A COURSE FOR CAREGIVERS:
GROUP WORK AS AN INTERVENTION
WITH FAMILY CAREGIVERS OF HOSPITALIZED ELDERLY

By

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ABSTRACT

The objective of this study was to examine the effects of a short-term support group on the reported stress of family caregivers of hospitalized elderly. In addition, it was designed to provide descriptive information on caregiver stress, the caregiving experience and the factors that influence the experience.

The sample of eight caregivers, drawn from a geriatric rehabilitation hospital, completed a stress scale pre- and post-group involvement as well as participated in an in-depth interview. Qualitative data was analyzed using a modified grounded theory approach.

The results from this study indicate that despite few changes in perception of stress following group involvement, there are benefits to be derived from participation in a caregiver support group. As a group, respondents reported minimal change in their experience of stress both during the interviews as well as on the standardized stress scale. However, respondents did indicate an increased sense of support as well as feeling more confident and prepared for the challenges of caregiving. Similar to previous studies, caregivers who attended the support group program generally reported satisfaction with the group experience.

The study highlights the significance of individual differences in caregiving situations and in the experience of
caregiver stress. The study also addresses issues of accountability within social work practice and provides direction for future service delivery to family caregivers of elderly persons.
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Chapter One
Introduction

Canada has and continues to experience a steady increase in the number and proportion of older adults (Statistics Canada, 1986). With advanced age, there is an increase in vulnerability to chronic disabling diseases -- conditions which create a need for emotional, physical and instrumental support for a growing part of the population. The central role of the family in providing such support to the frail elderly has been documented extensively as well as recognition that such involvement can create excessive demands for the family caregiver (Brody, 1985; Clarke & Rakowski, 1983; Shanas, 1979). Stress from caregiving has the potential to negatively impact a caregiver's psychological, social and physical well-being (Toseland, Rossiter, Peak & Smith, 1990). As hospitalization of a relative often marks the beginning of the caregiving role, it is a time of crisis for many (Hamlet & Reid, 1990). It has been suggested that practice and research need to focus on caregivers earlier in their caregiving tenure and when demands are more extreme (Malonebeach & Zarit, 1991). Given this, and that group work as an intervention modality with family caregivers has gained acceptance in the community setting (Toseland & Rossiter, 1989), it is intriguing to investigate the effect of group work with family caregivers in the hospital setting.
Statement of Problem

A review of the literature encourages the use of support groups with family caregivers as a means to address caregiver-related concerns. However, little attention has been given specifically to family caregivers of hospitalized elderly and the effects of a hospital-based support group on caregiver stress.

Purpose

The purpose of this study is to: a) examine the effects of a short-term support group on stress of family caregivers of hospitalized elderly; b) provide descriptive information on caregiver stress, the caregiving experience and the factors that influence the experience; and c) examine the relationship between stress scores, demographic characteristics and the caregiving experience.

Importance of the Inquiry

This inquiry is relevant to the field of social work for many reasons. Within health care settings, social workers are increasingly under scrutiny. With budget constraints and competition from other health care professionals, and with the apparent proliferation of self-help groups led by health care consumers, social work departments across Canada are needing to place emphasis on accountability and empirically based practice. Elimination of deficiencies has become a critical issue in health care and thus, evaluation of service needs to move beyond the
peer audits of the past (Simon, 1991). Evaluative research can provide evidence of social work's contribution in addressing psychosocial concerns within a multidisciplinary health care setting (Berkman, 1990). By examining outcomes of the support group, this study begins to address accountability of social work practice and programs. As research is not firmly entrenched in health care social workers' thinking and practice (Kane, 1983), this study is valuable as it contributes to fulfilling the critical need to move on from anecdotal reports as the basis for expanding the profession's knowledge base. The social work profession recognizes the vital role research plays in furthering its status and goals (Turnbull, Saltz & Gwyther, 1988) and influencing practice (Coulton, 1985). Further, the study highlights the importance of consumer feedback and involvement, conveying a message of interest and concern to the public.

As the support group program on which this study focuses is a newly developed program, the investigation is a beginning step in evaluating the program, generating information that will direct future caregiver program planning within hospital settings as well as in the community. The information revealed will inform social workers and other health care professionals as to issues and needs of family caregivers. An awareness and understanding of the stresses evoked by caregiving is necessary if life satisfaction is to be maintained for both the caregiver and care receiver (Robinson & Thurnher, 1979). Inattention to the plight of caregivers has implications for the individual, the
care receiver, the family system, the workplace, and the public health care system. The greater the burdens perceived by the caregiver of the caregiving situation, the more likely the physical, social and emotional well-being of the caregiver will suffer, and the less he/she will be able to continue to provide care (McCallion, Toseland & Diehl, 1994; Miller, 1989). The care receiver may then suffer direct consequences (i.e. insufficient care) as may the entire family system (i.e. negative feelings may develop including guilt and resentment leading to poor communication patterns). The workplace at large may also be impacted as stressed caregivers struggle with meeting home and work demands (McCallion et al, 1994). Finally, the health care system itself tends to be effected as stressed caregivers often require services for themselves and then additional services for their care receiver (Abel, 1990). As a result of the many implications, decreasing caregiver stress is an important outcome to investigate.

The study is also of importance as it further supports the existing literature on the benefits of group work and strengthens the case by moving beyond informal participant feedback to methods of quantitative and qualitative analysis. Thus, it is imperative that social workers examine the effects of professionally led support groups to meet quality assurance requirements, to justify the ongoing existence of these group programs, and to provide future practice and policy directions (Peterson & Anderson, 1984; Turnbull et al., 1988).
Summary and Organization of Thesis Content

In sum, the objective of the study is to begin to link research and practice in the field of caregiving by gathering clinical data and using it as a basis for action (ie. future programs, advocacy for caregivers).

The thesis has been organized as follows: Chapter One has introduced the issue of family caregiving, presented the problem and reasons for its exploration. Chapter Two provides a comprehensive literature review of pertinent areas including chronic illness, role of the family as caregivers, stress theory, support groups, and past relevant studies. Chapter Three describes the theoretical framework for the study. Chapter Four details the methodology of the study and Chapter Five presents the findings. Chapter Six discusses the findings and the thesis is concluded with Chapter Seven which highlights implications for social work practice and recommendations for future research.
Chapter Two
Literature Review

Introduction

In this chapter, a review of the literature on the topic areas of chronic illness, family caregivers, stress theory, support groups and past relevant research is presented and discussed as it relates to the study of group work with family caregivers of hospitalized elderly.

Chronic Illness

It is evident in the literature and highly visible in society that Canada is experiencing a steady increase in the number and proportion of older adults (Statistics Canada, 1986). In 1991, approximately 12% of Canada's population were age 65 and more, twice the proportion who were older adults in Canada at the turn of the century (Chappell, 1990; National Advisory Council on Aging, 1993). This segment of the population has recently been divided into age categories of the young-old, the middle-old and the old-old, with studies indicating recent rapid increases in the old-old age category (Chappell). With advanced age, there is an increase in vulnerability to chronic disabling diseases (Masciocchi, Thomas & Moeller, 1984). Approximately 85% of older adults have one or more chronic conditions which most frequently include heart and circulatory problems, arthritis and chronic rheumatism, hypertension, and vision and hearing problems not
relieved by glasses or aides (Chappell). This prevalence is a result, in part, of a shift in the epidemiology of disease from acute to chronic diseases as well as a decrease in accidental deaths. Concomitant advances in medicine and medical technology have combined to increase the numbers of individuals who survive serious trauma and chronic illness (Biegel, Sales & Schulz, 1991). Also, a decrease in death rates has increased the likelihood of person developing later life chronic disabling conditions such as Alzheimer's disease (Biegel et al.). Despite the prevalence of chronic diseases, only a relatively small proportion (5-8%) of older adults live in institutional settings (Connidis, 1989). Consequently, it has been estimated that nearly half of all noninstitutionalized elderly persons are limited by at least one chronic condition, conditions which limit functional activity and mobility, and require support on an ongoing basis (Biegel et al.). As a result, the need for well-functioning informal support systems to provide care to the elderly is of paramount importance.

Family Members as Caregivers

The central role of the family in caring for the frail elderly population has been documented extensively (Brody, 1985; Clarke & Rakowski, 1983; Shanas, 1979). The myth of abandonment of older adults by family members has been dispelled with estimates of 80-90% of care received by older adults being provided by family members (Brubaker & Brubaker, 1992; Chappell,
Moreover, current policies reflect an increased emphasis on the family as an appropriate caregiver (Barnes, Given & Given, 1992) and look to the family as a resource to hedge the rising costs of long-term care (Montgomery & Borgatta, 1989). Clearly, the involvement of the family, otherwise known as the informal family caregiver, is fundamental to the health and well-being of the aged and is, in fact, socially and financially necessary. It is important to recognize, however, that such involvement has the potential to create demands on the caregiver which challenges their ability to manage the situation. Support for caregivers, whether it is physical, emotional, social or financial, may enable the provision of care to continue, may encourage overall well-being for both the caregiver and care receiver, and may even decrease the rate of institutionalization and abuse of the elderly (Ballie, Norbeck & Barnes, 1988; Gnaedinger, 1989).

In simplest terms, caregiving refers to activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves (Pearlin, Mullan, Semple & Skaff, 1990). While a range of meanings are attributed to the term 'caregiver', most studies focus on family members within the realm of caregiving (Barer & Johnson, 1990). As a result of this and the above mentioned critical role family members play in the provision of care to older adults, the study focused solely on adult family caregivers.

Brody (1990) suggests there is a hierarchy in the family
relationship of caregiver to care receiver. When the care receiver is married, the spouse almost invariably becomes the principal caregiver. However, often due to limited capacities, the efforts of the elderly caregiving spouse are frequently supplemented by their adult children. Research indicates that just as family almost invariably refers to spouses or adult children, adult children most often means adult daughters (Brody, 1990; Horowitz, 1985; Stoller, 1983). Studies cite that 80-90% of care provided by adult children is provided by daughters or daughter-in-laws (Miller & Cafasso, 1992). Further, the roles played by daughters and sons tend to be somewhat different and are often gender-based. While equally inclined to offer emotional support, linkage services and financial support, daughters are much more likely than sons to provide instrumental, hands-on assistance including personal care, transportation, household chores and meal preparation (Chappell, 1990; Connidis, 1989; Horowitz, 1985). Gender differences are also believed to influence access to resources that may alleviate caregiver strain and appraisal of the caregiving experience (Miller & Cafasso).

More recent studies, interestingly, reveal the increasing participation of sons and husbands in the role of caregiver (Brubaker & Brubaker, 1992; Kaye & Applegate, 1990). With demographic trends including smaller families and increased proportion of women in labor market, different patterns of caregiving are emerging (Horowitz, 1985). Necessarily, the nature of the caregiving relationship varies between and among
spouses, adult sons and daughters, and siblings by virtue of the different issues uniquely inherent in each relationship. However, regardless of age, gender or relationship, it is generally recognized that the task of caregiving is associated with consequences which caregivers often perceive as stressful -- ie. shifts in family roles and in family homeostasis, decline in physical health, emotional strain, changes and adjustment in lifestyle (Brody, 1985; Cantor, 1983; Long, 1991).

Caregiving can be a rewarding yet demanding experience. It often involves a long-term commitment, challenging the caregiver's coping resources (Toseland, Rossiter, Peak & Smith, 1990). Changes in the care receiver's health and changes in the caregiver/care-recipient relationship, which are often caused by chronic physical and mental health problems, are factors that create a general sense of worry and caregiver stress. Stress from caregiving has the potential to negatively impact a caregiver's psychological, social and physical well-being (Toseland et al., 1990). Psychological difficulties associated with caregiving include depression, anxiety, anger, frustration, guilt and self-blame (Abel, 1990; McCarthy-Neundorfer, 1991; Toseland et al., 1990). Socially, caregivers often report feeling lonely and isolated. Conflicts with family members about caregiving responsibilities are commonly experienced (Cantor, 1983; Abel) as are conflicts with the care recipient (Toseland et al., 1990). A caregiver's physical health may also be at risk as a result of the physical tasks required (ie. lifting, toileting,
bathing) as well as a result of limited time for rest (McCarthy-Neundorfer; Toseland et al., 1990). Thus, recent studies have shown that severe and sometimes overwhelming stress can arise for family caregivers (Killeen, 1990; Long, 1991; Pearlin et al., 1990; Rankin, 1990), potentially impacting various aspects of their lives.

A Conceptualization of Stress

Life events in and of themselves are not stressful. Further, duration, quantity and magnitude of an event individually do not explain why some persons are debilitated by some events and others are not (Stolar, MacEntee & Hill, 1993). An individual's personal appraisal of the meaning of the event is what is of significance.

In the transactional model, a general approach taken by Lazarus, stress is defined as the outcome of interactions between the organism and the environment (Lazarus & Folkman, 1984; Singer & Davidson, 1991). More specifically, an event in the environment is considered to be a stressor only if the individual's appraisals of it, and of her/his own resources, suggest that it is threatening or disturbing. Appraisal refers to first evaluating the stressor in terms of its capacity to do harm, and second, to assessing the individual's ability to handle the stressor and the strategy most likely to reduce the potential harm (Singer & Davidson, 1991). Coping then consists of cognitive and behavioral efforts to deal with the demands that
are appraised as taxing or exceeding the resources of the individual (Folkman & Lazarus, 1991).

It is important to recognize that appraisals of person-environment relationships are influenced by individual differences. Such differences, or antecedent person characteristics, include patterns of motivation, beliefs about oneself and the world, and recognition of personal resources for coping (ie. financial means, social and problem-solving skills, health and energy) (Folkman & Lazarus, 1991). Individual differences in these variables may help to explain why an event may be appraised as a threat to one person and as neutral or a challenge by another. The process of appraisal may also be influenced by environmental variables including the nature of the danger, its imminence, predictability and duration, and the existence and quality of social support resources to facilitate coping (Folkman & Lazarus). Social support as a factor in ameliorating the effects of stress (Baillie et al., 1988; Singer & Davidson, 1991) will be addressed further in the discussion on group work as an intervention.

**Group Work as an Intervention Strategy**

In view of the growth and increasing vulnerability of the elderly population and the resultant demands on their families, the development of intervention strategies for family caregivers has received much attention. With the rapid growth of research and affirming findings on social supports as a buffer against the
negative impact of stress, professionals have readily adopted an ideology of support intervention and support groups have become a very common form of help offered (Chase-Goodman, 1991; Northen, 1990). Within the health care setting, groups have gained recognition for helping patients and family members cope with the emotional stress and socio-emotional problems that often accompany severe illness or disability (Northen). More specifically, the literature reveals support for the use of groups with caregivers of frail elderly as a means to address stress and other caregiving-related concerns (Monahan, Greene & Coleman, 1992; Toseland & Rossiter, 1989; Toseland, Rossiter & Labrecque, 1989).

Support groups most often refer to self-help groups and professionally led support and information groups. In general, the helping dynamic is a reciprocal exchange among individuals who have a similar problem (Chase-Goodman, 1991). Involvement in a support group provides a forum to share concerns, participate in the struggles of others, to feel normal in spite of stress, to express feelings and fears, to exchange ideas, and to provide an opportunity to help others (Chase-Goodman). Support groups aim to develop cohesiveness, enhance self-esteem, and produce better coping among its members.

With respect to caregiving, support groups have been developed for spouses, adult children, families and friends in general, and even for grandchildren. A review of several group intervention studies, existing support group programs and
personal experiences indicate the emergence of common themes that are addressed in these groups: information about the care receiver's condition, coping with feelings about caregiving, issues of unpreparedness, sense of feeling without options, guilt and responsibility, problems in limit setting, repression of taboo feelings, a need to 'save' the care receiver, caregivers' need to take care of themselves, unfinished business with family members, interpersonal and intergenerational relationships, communication, knowledge of resources outside the group, and home-care skills (Altschuler, Jacobs & Shiode, 1985; Popky-Hausman, 1979; McCarthy-Neundorfer, 1991; Toseland & Rossiter, 1989).

There is a small but growing body of literature documenting the effects of support group interventions in helping family caregivers with the consequences of caregiving. The studies reviewed consisted mostly of professionally led groups for family caregivers. Majority of the participants were women, reflecting the composition of family caregivers in the general population. The groups were short-term (four to ten sessions up to six months), using a supportive approach often in combination with an educational component (Biegel et al., 1991; Greene & Monohan, 1989; Toseland & Rossiter, 1989).

Overall, while findings demonstrate that support group participants are very satisfied with their group experience and report a number of benefits resulting from their group participation, findings are less conclusive when measuring the
effects of the groups in relieving caregiver distress (Biegel et al., 1991; Toseland & Rossiter, 1989). Some studies have concluded that group interventions have yielded no significant effects on depression, life satisfaction, social support and coping (Toseland, 1990). Other studies, however, have revealed more positive results (Clarke & Rakowski, 1983; Greene & Monahan, 1989; Whitlatch, Zarit, & von Eye, 1991). As an illustration, Greene & Monahan (1989) reported a caregiver support group program which produced statistically significant reductions in anxiety, depression and sense of burden. Toseland and colleagues (Toseland et al., 1989) reported improvements in psychological functioning and positive personal changes in caregivers following support group involvement. Zarit, Anthony & Boutselis (1987) also reported positive outcomes including decreases in perceived burden and psychiatric symptoms for group participants.

Despite unanimous conclusive evidence either in support of or refuting the positive effects of support groups, the review of past studies provides valuable information regarding methods previously used as well as indicating areas of caregiving research that require further attention.

Of importance is recognition that evaluation of the effects of group interventions have been based mostly on practitioner observation of group process and outcome and participant self-report questionnaires, with few studies using standardized measures or qualitative interviews (Biegel et al., 1991; Toseland & Rossiter, 1989). The review also indicates that the majority
of the studies have focused on caregivers of elderly relatives with mental illness or Alzheimer's Disease, with a lack of attention to caregiver groups of frail elderly with other disabilities.

With respect to the effects of caregiving such as anxiety, depression and more specifically stress, critiques of the existing research have raised questions as to the researcher's ability to evaluate such change without the use of a standardized measure (Toseland & Rossiter, 1989). In identifying the need to go beyond clinical impressions, researchers have also reinforced the value of using qualitative methods in research with caregivers, emphasizing the importance of capturing essential aspects of the caregiving experience (Biegel et al., 1991; Toseland & Rossiter, 1989). As a result, regarding future research directions in caregiving, the literature has recommended that designs should include qualitative and quantitative components in an effort to yield a balanced comprehensive piece of work reaping each respective analytic advantage (Abel, 1990; Barusch, 1991; McCracken, 1988). Given this, this research differs from past studies as the design utilizes both quantitative and qualitative methods—a standardized measure and in-depth interviews—and the reasons for their use will be discussed in Chapter Four - Methodology.

Of significance, only one descriptive study examining a hospital-based family caregiving support group has been found (Hamlet & Read, 1990). Rutchick (1990) suggests a few reasons
for the limited research on groups in health care settings including small sample size, difficulties inherent in increasing sample size by studying groups of varying populations or across settings, and the sheer limited number of existing groups due to the amount of time required in pre-and-post group activities.
Summary

As the population continues to age and older adults are challenged by disabling diseases over a longer period of time, involvement by family members will be pivotal to the overall well-being of the elderly. The provision of care is recognized as potentially stressful for caregivers as the demands of the caregiving situation often threaten to overwhelm caregivers' coping resources. Support groups are being used with increasing frequency to help caregivers cope with stresses of caregiving. Group interventions have the potential to prevent stressors from overwhelming caregivers by providing a forum for acceptance, universalization of concerns and feelings, and instillation of hope. Thus, it is apparent that while the literature seems to support the use of support groups in health care settings and with family caregivers of the elderly, few links have been made between family caregivers of hospitalized elderly and the effects of hospital-based support groups on the experience of caregiver stress.

In the chapter to follow, the theoretical framework and research question for the study is presented.
Chapter Three
Theoretical Framework and Research Question

Introduction
In this chapter, the perspective through which the study is examined, the theoretical framework, and the research question are presented.

Theoretical Framework
The presented study is based on the perspective that caregiving is an individualized experience which is influenced by many factors including the personalities of the caregiver and care receiver, their relationship, the nature of disability, supports available, age, gender and culture to name a few. Given this perspective, a caregiver stress-coping model developed by Biegel, Sales and Schultz (1991) has been adopted as the basis of the theoretical framework for the study (see Figure 1).

The model incorporates five categories of variables important to understanding caregiving and include the following: 1) objective conditions conducive to stress, 2) individual perceptions of stress, 3) short-term responses to perceived stress, 4) enduring outcomes, and 5) individual and situational conditioning variables that affect the relations among the other four sets of factors. Figure 1 illustrates the five categories of variables incorporated in the model along with examples of specific variables which represent each category.
Figure 1

Caregiver Stress - Coping Model

Conditioning Variables
- Health
- Income
- Social Support
- Satisfaction with Social Contacts
- Nature of Prior Relationship
- Personality Factors (Perceived Control)
- Coping Strategies

Conditions Conducive to Stress
- Functional Status (Independence in ADL, daily assistance needed)
- Patient Affective State
- Other Manifestations of Disability
- Nature of Disability Onset
- Prognosis
- Visibility

Responses to Stress
- Physiological
- Psychological
- Behavioral

Perceived Stress

Enduring Outcomes
- Psychological
- Life Satisfaction
- Depression
- Physical Well-being

Source: Biegel, Sales & Schultz, 1991, p.46
The utility of the model in understanding key concepts in the study is as follows. The objective conditions conducive to stress include issues related to chronic illness (i.e. care receivers' functional status, prognosis, affective state). Perceptions of stress relate to the individual caregiver. The short-term responses to stress (i.e. physiologic, psychologic, behavioral) and enduring outcomes (i.e. physical and psychologic well-being) address the effects of caregiving on the caregiver. Finally, the individual and situational variables (health, income, social support, nature of prior relationship) all influence the caregiving experience.

In an attempt to customize the model and to complete the theoretical framework for the study, stress theory, family systems theory and group theory are necessary building blocks. Stress theory (Lazarus & Folkman, 1984) is an integral building block as it complements the caregiver stress-coping model presented. The model encompasses components of stress theory (Lazarus & Folkman) highlighting the interactions between the individual and the environment, and the importance of appraisal.

As the concept of caregiving in this study occurs within a family system, family systems theory is also an important theory to consider in the framework as family dimensions influence the caregiving experience. Couper (1989) summarized the principles of family systems theory as they relate to family caregiving, emphasizing that each family member plays a role according to previously established family rules and patterns. Further, a
change of circumstances for one member affects the whole family and families alter patterns of interaction during crisis periods to regain balance. Also, differences in boundaries of individuals, generations and families exist impacting members and interactions. Thus, a family systems perspective provides insight as one acknowledges how these factors may influence stress and coping within the caregiving experience.

The final piece of the framework includes elements of group theory. The use of a support group as an intervention with caregivers is based on the perspective that group dynamics of acceptance, universalization of feelings and concerns, and instillation of hope help people face and deal with their emotional reactions (Monahan, Greene & Coleman, 1992; Northen, 1990).

Figure 2 illustrates the caregiver stress-coping model reflecting the additional components of the theoretical framework. As the focus of the study is to examine caregiver stress, the model presented is useful in organizing the relatedness of the key concepts of chronic illness, caregiving and stress. Further, the significance of family dimensions on conditioning variables and conditions conducive to stress, of one’s appraisal on the experience of stress, and of a group intervention on enduring outcomes is highlighted.
Caregiver Stress - Coping Model
Revised

Adapted From: Caregiver Stress - Coping Model
Developed by Biegel, Sales & Schultz, 1991
Research Question

Based on the literature review and theoretical framework presented, the study focuses on three general areas of inquiry -- family caregivers, stress and group work as an intervention modality. More specifically, the study addresses the following question: 'How does a short-term support group effect stress in family caregivers of hospitalized elderly?'.

For the purpose of this study, the key concepts are operationalized as follows. 'Short-term' referred to one and one half-hour sessions occurring weekly for four weeks. 'Support group' referred to an aggregate of persons who have a common concern and come together to support and aid one another in coping with certain stresses and difficulties (Northen, 1990). 'Stress' referred to "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.21) and was measured by the Perceived Stress Scale (Cohen, Kamarck & Mermelstein, 1983). It was further understood by eliciting the experiences of caregivers through in-depth interviews. 'Family caregivers' referred to persons (spouses, adult children, and siblings) who provide assistance (affective and instrumental tasks) on an ongoing basis to relatives who are unable to provide for themselves as a result of chronic illness. 'Hospitalized elderly' referred to persons sixty-five years and older who are currently in-patients at a geriatric rehabilitation hospital.
In the chapter to follow, the methodology used to examine the research question for the study is detailed.
Chapter Four
Methodology

Introduction

In this chapter, the support group program, research design, sampling procedure, data collection instruments and procedures, assumptions, limitations, ethical considerations and data analysis procedures are presented and discussed.

Description of Support Group Program

The support group program, 'A Course for Caregivers', was initially developed by two social workers at Holy Family Hospital (a geriatric rehabilitation hospital) and had been delivered twice before. As other support groups are offered in the community, it was decided not to open participation to the general public, but instead to focus on meeting the needs of families of patients of the hospital. The group consisted of four one and one-half hour sessions occurring in consecutive weeks from 4:30 - 6:00pm. This time of day seemed to accommodate most of the caregivers interested in attending as many would have just finished visiting their relative and others had just arrived for a visit on their way home from work. The group met in a meeting room at the hospital and refreshments (coffee/tea) were provided.

The support group was led by a social worker (who was also the researcher for the study) and followed a semi-structured
format to provide support and education. Open-ended discussions, a video and handouts were used to address the caregivers’ needs and issues. A description of the video and titles of the handouts are presented in Appendix A. The organization and content of the group sessions follows:

**Week 1**

The Caregiver Role
- Introductions and a video addressing issues related to caregiving.

**Week 2**

Excuse my unusual behavior...It’s only stress
- What is stress, how to recognize it and strategies for coping.

**Week 3**

When is it my time? Caring for yourself
- The importance of taking care of yourself and how to do it.

**Week 4**

Healthy Communication
- Communication styles, tips for good communication, resource information, and closure.

A pre-group meeting was held one week prior to the start of the support group program. The pre-group meeting was unique to this series of the program as it was mostly for the purpose of the research study. The meeting provided the opportunity for further explanation of the study and the requirements of participation. Also, during this meeting, consent forms were signed and data collection procedures began. The meeting provided the opportunity for participants to meet one another and to voice questions/concerns that they would like addressed in the group program.
Rationale for the Research Method

As stated in Chapter Two, both qualitative and quantitative research methods have been used in this study to provide a comprehensive approach that takes more fully into account the complex social reality (Allen-Meares, 1990). The qualitative component afforded the researcher the opportunity to isolate and define categories, and to look at patterns of interrelationship between the many categories (McCracken, 1988). It has been argued that qualitative methods are especially appropriate for studying older families because one of the most important characteristics of families is the interdependence of their members, and qualitative methods are better suited than survey data for conceptualizing such interdependence (Matthews, 1993). As well, since the questions for which data was sought were somewhat demanding and would possibly elicit less than precise answers, the more flexible net provided by qualitative techniques was appropriate (McCracken). Further, as the purpose of the study was not one of generalizability but that of access to the respondents' perspective, highlighting categories and assumptions of the caregiving experience, the intensive nature of qualitative research was appropriate (McCracken). Finally, the quantitative component provided the opportunity to observe a different aspect of the same reality, more specifically, perceived stress of family caregivers (McCracken).
Research Design

The level of design for this study was an exploratory-descriptive design and was chosen for several reasons. An exploratory-descriptive design is appropriate for use with small samples as it does not attempt to make generalizations (Reid & Smith, 1981). It is also well suited to qualitative methods as it is useful in examining impact and/or effect, and in describing the experience of the participants. Exploratory-descriptive designs provide a knowledge-building function, gathering information on characteristics of the phenomenon studied and the presence of an association among factors (Reid & Smith). While this type of design requires only a modest investment of resources, it can still help to inform action and/or lay groundwork for more definitive studies (Reid & Smith). As the study focused on a small sample size, the design described was appropriate. As well, the study sought to examine the effects of group intervention on stress of family caregivers and to gain knowledge of the caregiving experience through qualitative interviews and a quantitative measure.

Sample Procedures

Participants for the study were recruited from the seventy-five bed in-patient unit and the out-patient department at Holy Family Hospital in Vancouver. Prior to the initiation of recruitment procedures, approval to conduct the study was granted by the University of British Columbia Behavioral Sciences
Screening Committee for Research and Other Studies Involving Human Subjects (see Appendix B) and by Holy Family Hospital Research Committee (see Appendix C). Social workers at the hospital provided names of family caregivers potentially interested in participating in the support group and study. Each were invited to participate by letter (see Appendix D and E) and received a follow-up telephone call one week later.

The sample consisted of family caregivers of patients of Holy Family Hospital who attended a four week caregiver support group program. Initially, the sample was to include only caregivers of in-patients, but as a result of the small sample size, the sample parameters were expanded to include caregivers of out-patients as well. Criteria for inclusion in the study was not bound by age, gender, culture or relationship to the patient. Family caregivers had to have attended three or more sessions of the support group program to participate and only those family caregivers of patients at the hospital who did not attend the support group were excluded.

For the purposes of this study, the sample size was eight participants. The small sample size was chosen as it afforded greater attention to each subject, allowing for a more detailed examination of themes (Reid & Smith, 1981). The sample size was also manageable in terms of budget restraints and time required for transcription.

The method of sampling for the study was availability sampling as the method selects information-rich cases for in-
depth study (Patton, 1990). While the sample population was varied (i.e. respondents were of different age and cultural backgrounds), the sample type was homogenous as all the participants were similar with respect to the presenting problem and having had attended the support group.

**Instruments**

The instruments used in the study included a standardized stress scale - the Perceived Stress Scale (see Appendix F), an in-depth interview using a semi-structured interview guide (see Appendix G), a Demographic Profile (see Appendix H), and a caregiver support group evaluation form (see Appendix I).

**The Perceived Stress Scale**

The Perceived Stress Scale (PSS) was designed to measure the degree to which situations in one's life are appraised as stressful (Cohen et al., 1983). It was selected because it is sensitive to chronic stress deriving from ongoing circumstances and to stress from expectations concerning future events (Cohen et al.), both of which are characteristics of the caregiving experience (Biegel et al., 1991). As well, the items on the scale make reference to the time frame of one month, and in examining the effects of the group on the caregiver, the time frame of the scale is congruent with the length of the support group program. The PSS was designed to be used with samples of respondents who have a junior high school education, having easy to understand items and response alternatives (Cohen et al.).
Unlike other scales used in caregiving research, the PSS is not specific to any particular population group (i.e. age, gender or relationship). As the PSS has been proven to possess substantial reliability and validity (Cohen et al.), the scale is believed to add reliability and validity to the study.

The PSS was pre-tested with caregivers who attended a support group prior to the study and it was found to be easy to administer and complete, yielding interesting information that could be correlated to the caregiver’s situation. Another consideration that resulted from pre-testing the PSS was the potential for difficulties in completing the scale due to language barriers. A decision was made to offer assistance in completing the written requirements of the study (consent form, PSS, demographic profile) to all respondents. The PSS was administered during a pre-group meeting one week prior to the start of the support group and again during the final session of the group program.

Interviews

In-depth interviews occurred individually with the group members between 2 and 13 days after the final group meeting. The interviews were conducted by the researcher who, as stated earlier, was the group leader and a trained social worker. All of the interviews were conducted by the same researcher. Interviews allowed the caregivers the opportunity to express their experience in their terms and informed the research with a picture of the caregiver’s perspective and complex situation that
is beyond responses on a scaled questionnaire (Reid & Smith, 1981). Interviews with the caregivers also afforded the researcher the opportunity to obtain clarity of issues as well as address content and process issues (George, 1990).

An interview guide was utilized because of the flexibility it offers in altering the order and wording of questions in accordance with the participants and their experience (Patton, 1990). The questions in the interview guide were developed to examine the links between the respondents' caregiving experience, perceived stress and the effects of the support group program. More specifically, the questions used were designed to elicit information that related both to the theoretical framework presented earlier, highlighting the caregiving stress-coping model (Chapter Three), and to the effects of participation in the support group program. The interview guide was pre-tested with caregivers who had attended a previous support group as well as with colleagues in the field. This process provided an opportunity to observe and receive verbal suggestions and nonverbal clues, many of which were incorporated, adding to the soundness of the study.

From the initial draft to its final form, the interview guide underwent changes in order to flow more smoothly and to more effectively elicit the information necessary to address the research question. Open-ended questions are necessary in order to acquire the detailed data that permit interpretive analysis (Hutchinson & Skodol-Wilson, 1992). The interview guide began
with general open-ended, non-threatening questions about the respondents' caregiving situation. The questions then focused on reasons for attending the support group and ways in which the group effected them. The interview guide was limited to four main questions in recognition that participating in this type of an interview has the potential to be emotionally exhausting. As well, the guide was developed with an effort to be considerate of the respondents' competing responsibilities and resulting time restrictions. The questions as well as the probes were worded using language of everyday speech.

Demographic Profile Information

The demographic profile form was designed by the researcher to capture relevant demographic and caregiving information. It was completed during the pre-group session.

'A Course for Caregivers' Evaluation Form

The evaluation form was adapted from a format suggested by Barusch (1991) in October, 1993 by the support group leader/researcher. The form was accepted for use by the Social Work Department at Holy Family Hospital and had been used successfully prior to its use in the research study. The questions on the evaluation form were not designed to address the research question directly but did investigate the general areas of inquiry in a non-directive fashion.

Credibility and Soundness

In research, each phase of the project affects credibility and soundness of the final product. The reliability and validity
of the PSS was addressed previously. With respect to the interview as a measure, credibility was attended to by audiotaping the interviews thereby reducing interviewer selection bias. Also, the use of the same interviewer increased the likelihood of a similar presentation of questions to each respondent. Soundness of the interview guide was addressed by pre-testing the interview questions for flow, wording and relevance to the research purpose (Hutchinson & Skodol-Wilson, 1992). Further, the interviewer had good interviewing skills, using non-leading, open-ended questions which facilitated the detailed data necessary for interpretative analysis (Hutchinson & Skodol-Wilson). The interviewer was flexible, pursuing the respondent's lead and clarifying meaning throughout. The timing (within two weeks following the group cessation and at a convenient time for the respondent) and setting (in a quiet office in the hospital where the group was held) of the interviews remained constant for all the respondents and thus contributed to soundness. Finally, the audiotaped interviews were transcribed primarily by the researcher which contributed new ideas, stimulated the interviewer's personal feelings, and was useful in monitoring bias (Hutchinson & Skodol-Wilson).

In further considering the credibility, soundness and generalizability of the study, it must be openly recognised that qualitative studies by virtue of their nature cannot be replicated because the world and individual's experiences change (Marshall & Rossman, 1989). However, making explicit the
parameters of the study and the applicability of the study as previously detailed contributed to credibility and soundness of the study. As well, the previously explicit documentation of the perspective through which the study was conducted as well as the theoretical framework it is based upon enhanced credibility and soundness. Also, a journal detailing the research process was maintained in order to allow others to inspect procedures used and decisions made (Marshall & Rossman). The use of interview data as evidence of the researcher's inferences and in documenting analytic constructs that appear later in Chapter Five also add to the credibility (Marshall & Rossman).

Data Collection Procedures

The data was collected on three occasions during the study:

1. Data was first collected as the pre-group meeting was held at the hospital one week prior to the start of the support group program. The meeting involved discussions about the group program and the study as well as completion of a consent form (see Appendix J), the PSS, and a demographic profile by each participant. While assistance in completing the written requirements was offered to all respondents in an effort to avoid difficulties arising from language barriers, no assistance was requested.

2. Data was next collected during the last 15 minutes of the final session of the support group program as participants once again completed the PSS as well as the evaluation form.
3. Finally, within two weeks of the completion of the group, individual interviews with the participants were arranged and conducted. The researcher/interviewer conducted all the interviews using the interview guide. The interviews began with informal conversation and proceeded to review the purpose of the study, issues of confidentiality and ethical considerations. The first question in the guide was asked and an effort was made to ask the following questions in the same order for each interview. However, additional questions were asked if relevant to the study. The interviews ranged in length from 45-60 minutes. They were audiotaped and later transcribed for purposes of analysis (see Appendix K for an example of an interview transcript).

Assumptions

It was assumed that all respondents were able to reflect and comment on their caregiving experience. It was also assumed that data emerging from the PSS, demographic profiles, interviews and evaluation forms was an honest and accurate representation of the respondents' experience.

Limitations

The primary limitations of this study were as follows:

1. One must recognize that the broad inclusion of respondents (differences in age, cultural background, relationship to the patient) may mask the revelation of themes particular to certain subgroups (Zarit & Toseland, 1989). More
strict inclusion criteria may have served to increase the homogeneity of the sample, but at the same time may have further reduced the number of appropriate respondents (Holden, Rosenberg, Barker, Tuhrim & Brenner, 1993).

2. As participation in the support group and study was voluntary (self-selected), both the least stressed and the most severely stressed may be underrepresented (McCallion et al., 1994). Caregivers in self-selected samples tend to be concerned enough about caregiving to seek support, but are not so involved in caregiving that they are unable to get out to participate in a research or support group program (Malonebeach & Zarit, 1991). Excessive and competing time demands associated with caregiving may certainly influence the self-selection sample process (Dura & Kiecolt-Glaser, 1990). Therefore, caregivers who chose to participate may be different from those who did not (Barusch, 1991).

3. In qualitative research, the interviewer/investigator serves as the instrument in the collection and analysis of data, using a broad range of his/her own experience, imagination and intellect (McCracken, 1988). However, the interviewer must ensure that the testimony be elicited in an as unobtrusive, nondirective manner as possible in order to capture the categories and logic of the respondent and not that of the interviewer's own logic and categories (McCracken). The interviewer for the study was a trained social worker, skilled in interviewing techniques, educated in qualitative research interviewing yet inexperienced
in conducting qualitative research interviews.

As one strategy to attend to this type of limitation, Whyte (1982) suggests evaluating the degree of directiveness of a question/statement made by the interviewer by examining it in the context of what immediately preceded it during the interview. The scale ranges from low to highly directive responses beginning with responses that encourage the respondent to continue (i.e. Uh-huh, a nod of the head), reflective statements, probing the last remark made by the respondent, probing an idea preceding the last remark, probing an idea expressed in an earlier part of the interview, and introducing a new topic. The interviewer in this study examined a segment of each interview prior to conducting the next interview in order to monitor and ensure that the testimony was elicited in a unobtrusive and nondirective manner.

4. An important consideration in data collection was the significance of the practitioner (the support group leader) and the researcher being the same person. Research outcomes may be effected as a result of the practitioner/researcher experiencing role conflict (Proffitt, Byrne, Namei, King, Schmidt & Brott, 1993). Social workers, who are traditionally trained to provide service to consumers in response to identified needs, may struggle with assuming the role of helper during the research interview. Adhering to the rigors of scientific methodology has led to a separation of the roles of practitioner and researcher, often exacerbating existing conflicts in the research endeavor (Robinson & Thorne, 1988). However, support does exist for an
alternative approach, that of blending of the practitioner and researcher roles as the roles are so closely intertwined that each role in fact stimulates the other (Robinson & Thorne). It has been stated that such an approach can be more efficient and effective as the practitioner often has direct access to respondents and is familiar with the problem area (Kilpatrick & Lockhart, 1991). The researcher in this study attended to the potential for role conflict by carefully scrutinizing the interviewer's role in each interview and by debriefing with a colleague before proceeding with the next interview.

Another issue as a result of the blended role was the risk of bias. The risk was present as respondents who liked the group leader are more likely to report positively with reference to the group when the group leader is the one asking the questions (Biegel et al., 1991). To control for the potential bias, the in-depth interviews occurred after the group was completed. As well, respondents were asked to respond honestly as their information was to be used in improving the program and future planning for caregivers.

5. The size of the sample was small by virtue of the study being based on one series of the four week support group program, and a maximum of 14 individuals participate in the program at one time. The sample size was also limited by the number of participants who attended three or more group sessions. However, all who attended the program did participate in the study.

6. It must be accepted that the findings of the study are
context bound due in part to the small sample size and qualitative method used. The findings would be most applicable to other geriatric rehabilitation hospital-based caregiver support group programs. The themes presented in the findings may be more widely applicable to similar community based or self-help caregiver support groups. However, the extent of applicability cannot be determined by this study.

Ethical Considerations

Permission to conduct this study was granted by the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects (see Appendix B). Permission was also granted from the Research Committee at Holy Family Hospital (see Appendix C).

Each potential respondent of the study received an information letter detailing the purpose of the study and the nature and extent of the involvement requested. The letter also stated that they were under no obligation to participate and that a decision not to participate or to withdraw at any time would not affect the receipt of present or future service.

During the pre-group meeting, respondents completed the consent form which again explicitly stated what was required of them, reinforced that information would be held in confidence by the researcher, that identifying information would be omitted, and ensured that their receipt of service from the hospital would in no way be affected by their involvement in the study. Prior
to the interview, these points were repeated as well as clarifying each respondents' right to decline any answer. Respondents were asked to record their birth dates as an identification code on the PSS and demographic profile, and label the audiotape in the same manner following the interview to ensure anonymity yet provide a method to link the two measures. Upon completion of the interview, the availability of follow-up services was presented in the form of provision of the researcher's telephone number, offering of a subsequent visit and appropriate referrals.

Data Analysis

The method of data analysis employed both quantitative and qualitative methods. First, calculations were performed to determine changes in the respondents' perceived stress score. The data from the interviews was then used to add breadth and depth to the quantitative analysis of perceived stress. The intent of the qualitative analysis was to construct an exhaustive description of the major themes that emerged from the interviews. The interview data was organized and sorted using a modified grounded theory approach (Straus, 1989). The tape-recorded interviews were first transcribed and each tape listened to individually prior to the coding process to capture a feeling for the respondents' experience. Using line by line analysis, words, phrases and/or statements that pertained to the research question were underlined and extracted from the transcripts as elements.
The elements were written using the respondents' language in the right hand margin of the transcript. The elements were then clustered to form conceptual themes, reducing the number of units to be worked with. Care was taken to stay grounded in the original transcripts by using verbatim quotations in the analysis process. Memos were also used by recording ideas that came to mind during the coding process in the left hand margin of the transcript. A coded transcript is provided as an example (see Appendix K). Upon completion of coding, themes were referred back to the statements in the transcripts. Themes which were unique to a particular interview were not ignored but were recorded separately. Finally, the themes were organized to present an overall understanding of the data. An examination of each respondent's PSS score, demographic profile and caregiving situation was conducted in an attempt to identify connections and contribute to addressing the research question. Information from the evaluation forms were reviewed, collated and used to identify similarities/differences between what respondents as a group wrote and what was later stated in the interviews.
Summary

In this chapter, the support group program that was the focus of the study was described as well as the rationale for use of qualitative and quantitative research methods to conduct the study. The level of design for the study was an exploratory-descriptive design. The sample of family caregivers was recruited from Holy Family Hospital using a method of purposeful sampling. The instruments used to collect data included the PSS, a demographic profile, an in-depth interview using a semi-structured interview guide, and a group evaluation form. Calculations were performed on the data obtained from the PSS to determine changes in the respondents' perceived stress score. A modified grounded theory approach was used in the qualitative analysis of the interview data. Permission to conduct the study was granted by the Research Committee at Holy Family Hospital and the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies involving Human Subjects. Ethical considerations were attended to throughout the study.

In the following chapter, the findings of the study are presented.
Chapter Five
Presentation of Findings

Introduction

In this chapter, the sociodemographic characteristics of the sample will be presented and discussed. The findings from the in-depth interviews, the PSS and the evaluation form will then be presented.

Sociodemographic Characteristics of the Sample

The sociodemographic characteristics of the respondents are detailed in Table 1. The respondents ranged in age from 52 to 73 years, were predominately female and all were married. The relationship to the care receiver was either as a spouse or adult child. Three out of eight respondents had been providing 24-hour care. Only one respondent held a job at the same time.

The care receivers were between the ages of 65 and 87 years with the exception of one care receiver being 55 years old. Half of the care receivers were female and half were male. The majority were married and the remaining were widowed. Most of the care receivers had suffered strokes, with only two experiencing other disabilities (hip surgery related to arthritis). Five of the care receivers were currently in hospital and three were outpatients of Holy Family Hospital. The sociodemographic characteristics of the respondents and care receivers are summarized in Table 2.
<table>
<thead>
<tr>
<th><strong>Caregiver Characteristics</strong></th>
<th><strong>Respondent #1</strong></th>
<th><strong>Respondent #2</strong></th>
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<tr>
<td>Relation to Care Receiver</td>
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<td>Adult Child</td>
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<tr>
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<tr>
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<table>
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### TABLE 1
Continued

Sociodemographic Characteristics of the Sample

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</table>

<p>| Care Receiver Characteristics                      | 68            | 87            |
| <strong>Age</strong>                                            | Male          | Female        |
| <strong>Gender</strong>                                         | Married       | Widowed       |
| <strong>Marital Status</strong>                                 | Stroke        | Stroke        |
| <strong>Type of Disability</strong>                             | Inpatient     | Outpatient    |
| <strong>Connection to Hospital</strong>                         |               |               |</p>
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</tr>
<tr>
<td>Connection to Hospital</td>
<td>Inpatient</td>
<td>Outpatient</td>
</tr>
<tr>
<td>Caregiver Characteristics</td>
<td>Respondent #7</td>
<td>Respondent #8</td>
</tr>
<tr>
<td>-----------------------------------</td>
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</tr>
<tr>
<td>Age</td>
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<td>55</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married</td>
<td>Married</td>
</tr>
<tr>
<td>Relation to Care Receiver</td>
<td>Adult Child</td>
<td>Spouse</td>
</tr>
<tr>
<td>Length of Time as a Caregiver</td>
<td>3 months</td>
<td>1 year</td>
</tr>
<tr>
<td>No. of Hours/Day Providing Care</td>
<td>3 hours</td>
<td>24 hours</td>
</tr>
<tr>
<td>Employment Status</td>
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<td>Not employed</td>
</tr>
</tbody>
</table>

<p>| Care Receiver Characteristics     |               |               |
| Age                               | 72            | 55            |
| Gender                            | Female        | Male          |
| Marital Status                    | Widowed       | Married       |
| Type of Disability                | Hip surgery   | Stroke        |
| Connection to Hospital            | Inpatient     | Outpatient    |</p>
<table>
<thead>
<tr>
<th><strong>Caregivers</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>52-73 years of age</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>7 females and 1 male</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td>Married</td>
</tr>
<tr>
<td><strong>Relation to Care Receiver</strong></td>
<td>5 spouses and 3 adult children</td>
</tr>
<tr>
<td><strong>Length of time as a Caregiver</strong></td>
<td>7 providing care &gt; six months 1 providing care for 6 years</td>
</tr>
<tr>
<td><strong>No. of Hours/Day Providing Care</strong></td>
<td>1 hour to 24 hour care 3 provide 24 hour care</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td>4 retired 3 unemployed 1 employed full-time</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th><strong>Care Receivers</strong></th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>55-87 years of age</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>4 females and 4 males</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td>5 married and 3 widowed</td>
</tr>
<tr>
<td><strong>Type of Disability</strong></td>
<td>6 Stroke and 2 hip surgery</td>
</tr>
<tr>
<td><strong>Connection to Hospital</strong></td>
<td>5 inpatient and 3 outpatient</td>
</tr>
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</table>
It is interesting to note that for care receivers who were married, their spouse was the primary caregiver. For care receivers who were widowed, adult children were the primary caregivers and in each of these cases, the caregiver was a daughter. This sample accurately reflects the literature with respect to describing family caregivers (Brody, 1990; Horowitz, 1985; Stoller, 1983).

Qualitative Analysis of Interviews

From analysis of the interview data, themes emerged and yielded six stages which contribute to understanding of the caregiving experience. The order of the stages reflect the natural progression respondents took in sharing their caregiving experiences. The stages and associated major themes are presented in Table 3. For clarity, each stage is more fully described by highlighting the major themes and elements that comprise each stage and by using excerpts from the interview data as examples.

STAGE: Contributing Factors To Caregiver Stress

Throughout the interview and in response to inquiries regarding difficult parts of the caregiving job, several themes surfaced as contributing factors to stress including care receivers' behavior, care receivers' disability and need for continuous care, provision of physical, emotional and instrumental support, concern for the future, decision making, and competing responsibilities.
<table>
<thead>
<tr>
<th>Stage: Contributing factors to caregiver stress</th>
<th>Themes: Care receivers' behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Care receivers' disability</td>
</tr>
<tr>
<td></td>
<td>Continuous care</td>
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<tr>
<td></td>
<td>Provision of physical, emotional and instrumental support</td>
</tr>
<tr>
<td></td>
<td>Caregivers' concern for the future</td>
</tr>
<tr>
<td></td>
<td>Responsibility for decisions</td>
</tr>
<tr>
<td></td>
<td>Competing responsibilities</td>
</tr>
</tbody>
</table>

| Stage: Effects of caregiving on the caregiver | Themes: Physical effects of caregiving |
|                                               | Social effects of caregiving    |
|                                               | Emotional reaction related to caregiving |

| Stage: Support systems and coping mechanisms | Themes: Importance of family as a support |
|                                             | Caregiver group as a support |
|                                             | Cognitive ways of coping      |

<table>
<thead>
<tr>
<th>Stage: The group experience</th>
<th>Themes: Informative and educational</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Supportive</td>
</tr>
</tbody>
</table>

| Stage: Effects on the caregiver as a result of group participation | Themes: Increased insight into caregiving |
|                                                                  | Cognitive changes in coping with caregiving |
|                                                                  | Caregivers' behavioral changes            |
|                                                                  | Minimal change in perceived stress        |

| Stage: Caregivers' individual and situational variables | Themes: Health |
|                                                        | Income       |
|                                                        | Social support |
|                                                        | Nature of prior relationship with care receiver |
**Theme: Care receivers’ behavior**

The respondents reported various characteristics of the care receiver’s behavior as being particularly difficult. While some behaviors were a result of the disability, others were related to the care receivers’ adjustment process. Behaviors included crying, ignoring the caregiver, resistance to accepting services, lack of communication, being demanding, mood swings, poor memory, verbal repetition, and complaining. As an example:

He could sort of ignore me or do whatever he feels like. So it is sometimes hard to accept that when I am there, he'll listen to his record and read a book at the same time. (R1)

But now it is a wave...we are on an upper. He laughs and smiles and he giggles and I don’t know how long it is going to last. I never know from one day to the next what to expect. (R6)

She doesn't remember because her mind has been affected by the stroke. Ten or fifteen minutes and she is calling me again. She's like a record that's being played over and over again. It just drives me up the wall. (R4)

**Theme: Care receivers’ disability**

The respondents shared difficult experiences related specifically to functional limitations of their care receivers resulting from the chronic disabling illness. As an example:

Waiting for him to find the word. I'm in a hurry and he's right away upset. It's the difficulty there of expressing what he wants. (R3)
I am petrified all the time. I live in the fear that he is going to take the wrong step and fall. (R6)

Tomorrow is the last day [of therapy] for him. I think they cannot make him improve. He's not improving as much as they want and so they're going to stop. (R8)

Theme: Continuous Care

The respondents clearly indicated the time-consuming and intensive nature of providing care by describing themselves as being needed on a daily basis, 24 hours/day, providing constant and total care often with few or no breaks. As an example:

The actual caregiver in the small even minute-to-minute or hour-to-hour needs of the person who needs care. (R1)

I'd say it is a 24-hour helpmate, to be there. (R3)

It's really a total looking after a person who is not able to do so himself. (R4)

And I'll stay [up] late purposely...from 10:00pm - 1:00pm so he can go to the washroom...then he will not wake up again...then I feel safe to sleep. He is under my supervision for 24 hours...I become tired of all day long taking care of him. (R8)

Theme: Provision of physical, emotional and instrumental support

In discussing their roles as caregivers, the respondents revealed the many demands faced in meeting the needs of care receivers, including physical support (ie. helping with a bath, brushing teeth, lifting a wheelchair, assisting with walking and
movement, helping with exercises), emotional support (ie. providing reassurance, moral support and encouragement, dealing with care receivers' depression, adjustment issues and acceptance of disability), and instrumental support (ie. household management, meal preparation, bill payment, transportation, making doctor appointments). As an example:

When he wakes up, I have to brush his teeth, wash his face. If I have to take him to the doctor's, I have to change him, then before that I have to feed him breakfast...lunch and dinner. I have to cook special meal for him. (R8)

It is going to be a major thing now because she is realizing, it's four months...when am I getting better and I think this is a stage when there's going to be real depression setting in. (R4)

I feel we just gotta just keep giving them hope. (R1)

When I looked at that handout you gave us of all the tasks [that need to be done] and it was me, me, me! (R6)

**Theme: Caregivers' concern for the future**

Concern for the future in many respects was prevalent throughout each interview. Respondents shared concerns regarding the care receiver's mental well-being, physical abilities and future deterioration. References to general and pervasive worry about the future and feelings of uncertainty were common. As an example:
Course we don't know what he will be capable of when he comes home yet...I mean I think I know what it will be like, right, but I don't know for sure...So this is sort of in the back of your mind, if he has another stroke. (R1)

Going up and down the stairs worries me. Her being in the situation that she is with my sister-in-law is another problem that I worry about. Her being left alone at night...Worry and concern about how things will work out...The thought of taking care of her as closely as I do now. (R7)

Just worrying about my wife... and I am concerned about her. Well, I don't want her to have a relapse or die, quite frankly. (R5)

You know, you don't want to be worrying about it but there again, at night, it come flitting into your mind...and I say you silly old lady, what are you worrying for. Leave it for tomorrow. Well that is easier said than done. (R3)

Theme: Responsibility for decisions

The interview data revealed that caregivers were often faced with a variety of decisions, many of which they have never encountered before. Often the sole responsibility for making decisions seemed to accompany their role and added to their struggle. As an example:

We should find an apartment...Yesterday we talked about it and he did say he didn't want to [move] but I might have to go ahead and just do something...I can see some difficulty arising when a decision has to be made. (R1)

I give it alot of thought but I can't come to a decision or I haven't so far, I haven't acted. More and more it looks as if mom will have to be placed in a care facility. And it looks like a situation where the ship is sinking and the life raft can only take so
much and who goes in and who doesn’t. That kind of a situation and it looks as if I will have to call the shots. (R4)

Theme: Competing responsibilities

A majority of the respondents discussed previously held responsibilities that were now competing with caregiving responsibilities for their time and attention. Most commonly such responsibilities included spouse/children, other aging parents and work. As an example:

And then I have my husband’s mother. She lives alone, she’s going to be 84 in March, so...my husband is an only son, so you know we’re sort of looking after her as well. (R2)

You have to handle your own family as well and look after their needs, and you have a job. (R7)

To summarize, the themes identified in the interview data indicate several factors that place demands on caregivers, contributing to significant lifestyle changes and to the experience of caregiver stress. The effects of providing care on the caregiver grew naturally from the discussion and formed the next stage.

STAGE: Effects Of Caregiving On The Caregiver

Evidence of significant and often long lasting effects of caregiving on the caregivers was overwhelming. The effects of caregiving varied for each caregiver in type, number and
intensity yet certainly did exist to some extent for all. The consequences indicated by the respondents were clustered into themes of physical, social and emotional effects of caregiving.

Theme: Physical effects of caregiving

Physical effects of caregiving referred to physical exhaustion, general aches and pains, neglected personal care, and loss of weight. As an example:

I was doing everything and I was really getting snowed under and very tired physically. (R7)

...nerves, I’d lost weight, you know, and naturally you lose weight because I wasn’t making meals three times a day, I was here [at the hospital]. (R6)

[I am] nursing elbow joints and back pain right now...I kinda feel run down all the time...I know I have lost a few pounds...and I’m kind of constipated to some extent because I don’t have a quiet time. (R4)

I have become very exhausted...I was losing alot of hair. Big patches, the largest ones were larger than a loonie...My stress, I couldn’t eat. I had no time to eat. (R8)

Theme: Social effects of caregiving

The social effects of caregiving referred to decreased hobbies, little time for exercise, no personal time or family time, feeling housebound and having no social life. As an example:

The social life is gone zero now for us (referring to her husband)....Haven’t got a thing right now. No hobbies. No going out...It becomes impossible to have a little chat on the phone. (R4)
I can’t go fishing, or gardening or play bridge like I used to do. (R5)

Our sort of social life, we had an active social life, well, now it’s sort of down to almost nil...I mean we are always at home. (R6)

I cannot even go out with my friends, you know. He would not feel comfortable if he stays too long with my friends and my friends will not feel comfortable for, you know, neglecting him, not talking to him. Then who wants to go out with me again. (R8)

Theme: Emotional reaction related to caregiving

The interview data revealed the range and mix of emotions evoked by the caregiving experience including hope and optimism, isolation and self-pity, worry, nervousness, feelings of resignation and guilt. As an example:

Gives you heart...It sort of gives you hope, you know, that perhaps as time goes on, he’ll get stronger....I just feel a bit sorry for myself I guess...But sometimes I feel that something comes up and I am not handling it. (R1)

No matter what I did, nothing would satisfy him and then he would sort of wave me off and that is when I would get upset. I think oh I don’t know if I can handle this. It is like a rejection...I’ve never, never experienced being weakened like this, you know, just bat his eye, and I could cry. Mind you maybe its seeing him like that too, you know, it’s shocking. I just feel bad to see him like that. (R6)

The guilt won’t go away I find, whether I just continue living the present way or whether I put mother in a care facility, there is guilt one way or the other. Guilt
now because I feel I am leaving my husband on his own alot or if I put mom in there, I feel sad because I put her in there so the guilt part sits heavily. (R4)

In sum, respondents reported physical, social and emotional effects related to the incumbent demands and stresses of their caregiving role. Support systems of the respondents and their ways of coping with the challenges of caregiving tended to follow and formed the next stage.

STAGE: Support Systems And Coping Mechanisms

Analysis of the interview data revealed several themes which indicated sources of support and coping mechanisms for respondents in the caregiver role. More specifically, the importance of having other family members and the value of attending the caregiver support group were referred to frequently as well as cognitive ways of coping with their situations.

Theme: The importance of having family as a support

Though referred to somewhat differently, the value of support from other family members in the caregiving endeavour was addressed by each respondent. Some recognized the value of family by acknowledging their family members as assets while others pointed out their misfortune in the absence of family support. Support from family members referred mostly to emotional support but also to instrumental assistance. As an example:
We don’t have any relatives here, see cause that makes a difference too. Not having any relatives here...But when things are not going well, all of a sudden you are aware that you don’t have...anyone like that to call on. (R1)

I feel for some of them there that have nobody and I do have that lifeline with my family...So they were a wonderful source of strength. (R3)

...if I needed help, a phone call. That’s all it would take and they would be there. I would just have to say I need you and they would be there...Cause if I feel sort of down and I want to talk, she listens. So it is really good. (R6)

**Theme: Caregiver group as a support**

In discussing the reasons for attending the caregiver group, conversations indicated that the group provided an opportunity to learn about caregiving and to be supported in the caregiving effort. More specifically, the group environment decreased the respondents’ sense of isolation and allowed for the learning of resources, how to cope and provide care. As an example:

Sort of for the support...perhaps to hear what other people were going through or maybe gone through...To know that you are not alone because I did feel very much alone. I didn’t know anybody who was going through the same thing so you are really completely on your own. So it was nice to have a group where you were all having the same problems...and to hear some of the things I hadn’t thought of...and it was nice to hear that one man whose wife was improving. (R1)

I knew I would be a caregiver 24 hours ...and I wanted to learn and see what there was out there for help and how other managed and it
has helped. But it was more to listen to others...now I am so close to it, it has helped quite a bit. (R3)

Not being in this position before, I didn’t really know what was expected of me and I felt by attending the seminars that you’d get some sort of idea of what is expected of you and what you should expect of him. (R6)

I wanted to find out and make sure I was doing the right thing. It makes you feel a little better that you’re not alone in that group. (R5)

**Theme: Cognitive ways of coping**

The interview data revealed that, in coping with their caregiving situations, the respondents employed cognitive methods of coping. More specifically, respondents indicated attempts at accepting the things they could not change and reframing the situation more positively. Taking one day at a time and having an understanding of the illness was also useful. As an example:

You know you think we’ll never be able to do this or that but when you really think about it, it’s not really that important. It is just the road that has changed and it is not necessarily bad. (R3)

I tried to handle to the stress as philosophically as possible...to say that that is the nature of the illness and therefore I shouldn’t get annoyed. (R4)

While friends, formal supports (ie. homemaking help), and religion were mentioned by some as playing a part in their support system, an emphasis on family support, support group involvement and cognitive coping mechanisms were of more
significance to the respondents.

STAGE: The Group Experience

It was interesting to find that throughout the interviews respondents continually made reference to the experience of being in a caregiver group. The comments represented two themes, indicating the group experience to have been informative/educational and supportive.

Theme: Informative and educational

The respondents indicated that the group experience was beneficial because of the information shared regarding resources and caregiving issues in general. As an example:

I think it is educational. The different ideas and where to get different things, resources that could help you. (R1)

I found the group interesting. Problems varied and sharing of ideas. (R3)

Well, you sort of learn that maybe one way of doing something could be more beneficial to do it another way and somebody in the group has suggested this, so therefore you feel, well yes I have learned something. (R6)

...because you have given some places, names for us to get in touch with if we need to. (R8)

Theme: Supportive

A pervasive theme among the respondents was with regards to the support that was received and felt within the group. The word 'supportive' was used by the respondents as they described feeling less isolated and reassured. Also, they heard
experiences of others that were similar to their own, comparing and relating to others, and normalizing their feelings.

As an example:

It felt [good] to know that everybody there was involved in the same sort of problems. And so it felt good to know that you were not alone. Well it was support to know that there are other people who are going through exactly the same or almost exactly the same as what you are going through. (R1)

To see someone else and be able to say, you know, I was like that last week. and you can empathize with them. That is comforting. You don't mind talking about things because you know that either somebody's experiences the feeling or had it before or say they might get to feel like that too. I think it is very good when we are all in the same boat. (R3)

I felt like I had gotten away from it for awhile. And sharing similar situations and problems helped that's for sure. (R7)

...realized just the role of the caregiver and I found that possibly, part of it, I was doing right. (R6)

The fact that there are other people doing exactly the same thing that I was, looking after patients, and that they were surviving and I was going to survive too. (R5)

Overall, the themes that evolved regarding the group experience were positive and indicated satisfaction among respondents.

STAGE: Effects On The Caregiver As A Result Of Group Participation

Interview data revealed respondents' perceptions of the effects of participating in the support group. The themes that
emerged referred to an increase in insight, cognitive changes in coping and behavioral changes.

**Theme: Increased insight into caregiving**

One effect of participating in the caregiver group for the respondents was a better understanding of the caregiver role, recognition of how providing care effects each of them, and their limits in providing care. Respondents also stated having gained a greater awareness, feeling more informed and prepared. As an example:

I am more aware of what could happen and how things could be. Having that information, it won’t seem so bad when something happens that I don’t understand or can’t do anything about. Because I have the information that caregivers can get into different emotional states. So hopefully having that knowledge, I won’t feel bad about it, at least I’ll know that this could be fairly normal or acceptable. (R1)

I guess I was a little afraid of or not exactly afraid but the fear of the unknown but because now I am more aware of what it is all about. And I believe that has been very effective. (R3)

It’s a full-time job...I really just can’t pull you up and down the stairs...I don’t know if I could have my mom live with me full-time. I know I think it would be a big strain on me. I guess I’m starting to realize well you know actually I’m doing her a favor. (R2)

I understand his plight a lot better. (R6)

**Theme: Cognitive changes in coping with caregiving**

When questioned about changes that resulted from attending the group, responses indicated the development of different
perspectives to cope more effectively with their caregiving situation. Such cognitive reframing included a more positive outlook on caregiving, increased sense of confidence, a willingness to take one day at a time and acknowledgement of the caregiver having needs to be fulfilled. As an example:

I think I see it in a more positive light now because hearing the group talk and how some people were finding it really a [positive experience]. So it was nice to hear the different positives. So I think the positive things helped me a lot. (R1)

I think I ended up with more confidence. I’ve accepted it. And that helps too, you know, because you just have to sort of anticipate what could happen and what you want to do, and try to do some planning for it. (R5)

It really helped a lot because I decided that I am not as bad off as the other ladies...I don’t think of it as stress anymore. I just figure I am going to help him period...But just facing it day to day. I don’t get hyper anymore. At one time I’d get excited because I didn’t do something right. But now I don’t. I think, hey I gotta live too. (R6)

You realize that maybe I should feel that way (relaxed) too. I’m not going to solve all the problems whether I carry them on my shoulders or not. (R7)

It has been a little easier to say... allow myself to come to this decision of putting her into a care facility and that decision was very hard for me to come to. (R4)

But before you can come to that positive, you have to go through this stress and negative and then you can say ‘what’s the point’. (R7)

Theme: Caregivers’ behavioral changes
The respondents spoke of changes in how they would perform
their caregiving duties and in coping with their situation. Changes included asking for help, using resources, better communication, and encouraging the care receivers' independence (i.e. decreasing caregiver's tasks). Most prevalent though were comments about how they would better take care of themselves as a result of discussions in the group. As an example:

Trying to look after myself a little bit better. And asking for help. (R1)

It certainly reinforced looking after yourself...and those words have helped me formulate what I should do. (R4)

I think I would talk to [mother] more about it and explain, and really be honest with her and involve her in whatever we're thinking of doing. (R2)

You have to start asking for help. You have to open up and we can't do everything perfectly. I have started to realize ...that you just have to let go. So I found that it did help as I reflected back to the meetings and listening to some of the others. (R3)

I liked that the caring for myself emphasized the need to take care of myself. And I'm going to see our G.P. and I'd even deferred seeing our dentist and I'm going to see him next week and that is part of the reason. (R5)

...if I were doing something and sort of had the opportunity to discuss it with the group then you go home sort of aligned with the idea and let's try it this way...Now I am trying to make him independent. I feel better that I'm .helping him to try and be independent. (R6)

Theme: Minimal change in perceived stress

In response to queries regarding changes in perceptions of
their stress as a result of group participation, respondents indicated minimal or no differences in their experience of stress. As an example:

I am not really sure it has made that much difference with regards to stress. Mainly because I still look to prayer to relieve stress. I get a great peace with prayer and so I am not sure, it could have, I'm just not sure. (R1)

No, it is just that I think my nerves may be a bit worse then when I first joined because I am getting more of the caregiver job as he'll be coming home soon. (R3)

Despite the respondents' reports of acquired insights, cognitive changes in coping and behavioral changes, the respondents reported little or no change in their perception of stress related to caregiving. Descriptions of the final stage, the caregivers' individual and situational variables, provides some insight into this finding.

STAGE: Caregivers' Individual And Situational Variables

While respondents were similar in that they all were providing care to a chronically ill relative, the interview data revealed individual differences among them which made each situation unique. The caregivers' individual and situational variables effect each of the previous stages and included health, income, social support, nature of prior relationship with care receiver, generational and cultural expectations, and appraisal of situation.

As an example:
So much has to do with my physical you understand. Cause when you feel well you can handle everything. I mean when I feel well I am thinking of all the things I want to do. (R1)

So I thank G-d that I've got these women (referring to her daughters) around that, as nuisance as they are sometimes, all I have to do is say hi and they say what is the matter. They are there for me. (R3)

...the situation that she is in [with my sister-in-law] that's quite a pressure, quite stressful. (R7)

I mean we have been together for 48 years so there is no way that our life could be separated...we're both in it together. (R3)

I know that he loves me, he appreciates what I'm doing for him. He said I'm the best wife he has! (R8)

Now my problem is, if I don't work I will have financial problems but if I work, who will have him...and I'm afraid if this keeps on longer I might also have a nervous breakdown. (R8)

Because mom is the last of the seniors in our family. All the others have passed away and because she is the last and of course we have aged in the meantime, she gets the short end of the stick I feel. (R4)

Borne from the qualitative analysis of the interview data, an understanding and conceptualization of the caregiving experience, caregiver stress and the effects of support group involvement on stress developed. Elements clustered into themes which formed the presented stages. Findings indicate the existence of many contributing factors to caregiver stress and the various effects of caregiving on the caregiver. The
interview data revealed the importance of support systems in coping with the challenges of providing care. Moreover, the findings highlight the benefits derived from participating in a caregiver support group despite little or no change in perception of stress related to caregiving.

Quantitative analysis of PSS

The respondents pre-and post-group scores from the PSS were tabulated and are presented in Table 4. To further illustrate the data from the PSS, the scores have been transposed into a bar graph in Figure 3.

While the PSS is not a measure of psychological symptomatology, the scores do provide insight into assessing respondents' perception of their stress with a higher score indicating higher level of stress (Cohen et al., 1983; Cohen & Williamson, 1988). The scores for the group as a whole ranged from 21 to 33 (highest possible score - 56). Three respondents' scores increased following the group program, three respondents' scores decreased following the group, and two respondents' scores remained the same. For those three respondents whose scores decreased, the scores decreased by two points. For the three respondents' whose scores increased, the scores increased by four, two and five points respectively.
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<th>Perceived Stress Score</th>
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</tr>
<tr>
<td>5</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td>6</td>
<td>21</td>
<td>21</td>
</tr>
<tr>
<td>7</td>
<td>24</td>
<td>26</td>
</tr>
<tr>
<td>8</td>
<td>22</td>
<td>27</td>
</tr>
</tbody>
</table>
Figure 3

Bar Graph of Respondents' Perceived Stress Scores
Linking Qualitative and Quantitative Data

For each respondent, the quantitative data (scores from PSS) and significant aspects of the qualitative data (demographic, individual and situational information elicited during the interviews) were matched and are presented in Table 5.

In Table 5, the qualitative data provides possible explanations for the respondents' PSS scores, further corroborating the results of the PSS.

Support Group Evaluation Form

The evaluation form was completed by each respondent at the end of the final session of the group program. Completion of the evaluation form was not uniform in that not all respondents addressed each question as fully as others. Regardless, the feedback received was informative to the study as it provided an opportunity to examine the fit between responses on the evaluation form with responses during the interview. While no additional themes were revealed, the comments on the evaluation form did reinforce the themes which emerged from the interviews. Comments elicited on the evaluation form were collated and are presented in Table 6.
<table>
<thead>
<tr>
<th>Respondent</th>
<th>Perceived Stress Score Before Group/After Group</th>
<th>Interview Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>24/28</td>
<td>Caregiver was physically unwell, had few family supports, perceived little control over her situation, and had attended a hospital meeting regarding her care receiver in which a poor prognosis was given.</td>
</tr>
<tr>
<td>2</td>
<td>25/23</td>
<td>Caregiver was well supported by family, with shared decision making. Care receiver's health was improving and was described as a reasonable and understanding person. Home support services were readily accepted by the care receiver. Caregiver now felt choices made were appropriate.</td>
</tr>
<tr>
<td>3</td>
<td>23/21</td>
<td>Care receiver was still progressing in therapy. Caregiver had a very good relationship with care receiver and a strong sense of family support. Felt the group prepared her for the future.</td>
</tr>
<tr>
<td>4</td>
<td>24/22</td>
<td>Caregiver stated she felt she had explored every option available and that the group assisted her in working through the decision of facility care for her care receiver.</td>
</tr>
</tbody>
</table>
### TABLE 5
Findings from the PSS and Interviews

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Perceived Stress Score Before Group/After Group</th>
<th>Interview Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>33/33</td>
<td>Care receiver had made a good recovery. He spoke of confidence in providing care and takes his caregiving responsibilities seriously. Very strong attachment to care receiver.</td>
</tr>
<tr>
<td>6</td>
<td>21/21</td>
<td>Had care receiver home for a period of time and had established routines that were working well. Came to the group for affirmation of what she was doing.</td>
</tr>
<tr>
<td>7</td>
<td>24/26</td>
<td>Family feud was escalating. Caregiver's husband had unexpected operation. Care receiver was ready for discharge and would be living with caregiver temporarily.</td>
</tr>
<tr>
<td>8</td>
<td>22/27</td>
<td>Care receiver was no longer improving and soon to be discharged. Caregiver was providing 24 hour care with little family or homemaking support. Financial concerns were mounting.</td>
</tr>
</tbody>
</table>
TABLE 6
Summary of Support Group Evaluation Form

1. Please circle the number that best reflects your opinion of this program.
   • 3 circled 'Liked somewhat'
   • 5 circled 'Liked very much—I learned a lot!'

2. If you had a friend who was a caregiver, would you recommend the program?
   • Yes, to help a caregiver by letting him/her know of a possible resource.
   • Yes, a better understanding of stress.
   • Yes, I think it's very informative and helpful.
   • Yes, it improves caregiving.
   • Yes, to learn how to cope.

3. Has this program changed the way you feel about caregiving?
   • Yes, I realize how lucky I am.
   • Yes, I have more understanding of the different issues.
   • Yes, more prepared, more informed.
   • Yes, now I know I am not the only one in this situation but there are so many like me.
   • Yes, understanding the disabled party.
   • No, there are no simple answers and decisions are still a big worry.

4. Will you do things differently as a result of participating in the group?
   • Yes, take more time for myself and my family.
   • Yes, understanding, find a distraction.
   • Yes, I'll try to get help and give myself a little treat sometimes.
   • Yes, be more accepting of the program.
   • Yes, ask for help.
   • Yes, be more communicative.

5. Do you use anything you learned now?
   • Yes, improved communication.
   • Yes, being more understanding.
   • Yes, patience.
   • Yes, I'll try to accept the fact that the situation I am in now is somewhat out of my control. I'll just have to learn not to blame anybody.
6. Will you use anything you learned in the future?
   • Yes, not to feel guilty about myself.
   • Yes, take some time for myself, to be more balanced in coping with the situation.
   • Yes, caring for myself. (2 responses)
   • Yes, resources that we can get assistance.
   • Yes, not being afraid to ask for help whatever the case may be.
   • Maybe, one has to be strong and tough emotionally to face the realities of life.

7. Which parts of the program would you like to see more time spent on?
   • counselling for caregivers
   • healthy communication
   • keep as is
   • different ways to reduce stress
   • the experiences of caregivers

8. If we have to cut some things out of this program, what should we cut?
   • Nothing cut, just maybe shorten each topic a little.

General comments:

• I think it is an excellent program, especially when we talk about our particular problem and [the leader] or a member of the group gives his or her idea.

• Thank you for providing a sitter for my mother. Without this help, I would not have been able to attend these sessions.

• I appreciated the concern for caregivers and the effort to improve them.

• This has been a very helpful, informative series of meetings and I feel I gained insights into my situation I wouldn’t have otherwise.

• I like this program because people in the class were so willing to share the difficulties they are having with the persons they are caring for. That made me feel that I am not alone in this.

• Sharing our thoughts gives me some piece of mind. Sharing and caring are hand in hand.

• This program is beneficial - helps to understand both sides of illness. I now have a better outlook in accepting day to day problems and able to cope.
In the chapter to follow, the findings presented will be discussed in relation to the preceding literature review (Chapter 2) and the theoretical framework (Chapter 3).
Chapter Six
Discussion of Findings

Introduction

The following discussion will address the findings from the interviews, the PSS, the information yielded from the marriage between the two, and the evaluation form. The findings are presented in relation to the theoretical framework and related theories, relevant studies, and methodological issues.

A Conceptualization of Caregiver Stress and the Effects of Support Group Involvement on Stress

From the analysis of the interview data and the PSS scores, a conceptualization of caregiver stress and the effects of support group involvement on stress emerged and is presented in Figure 4. The conceptualization is useful in illustrating the findings of the study and in making linkages to the theoretical framework.

The conceptualization is comprised of stages constructed from the major themes uncovered in the interview data and is influenced by the findings of the PSS and the evaluation form. The understanding begins with the identification of contributing factors to stress as perceived by the caregivers and the various effects of caregiving on the caregiver. Support systems provide insight on coping mechanisms and influences the contributing factors to stress and the effects of caregiving on the caregiver. The experience of participating in a caregiver support group and
Figure 4
A Conceptualization of Caregiver Stress and the Effects of Support Group Involvement

Adapted From: Caregiver Stress - Coping Model
Developed by Biegel, Sales & Schultz, 1991
the changes that result also influence the factors contributing to stress and the effects of caregiving on the caregiver. Finally, individual and situational variables affect each of the preceding stages.

Similarities exist between the conceptualization presented in Figure 4 and the theoretical framework presented in Figure 2 (Chapter 3). Contributing factors to stress are represented in both, however, the findings from the study indicate additional factors (concern for the future, responsibility for decisions, and competing responsibilities) as significantly contributing to stress. The various effects (physical, social and emotional) on the caregiver are also identified in the conceptualization and the theoretical framework. The importance of support systems and the impact on the caregiving experience is revealed in the conceptualization and certainly relates to the influence of family dimensions in the theoretical framework. Finally, the individual and situational variables as they affect each stage resemble the conditioning variables in the framework, and includes the appraisal component in the experience of stress.

The conceptualization informs the theoretical framework, drawing attention to the intervention of group work and illustrating how the group experience and the effects on participation relate back to the contributing factors to stress and the effects of caregiving on the caregiver. The findings as illustrated in the figure further inform the literature on caregiving as it demonstrates the interactive nature of the
process of caregiving.

Overall, the analysis reveals many similarities that exist between the conceptualization derived from the findings and the theoretical framework which guided the study. It also provides additional information regarding group work as an intervention and its role in the caregiving experience. While the conceptualization is useful in integrating and illustrating the findings in a general sense, a brief discussion of significant findings from each of the instruments is warranted.

**Interviews**

The findings from the interviews indicate links between the respondents' caregiving experience, the Caregiver Stress-Coping Model (the model previously presented in Chapter Three), and the caregiving literature. More specifically, the themes which emerged to represent contributing factors to caregiver stress (care receivers' behavior and disability, provision of continuous care, concern for the future, decision making and competing responsibilities, and the provision of physical, emotional and instrumental assistance) and effects of caregiving on the caregiver (physical, social and emotional effects) are well supported in the literature and are closely related to variables in the Caregiver Stress-Coping Model (Abel, 1990; Cantor, 1983; McCallion et al., 1994; Toseland et al., 1990). The themes which emerged to represent the group experience (informative, educational and supportive) are also found in the literature (Biegel et al., 1991; Toseland et al., 1989).
With respect to changes in perceived stress, the interview data reveals that respondents indicated minimal or no change in stress as a result of attending the support group program. This finding can be understood given respondents indication that they could not isolate the effects of the group on their experience of stress as other influences existed concurrently (i.e. increased family support, physician involvement). The modest change is also understandable as respondents described the many facets of the caregiving role, facets which are not static, are ever changing and effect the experience of stress (i.e. current physical status of the care receiver, caregiver's physical well-being, caregiving tasks required). Similarly identified in the theoretical framework, the importance of individual and situational variables on caregiving and the experience of stress is highlighted here. The finding further suggests that the effects of attending a support group are, in part, related to the timing of the support group for each individual.

As the respondents shared their stories, certain aspects of their experience were expressed more passionately, warranting acknowledgement as they provide further insight into the experience of caregiver stress. Consistent with the theoretical framework, strong emphasis on the importance of family members for support was made by each respondent. While friends as support and religion as a source of strength were mentioned, reliance on other family members (i.e. spouses, adult children, siblings) for emotional and instrumental assistance was
pervasive. Interestingly, of the eight respondents, only two caregivers utilized formal supports such as homemaking help, reinforcing reliance on themselves and other family members to meet the care receivers' and their own needs. This is consistent with the literature as studies cite high percentages of care to the elderly being provided by family members (Brubaker & Brubaker, 1992; Chappell, 1990).

Although not developed into themes due to too infrequent reports, two remarks each made by different respondents are noteworthy and relevant to caregiver stress. First, the respondents presented a sense of commitment to the care receiver and their caregiving role, placing the care receiver's needs first and then accommodating their own lives. While such a commitment often resulted in drastic lifestyle changes and affected them physically, socially and emotionally, a sense of duty and obligation prevailed. Another interesting comment was made by respondents as they described their caregiving experience. Respondents referred to the existence of stages or cycles of caregiving, commenting on the process of caregiving -- learning how to provide care and how to cope, feeling uneasy and unsure and then gaining experience and confidence, moving onto acceptance and creating new ways of living, anticipating future changes and altering established routines as care needs change. Both comments -- the sense of commitment in providing care and the process of caregiving itself -- suggest that some amount and type of stress appears to be inherent in the caregiving
experience. This finding, which is supported in the literature (Abel, 1990), must be recognised when examining the effects of an intervention with family caregivers.

**Perceived Stress Scale**

The findings from the PSS -- scores indicating no statistically significant change in perceived stress among respondents as a group -- are consistent with other studies that show that time-limited psychoeducational support interventions have modest therapeutic benefits with respect to stress (Beigel et al., 1990; Toseland & Rossiter, 1989; Zarit & Toseland, 1989).

The lack of significant change in the respondents' stress level may be related to the self-selected sample in that some participants in the group may have been less distressed and therefore less likely to experience changes in terms of stress as a result of the intervention program. Despite problems associated with caregiving, not all caregivers suffer high levels of stress (McCallion et al., 1994) and some seek assistance to learn about alternatives in the event their situation should become worse (Zarit & Toseland, 1989). As well, the chronicity of stressors needs to be considered in conjunction with expectations of changes that can reasonably occur with a brief intervention. There is a growing feeling that a time-limited group of less than 12 weeks is too brief a period to demonstrate significant effects (Brown, Cook & Magwood, 1993; Whitlatch et al., 1991). Finally, the reported minimal change in perceived stress by the respondents during the interview may be related to
a tendency for family caregivers to underreport the experience of stress on measures (Zarit & Toseland, 1989).

As presented, the findings from the PSS indicate the scores ranged from 21-33 with the three highest scores (average between pre- and post-group scores) belonging to Respondents 1, 5 and 8, each of which were spouses. This finding is consistent with the literature which states higher levels of stress are reported by spouses than other family caregivers (Miller, 1989). Lazarus & Folkman (1984) cite evidence that the greater the strength of satisfaction, the more vulnerable an individual is to psychological stress in the area of that commitment. This finding might suggest a positive connection between caregiver/care receiver relationship or involvement and stress, a suggestion also echoed in the theoretical framework.

**Linking the Findings from the Interview Data and PSS**

Combining the findings from the interviews with the findings from the PSS allows for further interpretation of the results. While respondents' during the interview stated minimal or no change in their stress as a result of participating in the support group, findings from the PSS indicate that some individual scores did in fact increase and decrease slightly. As an explanation to account for the discrepancies between the interviews and PSS for those individuals, one might consider the fact that the point change for each individual respondent was small and likely not significant enough for respondents to perceive a felt change in their stress as a result of
participating in the group. Another explanation may be that with the time lapse between completion of the PSS and the interview, recollection of the effects of the group may be less accurate. Similarly, during the time lapse, the respondents continued in their caregiving role, subjected to occurrences which may have influenced their perception of stress and the effect of the group experience.

Overall, the results noted from the PSS indicate some respondents reported slight increases, decreases or remained the same. While participation in the group may certainly have contributed to the results, these findings can probably best be understood in conjunction with the interview data and from the perspectives of the stress process and the role of individual and situational variables. Each forces attention on the relationships among the many conditions leading to caregiver stress, the way these relationships change over time, and an individual’s cognitive appraisal of the situation.

Evaluation Form

The findings from the evaluation form reveal comments that are similar to the themes identified in the interview data with respect to the group experience (i.e. supportive, informative, changes that have resulted). Despite the questions on the form not directly adhering to the interview guide and being unable to link each respondents’ interview data with his/her evaluation form, this finding increases the validity of the study. Of interest, while results indicate participation in the support
group did not change respondents' perceived level of stress verbally or as recorded on the PSS, the respondents did report a strong sense of satisfaction with the group both on the evaluation form and in the interviews. Several points bear influence on this finding. The respondents may be satisfied with the group for reasons that have nothing to do with felt changes in stress (Biegel et al., 1991). For instance, they may have felt grateful someone paid attention to their needs and showed interest in their problems. They may also have felt positive about the group experience because they value the organization sponsoring the group and/or staff working with the group.
Summary

The data and analysis of the interviews, PSS and evaluation form yielded the themes and stages which contributed to the development of a conceptualization of caregiver stress and the effects of support group involvement on the experience of stress. Presentation and discussion of the conceptualization (Figure 4) illustrates the usefulness of the study's findings in understanding group work as an intervention and its role in the caregiving experience.

Consistent with the literature, the results suggest that caregiver stress must not be thought of as an event but instead as a mix of circumstances and one that varies considerably among caregivers (Pearlin et al., 1990). Further, supplying caregivers with supportive relationships through support groups does not ensure they will feel changes in their experience of caregiver stress. Regardless of results which prove an increase or decrease in caregiver stress following group intervention, we must be mindful of the needs of caregivers and recognize the many potential benefits of group intervention other than stress reduction (Abel, 1990; Toseland et al., 1990).
Chapter Seven
Conclusions, Implications and Recommendations

Introduction

The purpose of this study was to examine the effects of a short-term support group on stress of family caregivers of hospitalized elderly, and to provide descriptive information on the caregiving experience. Conclusions, implications for social work practice and recommendations for further research are presented in this chapter.

Conclusions

This study has contributed to the existing knowledge base within the field of caregiving, addressing the paucity in the literature with respect to the effects of group interventions on stress with family caregivers in the hospital setting. The Caregiver Stress-Coping Model (Biegel et al., 1991) presented in Chapter Three, in combination with family systems thinking, stress theory and group work theory, provided a framework to organize the findings, to understand the individualized multifactored caregiving experience, and to facilitate the conceptualization of the effects of support group interventions on stress in the caregiving experience.

The conceptualization contributes to the Caregiver Stress-Coping Model as it introduces support group work as an intervention and illustrates the ways in which the intervention can potentially effect the caregiver and their experience of...
stress. It is an interactive model as each stage generates the next one and relates back to previous stages. The model identifies individual differences as a variable which influences the entire caregiving experience.

A word most accurately describing family caregivers is heterogeneity. Although certain trends characterize them as a group (i.e. mostly spouses and adult children) and certain themes describe the caregiving experience (i.e. demanding, time consuming, rewarding), differences abound. Caregiving is an individualized experience and is a process occurring over time with stress being a normative component in the experience and process. As demonstrated, caregiving is influenced by key characteristics of the caregiver, care receiver and the situation and the effects are threaded throughout the stress process.

This study has also contributed to the existing models of research methodology by demonstrating the utility of combining researcher and practitioner roles as well as qualitative and quantitative methods of data collection. The value of the study design including both qualitative and quantitative components is observed as the findings of each complement and corroborate the other. It is believed that this added validity to the study. The design provided different perspectives of the same reality, affording identification and reinforcement of a significant finding -- the importance of individual differences in the caregiving experience.
While the risk of bias was present, the advantages of blending the roles of researcher and practitioner are significant. Recruitment procedures were less onerous as the researcher had direct access to potential respondents. Being familiar with the problem area facilitated the qualitative interview process as the researcher could better design the interview guide, focus the interviews and perhaps grasp meaning more fully upon analysis. The social work background of the researcher was also beneficial as a balance was struck between the principles of rigorous investigation and a nurturing concern for respondent welfare.

As the aging process continues and as disease progresses, care needs of the care receiver are likely to increase. Logically, the health of an aging relative is beyond the influence of group intervention and therefore it is not unreasonable to discover that caregiver stress does not always decrease because of such interventions (Toseland, Rossiter & Labrecque, 1989). However, based on the presented literature review and the findings of this study, many worthwhile benefits are derived from support group interventions for family caregivers. Feeling supported and not isolated, gaining information and education on providing care, and learning how to cope are tools that assist caregivers in fulfilling their demanding and valuable role. Enabling family caregivers in their efforts also serves the health care system, contributing to a decrease in caregiver illness and in hospital and institutional
care of care receivers. In light of government financial restraints and fewer professional to deliver service, support groups are a useful intervention modality in meeting the needs of the many caregivers who require attention.

Implications for Social Work Practice

The findings of the study give credibility to planning intervention strategies that offer tangible assistance and emotional support to caregivers. From both a clinical practice and public policy perspective, social work has a role in developing effective interventions to meet the needs of caregivers. The findings from this study suggest the following implications for social work practice.

Clinical Practice

- The model, with its emphasis on individual differences, forces social workers to look more closely at the members coming into the group, be aware of what their needs are, and attend to those needs by trying to identify common ground among the group members. The model further influences practice as it illustrates potential areas to be effected by the group process, directing program content.

- As caregivers have different needs and issues, caregiver support groups may be more effective by targeting specific subgroups within the caregiver population (ie. spouses, adult children, men or women) and designing content accordingly.

- For the purpose of the research study, a pre-group meeting was held prior to the start of the caregiver support group
program. The meeting allowed the group leader the opportunity to begin to assessing participants' needs as well as provided participants with the opportunity to meet one another (decrease anxieties) and to be involved in the planning of the content. As the meeting was successful at fostering a sense of comfort and support prior to the group program, such pre-group meetings should be built into the program.

- Informal contact with respondents occurred following the study and while obviously not scientifically measured, an indication of their ongoing needs was present. Given the process of caregiving itself, a maintenance strategy (ie. monthly meetings, a caregiver buddy system, facilitation of peer-led/self-help meetings) should be considered following the cessation of the group program.

- Support groups are simply one link in the chain of activities to assist caregivers. Depending on the types of problems facing a caregiver, individual intervention may be more appropriate or required as well. Group work does not replace individual counselling as it cannot address the varied concerns and problems caregivers face.

- Recruitment of participants/respondents for the group/study raised a logistical problem, one that is likely often overlooked yet critical to caregivers. Caregivers who are providing care 24 hours/day have difficulty attending support groups. The issue of care for the care receiver to enable caregivers to attend support groups needs to be addressed (ie. day care programs, homemakers, volunteers) and efforts are required to identify the
best possible time and location for caregivers to attend support group programs.

**Public Policy**

Unfortunately Canadian social policy appears to rest somewhat on the ethos of individual responsibility for social problems and is very vulnerable to shifts in the economic climate. With respect to the care of the elderly, the family is considered the logical source for a solution. In order for family support to be practical, there is a need for formal support services for older adults and for family members who care for them beyond caregiver support groups. Support groups need to be thought of as a supplemental measure, not as an end in and of themselves. Findings from the study indicate formal supports were not used by caregivers to any significant extent. From this study, one can only speculate this might be related to eligibility criteria or insufficient services available. Regardless of the reasons, fewer supports available or used by family caregivers means a greater reliance on themselves. Advocacy is required to increase various forms of support to caregivers such as material (equipment) and financial aid, homemaking and respite services in the home, and temporary placement. Efforts are also needed to raise the visibility of caregivers and the value of their contributions.
Recommendations for Further Research

This study has only begun to examine caregiver support group programs in the hospital setting and further research is recommended. One area requiring attention is on specific sub-groups of caregivers in order to identify similarities and/or differences and potential value in offering sub-group specific support groups. Future research endeavors should also investigate important outcomes other than stress reduction such as improving coping skills, preventing depression, and increases in caregiver support systems. Similarly, research investigating the effects or effectiveness of group interventions should incorporate measures that take into account the goals that caregivers have for themselves. Finally, an area which appears to have received little attention yet is central to the caregiving experience is with the care receivers themselves. Perhaps a better understanding of their role in the caregiving relationship would help guide future interventions with caregivers.

Advances in medicine and modern technology have been successful in adding years to life. However, one might say that the family have a central role in adding life to those years. The essence of family caregiving problems and a potential solution is captured in the following statement:

Often one must tend the ground around the tree to keep it thriving. We may find ourselves best caring for the aged by caring for those who are important to the aged. (Ebersole & Hess, 1981, p. 342).
REFERENCES


APPENDIX A

VIDEO: "When The Day Comes"
National Film Board, 1991
(28 minutes)

The video presents four women each doing their best to tend to an elderly loved one. Their stories show how constant caregiving takes its toll. Fatigue, depression and isolation are identified as common symptoms and issues related to the general caregiving experience are explored. The video illustrates the urgent need to improve and expand government services.

HANDOUTS:

Week 1
• Suggested positive and negative aspects of a caregiver's task
• Changes to be achieved

Week 2
• Thermometers of caregiving
  Social manifestations of burnout
  Physical manifestations of burnout
  Emotional manifestations of burnout
  Self-denial aspects of burnout
• Beliefs and values
• Common sense approaches to managing stress

Week 3
• Caring for yourself
• Family plan for delegation

Week 4
• Strengths and weaknesses in one's communication
• Characteristics of bad communication
• Do's & Don'ts of health communication
• How do you cope with anger
• Recognition and management of anger
• How to help a friend or loved one
• Tips for dealing with an older adult at home
• Increasing your relative's safety at home
• Legal issues
• Relaxation techniques
• Resource information
• Reading list - Books on caregiving
Certificate of Approval

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR</th>
<th>DEPARTMENT</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stolar, G.E.</td>
<td>Social Work</td>
<td>B93-0786</td>
</tr>
</tbody>
</table>

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT

UBC. Campus

CO-INVESTIGATORS:

Book, E.; Social Work

SPONSORING AGENCIES

A course for caregivers: Group work as an intervention with family caregivers of hospitalized elderly

APPROVAL DATE: JAN 14 1994

TERM (YEARS): 3

AMENDED:

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Dr. R. Corteen
Dr. I. Franks, Associate Chairs

Dr. R. D. Spratley
Director, Research Services

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.
September 27, 1993

To Whom It May Concern:

Holy Family Hospital acknowledges the current enrolment of Elaine Book in the Master of Social Work degree program at the University of British Columbia.

Elaine Book's research proposal on the caregiver support group program has been reviewed and is supported as presented by Ms. Book. Pending approval by the University of British Columbia Ethics Committee, Holy Family Hospital will permit the research to be carried out at this facility. The Research Committee will require Ms. Book to obtain informed consent from each participant.

We are pleased to assist Ms. Book in her research endeavour.

Dr. I. V. Tsang
Chair, Research Committee
Holy Family Hospital

Mr. W. T. Frier
President
Holy Family Hospital
January 4, 1994

Dear:

Having a relative or friend in hospital can often be a confusing and stressful time. For this reason, the Social Work Department at Holy Family Hospital is offering a four week "Course for Caregivers". We would like to invite you to attend as many sessions as possible and to bring with you any concerns or questions.

WHEN: Tuesdays, January 25, February 1, 8 and 15

TIME: 4:30 to 6:00 p.m.

WHERE: Holy Family Hospital, Education Room Level I

WHO IS INVITED: Families and friends of rehabilitation patients (Patients will not attend)

WHAT ARE WE TALKING ABOUT:

January 25 The Caregiver Role
February 1 Excuse my unusual behaviour - It's only stress
February 8 When is it my time? Caring for yourself
February 15 Healthy Communication

As space is limited, please register by contacting Elaine Book at 321-2651.

Also, attached is a letter with details of a study on caregivers which we will be conducting.

If you have any questions, please feel free to contact us.

Elaine Book, BSW
321-2661, local 353

Dianne Watt, MSW
321-2661, local 348
Dear

My name is Elaine Book. I am a graduate student at the University of British Columbia, School of Social Work.

I would like to invite you to participate in a research study seeking to examine the effects of participation in the "Course for Caregivers" program at Holy Family Hospital.

I am interested in learning how participation in this group program has impacted your life as a caregiver. The purpose of this study is to better understand your experience which will help improve our knowledge and services in this area.

The research will be conducted by completing two questionnaires and an interview which will take approximately two hours of your time. Interviews will be audiotaped to ensure accuracy and will be erased upon completion of this project. All identifying information will be held in confidence by the researcher and identifiable individual responses will not appear in the final report.

Your participation in this project is completely voluntary. You may choose to withdraw at any time, and/or may choose not to answer any question. Your decision to participate will in no way affect services you may be receiving now or in the future from Holy Family Hospital.

Within three to four days of receiving this letter I will contact you by phone. Should you be interested in participating in the study, a brief meeting will be held on January 18, 1994 prior to the group beginning on January 25, 1994.

Should you have any questions or wish to contact me, please feel free to call me at 321-2661 or my thesis advisor Elaine Stolar at 822-2277.

Thank you for your time.

Sincerely,

Elaine Book
The questionnaire will ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

For each question, circle the number that corresponds with the following alternatives:

0 never
1 almost never
2 sometimes
3 fairly often
4 very often

1. In the last month, how often have you been upset because of something that happened unexpectedly?
   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?
   0 1 2 3 4

3. In the last month, how often have you felt nervous and "stressed"?
   0 1 2 3 4

4. In the last month, how often have you dealt successfully with irritating life hassles?
   0 1 2 3 4

5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?
   0 1 2 3 4

6. In the last month, how often have you felt confident about your ability to handle your personal problems?
   0 1 2 3 4

7. In the last month, how often have you felt things were going your way?
   0 1 2 3 4

8. In the last month, how often have you found that you could not cope with all the things that you had to do?
   0 1 2 3 4
9. In the last month, how often have you been able to control irritations in your life?
   0 1 2 3 4

10. In the last month, how often have you felt that you were on top of things?
    0 1 2 3 4

11. In the last month, how often have you been angered because of things that happened that were outside of you control?
    0 1 2 3 4

12. In the last month, how often have you found yourself thinking about things that you have to accomplish?
    0 1 2 3 4

13. In the last month, how often have you been able to control the way you spend your time?
    0 1 2 3 4

14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?
    0 1 2 3 4

Please record your birth date as an identification code.
___  ___  ___
day  mo.  yr.

Thank you for your cooperation and time.
APPENDIX G
INTERVIEW GUIDE

1. Can you tell me what the word 'caregiver' means to you?

2. Can you tell me about why you were interested in coming to the caregiver group?
   Probes:
   Difficulties you may be experiencing

   What are some the difficult parts of your caregiving job?
   (physical demands, emotional support, long hours, decisions)

   How have you dealt with these difficulties?

   How did you think being a caregiver has affected you?
   (physically, socially, emotionally)

3. Can you tell me what it was like being in the group?
   Informative, supportive, emotional, unsettling?

4. In what ways has being in the group changed things for you?
   Probes:
   The difficult parts of your caregiving job?

   How you deal with these difficulties?

   How being a caregiver affects you since being in the group?

   How are you coping?
APPENDIX H

PROFILES

YOUR RELATIVE'S PROFILE

Your relative is currently:
  ___an in-patient at Holy Family Hospital
  ___an out-patient at Holy Family Hospital
  ___a resident on the Extended Care Unit
  ___living in the community

Your relative has had:
  ___a stroke  ___orthopedic surgery  ___an amputation
  ___other (please specify)

Your relative's age is___.
Your relative is male___ or female____.
Your relative's marital status is:
  ___single  ___married  ___widowed
  ___divorced  ___separated

YOUR PROFILE

Your relationship to the patient:
  ___spouse  ___adult child
  ___brother  ___friend  ___other (please specify)

Your age is___.
Your gender is male____ or female____.
Your marital status:
  ___single  ___married  ___widowed
  ___divorced  ___separated

The length of time you have been involved as a caregiver is:
  ___months
  ___years

The number of hours per day that you spend helping, in any way, your relative is____.

Your employment status:
  ___full-time  ___part-time  ___not employed  ___retired

Please record your birth date as an identification code
  ___ ___ ___
  day  mo.  yr.

Thank you for your time and cooperation.
APPENDIX I
"A COURSE FOR CAREGIVERS"

EVALUATION

1. Please circle the number that best reflects your opinion of this program:

   1 2 3 4 5
   Disliked Disliked Neutral Liked Liked
   very much - somewhat not sure somewhat very much -
   "A waste "I learned
   of time" a lot!"

2. If you had a friend who was a caregiver, would you recommend that he or she participate in this program? Yes No
   Why or why not?

3. Has this program changed the way you feel about caregiving? Yes No
   Why or why not?

4. Will you do things differently as a result of participating in this program? No Yes
   If so, what?

5. Do you use anything you learned now? No Yes
   If so, what?

6. Will you use anything you learned in the future? No Yes
   If so, what?

7. Which parts of the program would you like to see more time spent on?

8. If we have to cut some things out of this program, what should we cut?

General Comments: We welcome any thoughts you would like to share about this program.
CONSENT FORM

For the Research Project Titled: A Course for Caregivers: Group Work as an Intervention with Family Caregivers of Hospitalized Elderly

Researcher: Elaine Book, B.S.W., M.S.W. (Candidate)

I _______________ understand that the purpose of this study is to evaluate the group program in which I am a participant. I understand that participation in this study involves the completion of two questionnaires (one at the beginning of the program and one at the end, each requiring five minutes of my time) as well as an in-person interview (approximately one hour) conducted by Elaine Book.

I understand that my participation is completely voluntary and that I may choose to withdraw at any time from the study. Further, I consent to the interview being audiotaped and understand that the audiotape will be erased upon completion of this research project.

All the information that I choose to provide will be held in confidence by the researcher. All identifying information will be omitted in the final report. Any services received from Holy Family Hospital will in no way be affected by my decision to participate. Should I have any questions about the study, I am able to contact Elaine Book or Elaine Stolar, Faculty Advisor.

My signature is acknowledgement of receipt of a copy of this form and my consent to participate in the study.

Participant Signature: _______________ Date: ________
Interviewer Signature: _______________ Date: ________

Elaine Book
321-2661

Elaine Stolar
822-2277
APPENDIX K

I: I think maybe a good place to begin is with what the word caregiver means to you. I think that that word is being used a lot and that was the name of the group and I am wondering what that word means to you.

R: Well it means being the main support and the main caregiver in every day functions at home. I guess that covers it.

I: O.K. So the main support...

R: The main support and the main, the actual caregiver in the small the small even minute to minute or hour to hour needs of the person who needs care.

I: So would that... when you say support do you mean support in what senses?

R: Uhm...oh perhaps to keep their morale up

I: uh huh

R: and uh make sure that nothing gets behind like bills paid, things like that that may worry the person who is the patient. I guess to try to reassure them that uh that we are managing o.k.

I: It sounds like you are talking about quite a bit of emotional support.

R: I think sort of I think especially in his case you know if he, he is pretty well always teary. I think he does uhm probably does because he is not able to walk either.

I: uh huh

R: I think he does need perhaps maybe more moral support than perhaps someone who is able to get up and do whether it is the washroom or you know easily. Course we don't know what he will be capable of when he comes home yet. I am different from some of the caregivers who are already giving care in other words.

I: In your eyes you see yourself as being different than the other caregivers

R: Well the other caregivers who have already and have experienced because their husband or parent is already home. I have to experience
R: Well the other caregivers who have already and have experienced because their husband or parent is already home. I have to experience you know I mean I think I know what it will be like right but I don't know for sure. Because it may be quite different umh. He at the moment wasn't getting care you see, so he could sort of ignore me or do whatever he feels like and it is not going to effect whether he gets fed but maybe once he is home, he may change a bit. So it is sometimes hard to accept that when I am there and he'll listen to his record and read a book at the same time (Laugh). So that's a little hard but perhaps when he is home he won't do that.

I: And when you say that his behavior may change when you are home because you are going to be the one who is he is going to depend upon to do some of the things like the cooking and the cleaning those kind of things that he now has taken care of for him.

R: Uh Hun. I hope so.

I: You hope that it is going to change.

R: Yes I mean yes I hope it will.

I: It sounds like that may be one of the difficulties that you may be experiencing right now is around the communication.

R: yeh 'cause he doesn't want to discuss much... on he will say have you paid the bill but not even that so much anymore and he would ask certain questions and he doesn't anymore, he doesn't do that very much now. In other words I do everything, well I was doing it anyway but I mean he would ask if I had paid the electric bill or phone bill or whatever but he doesn't do that anymore so in other words he not sort of you know past that off to me, which is no big deal the bill comes in and it is not as if I have to remember to go and pay it without the bill... the bill comes in and so you go pay it. But he is not showing that interest anymore right now.

I: were those some of his tasks before?  

R: Yeh. He usually made sure the bills were
I: And now that is one that he is handing over to you.

R: Well I had been doing it for most...I had pretty well always done it really. He hadn't paid too much attention to it but then he did. But then I think at one point I heard about when women are often left and they don't know what to do and I thought, gee, if he were left he would be in the same boat. So I think it is time he took on these responsibilities so I just suggested that he do. And he took it over. It is not much but at the same time he knew what was going on and since I had already done it, it didn't make any difference to me.

0: O.K. What was it about the group that you were interested in coming to?

R: Well I guess to hear...uhm sort of for the support group, for the uhm perhaps to hear what other people were going through or maybe have gone through. I think that...to know that you are not alone because I did feel very much alone. Like when he was in the other hospital, I was kinda alone. I didn't know anybody who was going through the same thing so you are really completely on your own. So it was nice to have a group where you were all having the same problems.

I: Going through the same things, experiencing maybe some of the same difficulties.

R: Yes and to hear...some of the things I hadn't thought of, of course because you can't know everything and it was nice near that, like the one man whose wife was improving so much and so that was nice to hear.

I: That was encouraging.

R: Yes, it was, because sometimes you think that the way it will always be and here that man said his wife was improving greatly and improving all the time. Gives you heart.

I: Gives you heart and the morale support for you.
R: I think so. It gives you sort of hope, you know, that perhaps as time goes on, he'll get stronger and if he does his exercises and all the things he is supposed to do, that he may, may be not be able to walk a lot, may be he'll be able to walk, cause one thing I was concerned about was going to the bathroom and that was the main one I guess, just being able to go to the bathroom umm. I thought if he could walk to the bathroom that would make it because I couldn't with my shoulder and back, I can't take any of his weight and so that was my main concern.

I: And so hearing some of the other caregivers talk about their experiences to you was reassuring.

R: Well it was. It was because like my son what he, you know he had only mentioned it two or three times but these things stick in your mind and it was well he knew his grandfather had died, my father had died from stroke. He had, he was eighty, he had a small stroke which he completely recovered from but then when he was eighty four he had a massive and my son knew that so of course it was one thing he was concerned about "On Mom" or the way he put was "we might have to go through this again". So this is always sort of in your mind umm and my husband's was quite bad but then if he did have another one so that was kinds in my mind too. Although he is a much younger man than my father umm but you know I think my son is very concerned and having to go through something like this so I am trying to alloy his fears and say dad is improving and so it was nice to near someone else's relative had improved. Now I'm not sure what age his wife is but umm she would be at least sixty I would imagine maybe a little older and so it was nice to near that somebody was improving.

I: So it sounds like for you it is hearing others talking, talking with other people who are in a similar situation, receiving support and maybe getting some ideas of how to cope and how to tackle the situations.

R: Yes I think so.
I: You talked a little bit about how you started talking about some of the difficulties that you experience as a caregiver now because as you say you don't have him at home, but it certainly sounds as though there are certainly some challenges that you are coming up in your role as it is right now around how he is dealing with his illness.

R: I am not sure uh like we have to find and have been for some time, we should find an apartment or something that was all on one level cause he had arthritis and I could see he was getting worse, but he has his workshop in the basement and uh, he builds model ships. And uh last year we didn't get anything in the garden at all. That was the first year and so I have been saying for quite a few years we should be finding some place like an apartment might be the best, cause I could see him getting worse so I thought well if we have to go into a wheelchair or use a wheelchair for certain parts of the time at least he would have access, if it was an electric wheelchair, this was before the stroke, then he could still have access to say the mail, could still go there on his own and he wouldn't have to have me with him if he felt like just, you know he liked spending alot of time in bookstores and I am not really. I go into a bookstore it is for something specific, but he likes to spend time in there and different places. So he could do that on his own and I could maybe shop somewhere else and uh but there was always so many obstacles like "I'm not going there because I don't want people above me, below me, penning me. You know you can't control other people and they could start a fire and I'd be caught in it. They don't like cats." It would be an obstacle after obstacle and I said we have to find something that you can't do up and down stairs and you shouldn't be doing it now. Well maybe we could agree because I had great content with an apartment where we didn't have the extra thoughts of up keep, what needs doing. You know if you're in an apartment it is a lot of inside that we would have to contend with. I wouldn't have to worry about gardens, although I'm sure miss the garden. But anyway (Laugh), get a window box. But you know he is very strong, very strong. "No, it all
these things didn’t happen”. And while he was in the other hospital, they would go and look at an apartment and when we would talk to him about it, it was a new building not far from where we are. I’d like to stay in our general area if possible and um so we, a friend of mine and I, want to see this apartment. Unfortunately, there were only 2 left un on the ground floor and the other was facing a wall. If you had been on the second or third, you would look over the traffic and that would have been fine. But we didn’t go further with it because it was part of a complex. And I just didn’t think that while he was ill in bad, for him to move would be very good. So I didn’t. So it is something, yesterday we talked about it by the way and um he did say he didn’t want to but I might have to go ahead and just do something and I know he won’t be happy. But that might cause a problem.

I: So that is something you foresee as a problem.

R: Oh yeh.

I: And it sounds like it is even a bit of a difficulty for you right now because you perceiving a decision and a move that needs to be made and he is resisting that.

R: Yeh. Before he had so many reasons why we couldn’t do this and couldn’t do that, and I thought well a high rise we could have a beautiful view and at least even if you are bored, you can look out and there is something to see. But I can see that is going to be a bit of a problem. I am the more realistic one and more sort of...like when we are looking on the T.V. on the homes, he doesn’t say any interest until he sees one at two million dollars where I am looking at a hundred and fifty thousand. I am looking at what we can afford and he is looking at what he would really like. I can see some difficulty arising when a decision has to be made.

I: What are some of the other difficulties that you perceive in your role right now, decision making one of them, communication is
R: But when things are not going well, all of a sudden you are aware that you don’t have … and then you hear different people talking at the group say about having their daughters or their whatever, it makes it even more so you realize, my goodness I don’t really have anyone like that to call on. So don’t want to feel sorry for myself but it makes you more aware.

I: With some of the difficulties (noticed tears in her eyes) Would you like a tissue?

R: Oh thank you.

I: Are you o.k.?

R: Oh yeh I just feel abit sorry for myself I guess.

I: And that’s o.k. every now and again. Pause With some of the difficulties that you have been talking about, how have you dealt with them?

R: I am not sure if I sort of just kinda try not to think about them very much. Try not to… because I know it doesn’t help because I can’t come up with the solutions on my own. So I can’t really change them because part of them are my husband. And so I haven’t really handled them, not really.

I: Or handled them by way of accepting the things that you can and do have control over or I am not sure I understand.

R: It is sort of uh I think it probably is accepting the fact that maybe I am reading a great book and say he doesn’t want to read it, he’s not interested in it, I accept the fact that he’s not interested, so I guess there is a fair bit of just accepting that I can’t change what he does like and doesn’t like.

I: uh huh

R: Say for moving, well I can’t just accept that because that is something that has to be done. But I haven’t really faced what I am going to do. I know what we have to do but I just haven’t sort of faced it. I thought I
R: Yah, there is sort of, we do have different interests. He is interested in photography and I like taking a picture and that is it. He likes model ships and I love to read. I love to walk well he likes to walk a bit. So we had sort of different interests in a way and trying to find something that we can share together. Even just one thing. He likes to cook and he does a better job than I eventhough he came to it late. But perhaps we could go walking but now he can't. But maybe when he has his wheelchair maybe we could still go out. You know even our reading materials are so different too. He likes war books. But just to find something you know. I am just not really sure. Because we don't have any relatives here see cause that makes a difference too. Not having any relatives here.

I: How does that make a difference for you?

R: Well, it is not like... well there are 5 girls in my family and my husband is an only child. So he never had that family you know brother - sister. But I had 4 sisters and we were all very close and so you could talk to them about anything and share anything but it is hard long distance 'cause they live overseas and in the United States.

I: oh oh

R: So it makes a difference. And now my parents have passed away too. So like when I go back, it is just like I'd never left. We just pick up and go on like I have never left. They are the same and I guess I am the same. Haven't really changed that much. As though I had never left you know that type of thing which is nice.

I: Is it almost like a sense of comfort?

R: I think so just to know that there is somebody there and while we were here and everybody was well and fine, you were capable and able to handle everything.

I: uh uh
might discuss it with my neighbor. She is very good; I have known her for a long time. They travel a lot. I thought I might try to discuss it with her just to see if you know to get... she is very good at suggestions and she doesn't feel bad if you don't take them in other words.

R: un un

I: Can you give me an example? Something you feel you are not capable of handling.

R: Well my own shoulder problem. It has been going on and on for so many years. I did find a doctor who saw that there was something wrong but I am not sure that he saw the right thing. I really have a problem and I wasn't able to get thought to the doctors so I just accepted it as it was, and I thought as soon as I am well I am going back home to get medical attention because I felt at least I would have sisters that could observe me when I go to the doctor could come along and say "Yeh I saw her" I was very emotional in every way. Now I don't feel quite that bad so he did help me a little bit.

Pause

I: Uh before coming to the group, how did you feel you were coping overall?

R: Uh I guess in a way...sometimes I felt I was coping o.k. because the only thing I could do was go to the hospital and visit him every day. Course it was twice a day til the hours changed in October and then I changed to once a day. I think I was sort of coping fairly well. I would come home and make supper and lay down a bit and go to bed. I was sort of resting a lot.
R: uhm and trying not to let everything get over my head type of thing emotionally. And there were some days I would feel a bit better, and other days I wouldn't feel so great but I always went to the hospital because I felt at least as long as I saw how he was and he saw that I was there, that made a difference.

I: When you say not feeling so well, would that be physically or would that be emotionally?

R: Well physically I was never really great but emotionally and I think even mentally. But for the first two three months I guess you know it was really hard. Mind you there were more people who went to see him because he was closer to home and so I wasn't quite so... I didn't feel as though he was being neglected or anything because there were quite a few people went up. But as time went on people do get on with their lives you know and they have their own families you know.

I: uh huh

R: Then I began to feel a little bit worse. I wasn't able to and stay as long as some of the other people who would stay forever where maybe I could stay only twenty minutes and then I had to leave. So I suppose coping is one thing and at the same time, I had allot of time to sort of think about what would happen and then I would get down emotionally too because I just didn't know what was happening. You know his hand and his leg weren't coming back so I had more time to think about him and the future and then I realized that well really I had to just wait and see what happens because you can't live in what might happen and what might not, you're taking on not only today's problems but every other day and it is just such an I sort of came to realize that I can't do that.

I: You would come to realize that you had to just take care of today.

R: Ye ye

I: So it sounds like that since your husband
has been ill and since you’ve been a caregiver that you have been affected emotionally...

R: uh huh

I: and mentally

R: uh huh

Q: How about physically?

R: Physically I guess I am the same as always. My general health is good. I had a check up. I mean didn’t see a doctor for 20 years because I was always well therefore when I did go with this problem, the doctor didn’t know me of course and so he asked what is your age. And as soon as he heard my age, well here is estrogen as if that is the solution to everything. I found that very hard because I don’t go to doctors unless there is something wrong but then they don’t know that because they don’t know me. So that was kinda hard to take.

I: Do you think your shoulder or any other kinds of aches or pains have been related to the time?

R: Not really, it had improved actually since I went to the chiropractor. My shoulder has definitely improved. I couldn’t sit this long before so he has done something. I am afraid to go back because he may do something to make it worse. I like him to make it better.

I: Uh huh...uhm How has being a caregiver affected you socially?

R: Uhm we haven’t had really what you would call a social life for quite awhile because he has been home with colitis. When he first got colitis. I am trying to think how many years ago that is. And he had always worked afternoon shift so that sort of cut down our social life quite a bit. And I had worked during the day so... gradually over the years a lot of the people we’ve known have moved away so our social life was quite come down except a few people. And some of them are no longer with us. Uhm so I don’t know that that in itself has really affected it. I think... I do
go to church and we have the seniors on Tuesday. I do go there on Tuesday mornings and uh but he never went so it wasn’t something we shared.

I: O.K. how about socially for you then?

R: As I say it is mainly it would be around my church cause it is not to far from where I live and uh...

I: so you haven’t not been able to go as often as you had before or what I am saying is you still have been able to do what you ...

R: I think so.

I: Maintain the social contacts that you had before.

R: I would say about the same, yeh. I haven’t got any difference that way.

I: Can you tell me about what it was like being in the group?

R: Uhm it felt ... I don’t like to say good, but it felt to know that everybody there was involved in the same sort of problems in a way of caregiving because I could hear there was problems with caregiving. And so it felt good to know that you were not alone. Well it was support to know that there are other people who are going through exactly the same or almost exactly the same as what you are going through. So yeh I think it was... I think I benefitted from it and I am glad I went and that I was able to go because I really didn’t think that I would be able to go.

I: Right. Did you find it informative or educational?

R: I think both. Yeh both from what I heard and from the papers you gave us.

I: In what ways?

R: Well I think when you gave us the thermometers to know that these could be normal and that these could happen when you go into the different stages that something...
I hadn't thought of as stages, I had just thought of as you know you handle it or you don't. So that was informative. And you can always check on that and say well it is part of the caregiver's group and you have to learn how to handle it as they come along. It helped me to understand because I didn't know anything about... well I didn't know anything about the different stages you go through and now I am aware this can happen and try to take things as easy as possible I think so perhaps you don't get to the point where you are high on the thermometer. And it might happen and I think some of it will depend on him whether he is cooperative or not because if you are trying to do your best for someone and they are not cooperating... there was one lady there and with her mother and how she is having rather a difficult time it sounds at times. Now I am not sure whether her mother was cooperative or uncooperative or whether it just constant care makes you more edgy, I am not sure so I guess maybe it would depend on how my husband is. Uhm...

I: But again being in the group allowed you to hear those other experiences?

R: Exactly.

I: So was it emotional for you to be in the group?

R: I am not sure that it really affected me emotionally. Perhaps if I was already giving care at home then I feel that talking about some of these things and applied to me it might have but he is not home yet, I am not sure if it affected me emotionally. I think it was more information and educational and more knowledge which I hadn't known. I would say on that side.

I: Was it a comfortable setting for you?

R: I found it quite comfortable there.

I: In what ways then has being in the group changed things for you?

R: umm well I think I am being more aware of what could happen and how things could be.
Having that information because if you have the information it wouldn't seem so bad when something happens that I don't understand or can't do anything about. Because I have the information that the caregiver can get into different emotional states. So hopefully having that knowledge and at least I won't feel bad about it. at least I'll know that well this could be fairly normal or acceptable or it could be part of the pattern.

I: And maybe his disability and his illness? Part of his adjustment?

R: Yeh and I shouldn't let it affect me too much. It will affect me sometimes. You can't look at somebody who had been walking and know he is in a wheelchair but if he can accept it, I'll find it easier as well.

I: So if we looked at the group and the changes that it may have brought for you around dealing with some of the difficulties you have talked about earlier today like uhm some of the communication difficulties, have some of the things from the group changed how you are going to deal with that?

R: I hadn't really thought about that yet.

I: Or even around decision making which you identified as being a ... 

R: uh

I: As you talk it sounds like, and I don't want to be putting words in your mouth so tell me if I am right or wrong. but it sounds like you have become stronger emotionally in order to deal with some of the challenges that you are going to be facing.

R: I think that is true. I think that is true but the fact that I also feel a bit better with my shoulder. I am really quite a strong person physically and have emotionally, mentally. Now that my shoulder is a bit better I do believe that I can handle things better than I would have even a couple months ago.

I: Uhm have there been differences for you in
how you deal with stress?

R: I am not really sure that it has made that much difference with regards to stress. Mainly because I still look to prayer mainly to relieve stress. I get a great peace with prayer and so I am not sure, it could have. I'm just not sure.

I: O.K. How about things in terms of caring for yourself? Pause. Um certainly understanding your husband and his illness. Has it made some changes for you in that way of thinking about those things.

R: No I don't think so. I have never really been a person to spend a lot of time on myself. You know, I always felt as long as I was presentable, I have never really been one for going to the hairdresser. I always feel as long as I am presentable, I don't spend a lot of time on myself.

I: What about caring for yourself in the other senses when we talked about doing the things that you like to do? Like I recall you talking about visiting with the neighbors. Has the group been an influence in that way?

R: Uh trying to think...I am not really sure about that because the neighbor I visited actually has come over to me so many times that I just when I felt a bit better I thought I might just go over and visit her. So I did. So I'm not really sure whether the group had anything to do with that, it could have. But I am not sure. I would like to be a lot more socialize. There are so many things I love to do unfortunately physically at the moment anyway I am just not really able to. Because when the pressure builds up in my shoulder then my face... I don't know is it getting red now?

I: I think it is very warm in here.

R: It does get very red when the pressure builds up.

I: Are you feeling it start to build up now?

R: There is a little bit, not much through...
know when I have reached my limit.

I: Again with respect to the influence of the group on how you perceive being a caregiver, any thoughts on that?

R: uh

I: More positively, more negatively, more difficult?

R: Well I think I see it in a more positive light now because I... hearing the group talk and how some people were finding it really... the 2 ladies opposite me with their mother were perhaps sharing the duties but they had a positive outlook because their mother was doing very well and they seemed to be handling it o.k. and so that was nice to hear the positives too. Because when you have, especially in the first few months and when you know you are going to be a caregiver too, I think a lot of it is negative. So it was nice to hear the different positives. So I think the positive things that I heard from the group helped me a lot.

I: And overall, how you are coping now versus how you were coping before the group?

R: Uhm so much has to go with my physical you understand. Cause when you feel well you can handle everything. I mean when I feel well I am thinking of all the things I want to do but then... anyway but yes I think it has been very positive for me. It has helped me to understand alot.

I: uh nun

R: And also to accept some of the things which I guess we are a little afraid of or not exactly afraid, but the fear of the unknown because now I am more aware of what it is all about. And I believe that has been very effective.

I: Is there anything that I haven't addressed that you would like us to know, anything about either the group experience or being a caregiver that would really inform us?
yet it is a little difficult to say because I am sure many things will come up. You know if you are already giving care to someone on a 24 hour basis, then I think you are more aware of what is involved. I still... I have an idea of what it is all about but until he is home and every situation is different, uh, but I would say the whole group was great.

I: Well I really want to thank you for your time and for participating. It was a real pleasure having you and the information that you shared was valuable and had an impact on others too.

R: Well I hope so.