b>How did respondent find out about the service?</b>		
-Family	0	--
-Friend	0	--
-Professionals	1	100.0
-Other	0	--
<b>How useful was the service?</b>		
-Very useful	1	100.0
-Somewhat useful	0	--
-Useful	0	--
-Not useful	0	--
<b>Service available:(n=20)</b>		
-Yes	20	100.0
- No	0	--
<b>If service not available would it be useful to have</b>		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b>62. Physical Therapy Services-</b>		
-Yes	2	10.0
-No	18	90.0
<b>If yes:(n=2)</b>		
<b>At what point in time during caregiving?</b>		
-Beginning	1	50.0
-Middle	1	50.0
-Toward the end	0	--
<b>Who paid?-Caregiver</b>	0	--
-Recipient of care	0	--
-Government service	2	100.0
-Insurance	0	--
<b>How did respondent find out about the service?</b>		
-Family	0	--
-Friend	0	--
-Professionals	2	100.0
-Other	0	--
<b>How useful was the service?</b>		
-Very useful	1	50.0
-Somewhat useful	1	50.0
-Useful	0	--
-Not useful	0	--
<b>Service available:(n=20)</b>		
-Yes	20	100.0
-No	0	--
<b>If service not available would it be useful to have?</b>		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>63. Home Care Nurse Service-</u></b>		
-Yes	13	65.0
-No	7	35.0
<b>If yes:(n=13)</b>		
<b>At what point in time during caregiving?</b>		
-Beginning	3	23.0
-Middle	6	46.0
-Toward the end	4	31.0
<b>Who paid?-Caregiver</b>	0	--
-Recipient of care	0	--
-Government service	13	100.0
-Insurance	0	--
<b>How did respondent find out about the service?</b>		
-Family	1	8.0
-Friend	1	8.0
-Professionals	11	84.0
-Other	0	--
<b>How useful was the service?</b>		
-Very useful	11	84.0
-Somewhat useful	2	16.0
-Useful	0	--
-Not useful	0	--
<b>Service available: (n=20)</b>		
-Yes	20	100.0
- No	0	--
<b>If service not available would it be useful to have?</b>		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b>64. Respite Care-</b>		
-Yes	2	10.0
-No	18	90.0
If yes:(n=2)		
At what point in time during caregiving?		
-Beginning	0	--
-Middle	2	100.0
-Toward the end	0	--
Who paid?-Caregiver	0	--
-Recipient of care	2	100.0
-Government service	0	--
-Insurance	0	--
How did respondent find out about the service?		
-Family	0	--
-Friend	0	--
-Professionals	2	100.0
-Other	0	--
How useful was the service?		
-Very useful	1	50.0
-Somewhat useful	0	--
-Useful	1	50.0
-Not useful	0	--
Service available:(n=20)		
-Yes	20	100.0
-No	0	--
If service not available would it be useful to have?		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b>65. Nursing Home-</b>		
-Yes	3	15.0
-No	17	85.0
<b>If yes:(n=3)</b>		
At what point in time during caregiving?		
-Beginning	0	--
-Middle	0	--
-Toward the end	3	100.0
Who paid?-Caregiver	0	--
-Recipient of care	1	33.0
-Government service	2	67.0
-Insurance	0	--
How did respondent find out about the service?		
-Family	0	--
-Friend	0	--
-Professionals	3	100.0
-Other	0	--
How useful was the service?		
-Very useful	3	100.0
-Somewhat useful	0	--
-Useful	0	--
-Not useful	0	--
Service available:(n=20)		
-Yes	20	100.0
-No	0	--
If service not available would it be useful to have?		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--

Note: There is no nursing home located in the study municipality, however access to nursing home services is available, therefore the answer to this question is a 'yes.'

<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<b><u>66. Aides/Adaptions/Hospital Equipment-</u></b>		
-Yes	20	100.0
-No	0	--
<b>If yes: (n=20)</b>		
<b>At what point in time during caregiving?</b>		
-Beginning	9	45.0
-Middle	7	35.0
-Toward the end	4	20.0
<b>Who paid?-Caregiver</b>	0	--
-Recipient of care	1	5.0
-Government service	19	95.0
-Insurance	0	--
<b>How did respondent find out about the service?</b>		
-Family	1	5.0
-Friend	0	--
-Professionals	18	90.0
-Other	1	5.0
<b>How useful was the service?</b>		
-Very useful	18	90.0
-Somewhat useful	0	--
-Useful	1	5.0
-Not useful	1	5.0
<b>Service available:- Yes</b>	20	100.0
- No	0	--
<b>If service not available would it be useful to have?</b>		
-Yes	0	--
-No	0	--
-N/A as is available	20	100.0
-No response	0	--



<b>VARIABLE</b>	<b>NUMBER</b>	<b>PERCENT</b>
<u>67. Other-</u>		
-Yes	5	25.0
-No	15	75.0

Other= -Minister

- Respite for daughter in foster home
- Social Assistance
- Social Service Counsellor in Hospital
- Hairdresser came to home

68. If you received outside care, how satisfied were you with this service?

-Very satisfied	9	50.0
-Somewhat satisfied	1	5.5
-Satisfied	7	39.0
-Dissatisfied	1	5.5
-Very Dissatisfied	0	--
-Equipment Only	2	10.0

**Other Resources-**

84. Is there anything else you would like to add to our discussion regarding your caregiving experience?

-Yes	12	60
-No	8	40

See attached for qualitative response to this question.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:****Question 68. If you received outside care, how satisfied were you with this service?**

**1=very satisfied    2=somewhat satisfied    3=satisfied    4=dissatisfied  
5=very dissatisfied    6=did not receive outside care**

The purpose of this question is to expand on needs related to community services.

**Subject #:**

- #1    6
- #2    1-Partially decreased my level of stress-made one feel more comfortable while I was at work.
- #3    1-Decreased my level of stress.
- #4    1-Decreased stress by service in home, provided some relaxation time and did improve knowledge of caregiving and increased confidence. The fact staff can encourage you ...
- #5    1-Decreased level of stress, strangers initially may have felt uncomfortable but didn't end up that way. Increased level of confidence, but still at times wondered if I did things okay...
- #6    1-Decreased level of stress, someone to talk to, helpful, keeping an eye on him, to tell if he was gaining or losing weight.
- #7    3-There was a decrease in the level of stress, improved knowledge and increased confidence.
- #8    4-Dissatisfied, felt could have done with more hours and staff more punctual, this increased my level of stress when supposed to be at a place at certain time and patient wanting to eat, meal not ready.
- #9    3-Decreased level of stress, all so good and did provide relaxation time, no improvement in knowledge.
- #10    1-Only service was \_\_\_ who provided husband with counselling .... Service like home care increased his level of stress, husband didn't want any one strange in the house.
- #11    3-No change in stress, never told children "I was not happy."

Subject #:

- #12 6-
- #13 1-Decreased level of stress, increased confidence, able to sleep some, someone on the other end of the telephone increased confidence, being able to talk with someone knowledgeable only had to call 2 or 3 times, if he was reacting to thing...his needs were different, less medicated, more self sufficient, professional presence helpful.
- #14 1-Decreased level of stress, provided some relaxation time, no improvement in knowledge of caregiving and did increase confidence.
- #15 3-Services were good, some question about the caregivers weren't always doing enough for what they were being paid, increased my confidence and provided some relaxation time. In the apartment, I would like to see them check in more often, do spot check. (This service was not located in the study municipal home care service)
- #16 3-Decreased level of stress, did provide some relaxation time, did improve knowledge of caregiving, and did increase confidence.
- #17 1-Helped decrease stress, provided a little relaxation time, did not increase knowledge of caregiving.
- #18 2-Related to stress, no, it helped. I felt I needed more, not much relaxation time, and any knowledge of caregiving, felt self-taught, did increase my self confidence. Nursing service needed more. Felt that there were more services. No one gave me lessons on how to pick people up... Felt strongly on the few times on the long weekend, I could never get a break. I wish a system where home care nursing care could be on weekends, and holidays and was an important commodity. I would have weekends off, holidays dreaded it, because I worked double.
- #19 3-Decreased level of stress, did not provide relaxation time and knowledge of caregiving self-learning. Increased my level of confidence.
- #20 3-Decreased level of stress, did provide relaxation time, no improvement in caregiver knowledge, didn't have a long term. of service.

**CAREGIVER QUESTIONNAIRE QUALITATIVE DATA ENTRY:**

**Question #84: Is there anything else you would like to add to our discussion regarding your caregiving experience? Yes/No. Example: Other services needed.**

**Subject #:**

- #1 -No response.
- #2 - Singles club, feels past workshops on eating/cooking; support for widows, not sure...
- #3 -Would like something beyond the bereavement group, for example group visits, get together, not labelled as such but a follow support group of some sort.
- #4 -24 hour hot line would help; training for caregivers; administration of education and side-effects of drugs, personal talks for bed-ridden person, transportation in area, less than an ambulance, but more than a car.
- #5 - Patient support workshop, someplace you could just phone, 24 hours service when things happened you didn't know what to do, where to go, workshops on what to expect, time may of been a factor in ability to attend at the beginning.
- #6 -24 hour answering service, workshops if I wasn't a \_\_ would of been helpful related to transferring, personal care, visitor service especially if one didn't have family.
- #7 -No workshops, no to 24 hour telephone as had family close to me.
- #8 -No
- #9 -Need a personal care home in\_\_\_\_\_.
- #10 -Continue to promote palliative care; school system is good, needs counselling for children,... older people "loneliness"; people who died suddenly whole different ball game.
- #11 -More senior housing , I would be able to move in with people my own age, who understood that you are older; feel at night to be afraid to be alone, "I don't want to be alone."

**Subject #:**

- #12 -No.
- #13 -No , because there just wasn't time to go to workshops...
- #14 -No as it was such a short time, and home care came in quickly.
- #15 -Yes to workshops, for easier way of handling people.
- #16 -Would have attended workshops on patient care; support groups/counselling yes.
- #17 -No need, the help was there when she finally chose to accept it.
- #18 -Caregiving workshops, lifting medication bathing, support groups , I didn't know what was / is available, would like...felt let down, ... Should have provided more especially on holidays/weekends/mornings.
- #19 -Caregiver workshops/general sit and talk to other people who were in similar situation 'support group.'
- #20 -No.

## APPENDIX I Caregiver Assessment Guide

**TABLE 1**  
**Caregiver Assessment Guide for Use in Primary Health Care**  
(To be filled out by caregiver)

<p>Caregiver's Name _____</p> <p>Address _____</p> <p>Telephone _____</p> <p>Relationship to care recipient _____</p> <p>Age _____ Gender _____ Marital status _____</p> <p>Children _____ Ages _____</p> <p>Number of children living with caregiver _____</p> <p>If child(ren) live(s) with caregiver, any special care required? (describe) _____</p> <p>How many hours do you spend caring for children? _____</p> <p>Is care recipient residing with caregiver? Yes _____ No _____</p> <p>If no, how far away do you live? _____</p> <p>How many hours do you spend caring for the care recipient? Per day _____ Per week _____</p> <p>Are you providing daily care? Yes _____ No _____</p> <p>For how long have you been providing care? _____ Years _____ Months _____</p> <p>Has caregiving decreased your ability to participate in social activities and personal interests? Yes _____ No _____</p> <p>Describe the nature of caregiving responsibilities: _____</p> <p>_____</p> <p>_____</p>	<p>Who assists you with caregiving? _____</p> <p>What is their relationship to the care recipient? _____</p> <p>How do they assist? _____</p> <p>How often do they help? _____</p> <p>Are you satisfied with the help received from family and friends in meeting caregiving responsibilities? Yes _____ No _____</p> <p>Do visits from other family members decrease stress associated with caregiving? For you? Yes _____ No _____ For the care recipient? Yes _____ No _____ Not applicable (no other family members visit) _____</p> <p>Does the care recipient receive formal assistance from: Home health aides? Yes _____ No _____ Respite care (temporary relief from caregiving)? Yes _____ No _____ Meals on Wheels? Yes _____ No _____ Adult day health care? Yes _____ No _____ Transportation? Yes _____ No _____ Other (describe) _____</p>
<p><b>CAREGIVER'S EMPLOYMENT</b></p> <p>What kind of work are you doing? _____</p> <p>Where? _____</p> <p>How long does it take to get to work? _____</p> <p>How many hours per week do you work? _____</p> <p>What are the hours and days you work? _____</p> <p>To what degree do you find caregiving interferes with your work responsibilities? (Circle the best answer) (a) not at all; (b) somewhat; (c) quite a bit; (d) a great deal; (e) not applicable</p> <p>Have caregiving emergencies occurred? Yes _____ No _____</p> <p>If yes, what was the nature of these emergencies? _____</p> <p>_____</p> <p>How many times in the past year has this happened? _____</p> <p>How would/did you handle this? (Check all that apply) Leave of absence _____ Using flextime _____ Time off _____ Telephoning care recipient from work _____ Other _____</p>	<p><b>CAREGIVER HEALTH STATUS</b></p> <p>How is your own health? Excellent _____ Good _____ Fair _____ Poor _____</p> <p>Has your health changed? Yes _____ No _____</p> <p>Describe the change: _____</p> <p>_____</p> <p>Do you believe your health has suffered as a result of assuming caregiving responsibilities? Yes _____ No _____</p> <p>How are you coping with caregiving responsibilities? Well _____ Fairly well _____ Poorly _____</p> <p>Do you feel the care recipient makes undue demands on your time and energy? Never _____ Sometimes _____ Frequently _____ Always _____</p>
<p><b>RESOURCES AVAILABLE</b></p> <p>Are care recipient's economic resources adequate to meet his/her own needs? Yes _____ No _____</p> <p>Are your economic resources adequate to meet care recipient's needs? Yes _____ No _____</p> <p>Are you providing money for care recipient? Yes _____ No _____</p> <p>Are there others who can/do help with care recipient's money needs? Yes _____ No _____</p> <p>Are there others who can/do help with caregiving time? Yes _____ No _____</p>	<p><b>CAREGIVER/CARE RECIPIENT RELATIONSHIP</b></p> <p>Are members of your family household distressed by the caregiving situation? Yes _____ No _____</p> <p>Do you have a plan for caregiving in case you become sick or are injured? Yes _____ No _____</p> <p>Do you have a plan in case the care recipient becomes sick or injured? Yes _____ No _____</p> <p>What help, if any, do you need to assist you with caregiving? _____</p> <p>_____</p> <p>What are the positive aspects of your caregiving role? _____</p> <p>_____</p> <p>What is your relationship with the care recipient like? _____</p> <p>_____</p>

This tool was developed by Karen Covance, MEd, Ph.D., R.N., C.S.; Mary Fubus, Ph.D., F.A.A.N.; and Mary Lou Edwards, R.N./M.S., C.S.

Does the care recipient accept your help:  
 Gladly? Yes \_\_\_\_\_ No \_\_\_\_\_  
 Reluctantly? Yes \_\_\_\_\_ No \_\_\_\_\_  
 Resents it? Yes \_\_\_\_\_ No \_\_\_\_\_  
 Accepts only when desperate? Yes \_\_\_\_\_ No \_\_\_\_\_

Where and how does care recipient spend most of his/her time?  
 \_\_\_\_\_  
 \_\_\_\_\_

Can care recipient be left alone? Yes \_\_\_\_\_ No \_\_\_\_\_  
 If yes, for how long? \_\_\_\_\_

Have care recipient's dependency needs increased since you began caregiving? Yes \_\_\_\_\_ No \_\_\_\_\_  
 If yes, describe: \_\_\_\_\_  
 \_\_\_\_\_

**RATING OF CARE RECIPIENT'S HEALTH AND BEHAVIOR**

ADLs (Activities of Daily Living)	Performs Unassisted	Needs Some Assistance	Needs Full Assistance
Feeding	_____	_____	_____
Bathing	_____	_____	_____
Dressing	_____	_____	_____
Grooming	_____	_____	_____
Toileting	_____	_____	_____
Walking	_____	_____	_____
Transfer to bed	_____	_____	_____
Transfer to toilet	_____	_____	_____

IADLs (Instrumental Activities of Daily Living)	Performs Unassisted	Needs Some Assistance	Needs Full Assistance
Writing	_____	_____	_____
Reading	_____	_____	_____
Cooking	_____	_____	_____
Shopping	_____	_____	_____
Laundry	_____	_____	_____
Finances	_____	_____	_____
Telephoning	_____	_____	_____
Housework	_____	_____	_____
Medical appts.	_____	_____	_____
Transportation	_____	_____	_____
Handling emergencies	_____	_____	_____

Do you need help with managing care recipient problems in any of these areas? Yes \_\_\_\_\_ No \_\_\_\_\_  
 If yes, describe: \_\_\_\_\_  
 \_\_\_\_\_

Are there any activities you perform for the recipient that you feel:  
 Physically uncomfortable performing (e.g., lifting)?  
 Yes \_\_\_\_\_ No \_\_\_\_\_  
 Psychologically uncomfortable performing (e.g., feeding, toileting)? Yes \_\_\_\_\_ No \_\_\_\_\_  
 If yes, describe: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

	Impaired	Somewhat Impaired	Not Impaired
Thought process	_____	_____	_____
Mood	_____	_____	_____
Behavior	_____	_____	_____
Hearing	_____	_____	_____
Vision	_____	_____	_____
Speech	_____	_____	_____
Sleep	_____	_____	_____
Weight: Normal _____ Overweight _____ Underweight _____			
Medical diagnoses (if known) _____			

Medications (over-the-counter and prescription): Can you list the name(s)?  
 \_\_\_\_\_  
 \_\_\_\_\_

The dose(s)? \_\_\_\_\_  
 How often? \_\_\_\_\_

Does the care recipient take his/her own medication?  
 Yes \_\_\_\_\_ No \_\_\_\_\_

Do you prepare the medications for administration?  
 Yes \_\_\_\_\_ No \_\_\_\_\_

Do you administer the medication? Yes \_\_\_\_\_ No \_\_\_\_\_

Do you have questions about how to administer the medication?  
 Yes \_\_\_\_\_ No \_\_\_\_\_

Do you know the intended effects and adverse effects of the medication? Yes \_\_\_\_\_ No \_\_\_\_\_

Would you like information about:	Yes	No
1. Available community resources	_____	_____
2. Basic medical information about: care recipient's condition disease course symptoms treatments medications	_____	_____
3. Behavior problems and their management	_____	_____
4. The aging process	_____	_____
5. Common family reactions to stress	_____	_____
6. Preventing further disabilities	_____	_____
7. Home environment modifications	_____	_____
8. Health promotion/wellness	_____	_____
9. Exercise	_____	_____

Would you like referred to these services:	Yes	No
1. Respite care/temporary relief	_____	_____
2. Insurance/Medicare/Medicaid	_____	_____
3. Home health aides/homemaker/chore services	_____	_____
4. Adult day care	_____	_____
5. Transportation services	_____	_____
6. Nursing home evaluation	_____	_____
7. Support groups	_____	_____
8. Individual counseling	_____	_____
9. Other (describe): _____	_____	_____

**TABLE 1 (cont.)**  
 (To be completed by health care provider)

**ASSESSMENT:**

- Managing situation satisfactorily \_\_\_\_\_
- Managing at acceptable level but resources/demands threaten to create crisis if situation not resolved \_\_\_\_\_
- Not managing at acceptable level; needs a referral \_\_\_\_\_
- Needs information/education \_\_\_\_\_
- Ability to manage caregiving situation is unclear; further data required \_\_\_\_\_

**PLAN:**

Education (specify what information is needed): \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Referral (specify; e.g., community service agencies, employee benefits dept.):  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Followup (specify):  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Counseling/support groups (specify):  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

This tool was developed by Karen Devereaux Melillo, Ph.D., R.N., C.S.; May Petrell, Ph.D., F.A.A.N.; and Mary Lou Espeita, R.N., M.S., C.S.