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**Evaluation of Education and Support Initiatives for Family Caregivers**

by

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**A Dissertation Submitted in Partial Fulfillment of the**

**Requirements for the Degree of**

**DOCTOR OF PHILOSOPHY**

**Human and Social Development, School of Nursing**

**We accept this dissertation as conforming to the required standard**

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## ABSTRACT

As Canada's population gradually ages, provinces such as British Columbia are beginning to explore initiatives to support family caregivers of the frail elderly. The focus of this dissertation is the evaluation of one such initiative; a program sponsored by the B.C. Ministry of Health (Continuing Care Division) called "Supporting Caregivers in B.C." (SCBC). The SCBC program was created as a province-wide community development initiative to establish caregiver education and support groups in 17 communities throughout B.C.

This dissertation research included nine research questions, which in turn were organized into four levels of evaluation questions: the individual caregiver level; the small group level; the community level; and the health care services level. These levels reflect the various levels at which the SCBC program was intended to have impacts, as well as the various empowering strategies the program aimed to employ.

Due to the traditional over-reliance on quantitative methodologies used to evaluate caregiver groups, this dissertation research used a combination of research methodologies. These included participatory action research, qualitative evaluation research (focus group interviews) and quantitative survey research. Research participants included 76 family caregivers participating in the SCBC program, six SCBC caregiver support groups, and six SCBC community steering

committees (which were responsible for the community development process in each community).

The findings were varied, and related to both the outcomes and processes of the SCBC program. At the individual caregiver level, caregivers described a number of positive impacts the program had on them. In addition, participation in the program was associated with overall increases in the amount of social support caregivers received, as well as decreases in feelings of powerlessness and increases in feelings of powerfulness. At the small group level, caregiver groups provided information on what they needed for long-term sustainability, as well as describing what they felt were the essential beneficial aspects of their group process. At the community level, steering committees provided a profile of community characteristics affecting the SCBC community development process, and offered insights into the overall community development process. Finally, at the health care services level, although participation in the SCBC program was associated with increases in caregiver's knowledge of community health services, it was not associated with changes in usage of those services, or changes in caregiver's plans to place their care-receiver in a long-term care facility.

**Examiners:**

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## CHAPTER ONE: INTRODUCTION

### Purpose and Scope

The purpose of this chapter is to introduce my doctoral dissertation, “Evaluation of Education and Support Initiatives for Family Caregivers.” In this chapter, I will review the background and history to the dissertation, its purpose and significance, the research questions, assumptions and beliefs, terms used, and an overview of the research methodology.

In chapter two of the dissertation, I will present a review of relevant selected literature, focusing primarily on community development, self-help / mutual aid, the evaluation of caregiver support groups, and public policy. In chapter three of the dissertation, I will present a more in-depth discussion of the methodology used in the dissertation, and will include a description of the caregiver support group program, its participants, research methods and procedures, ethical considerations and the data analysis plan. In chapter four, I will include a presentation of the results of the main research findings, and finally, in chapter five, I will discuss those findings in the light of relevant literature and offer recommendations for practice, policy and further research.

## Background and History

### Growing Importance of Informal Caregiving for Frail Elders

#### Changing Demographics

As the percentage of the population that is aged 65 and over continues to rise in Canada, it has been predicted that by the year 2031, 25% of the population will be aged 65 or over (Statistics Canada, 1990). Due to this large cohort of aging “baby-boomers,” it has been predicted that there will be a large corresponding increase in the demand for health and long-term care services (Foot & Stoffman, 1996). This increase in demand for health and long-term care services will be particularly pronounced as the prevalence of dementias, such as Alzheimer’s disease, increases in the next few decades (National Health and Welfare, 1991).

Currently, a little over a quarter million Canadians suffer from Alzheimer’s disease and related dementias (Alzheimer Society of Canada, 1996). The prevalence rate of dementia rises from 2.4% of those aged 65 to 74, to 34.5% among those aged 85 and over -- currently the largest growing segment of our population (Canadian Study of Health and Aging Working Group, 1994). Assuming that current prevalence estimates remain constant, the number of

Canadians with dementia will more than double by 2021, and will triple by the year 2030 to more than 3/4 million Canadians (Canadian Study of Health and Aging Working Group, 1994; Alzheimer Society of Canada, 1996). These projections are extremely significant, as the current annual net cost of dementia in Canada was estimated to be over 3.9 billion dollars in 1994 (Ostbye & Crosse, 1994), a figure which could easily triple to 12 billion dollars annually by 2030.

These demographic changes will not only impact society with a considerable financial cost, but there is also an immense human cost as well, incurred by those who care for frail elderly family members with such conditions as dementia. A recent study conducted at the University of Victoria Center on Aging found that one in every 16 British Columbians is a family caregiver, many of whom provide care to an elderly family member or friend (Chappell & Litkenhaus, 1995). These ranks of hardworking and often exhausted family caregivers -- the majority of which are currently women -- are expected to mushroom along with the rising numbers of frail elderly needing care. Without the "invisible work" (Kaplan-Daniels, 1987) which these family members provide in the community, the formal care system would likely be overwhelmed. It has been estimated, for example, that for every individual with a severe dementia in a long-term care institution, there are at least two living in the community supported by a family member, usually a spouse or daughter (Gurland & Cross, 1982).

### Awareness of Governments About the Need to Support Family Caregivers

In response to the aforementioned demographic trends, many policy makers and varying levels of government have begun to realize the importance of informal family caregivers of the frail elderly (Forbes, Jackson & Kraus, 1987). It is not surprising, therefore, that the B.C. government's efforts to create a renewed health care system, the "New Directions for a Healthy British Columbia" initiatives, include a heavy emphasis on care being provided in the "community" and in people's homes, with the assistance of informal (unpaid) caregivers. As one New Directions paper states:

Most British Columbians believe that health service at home or close to home is preferable to care elsewhere. Most people feel better and get better more quickly in familiar environments *with the support of family members and friends close at home* (italics added) (Ministry of Health and Ministry Responsible for Seniors, 1993, p. 14)

The B.C. Ministry of Health is also attempting to implement health programs where the emphasis is on preventing health problems before they begin - as well as programs which recognize the broader socioenvironmental determinants of health, encourage public participation and "grass-roots" involvement in health matters, and emphasize community development/action

rather than relying solely on one-to-one delivery of services (Epp, 1986; Altman & Martin, 1994). Again, much of the impetus for these changes in philosophy is economic; the theory being that it will be less expensive in the long run to enable local citizens to promote their own health and well-being, than to continue pouring money into an expensive institutional and disease-focused system.

Thus, a combination of demographic and economic forces have resulted in some initial government commitment towards offering new programs, based on the principles of health promotion and community development, targeted at supporting family caregivers in the community. In particular, programs which support self-help and mutual aid are being promoted and explored. The “Supporting Caregivers in British Columbia” (SCBC) project, a group support and education program for caregivers, is one such program.

### History of the Supporting Caregivers in British Columbia (SCBC) Initiative

#### Origins: The Kamloops and C.A.B.C. Proposal

In 1993, a small group of former and current caregivers from the Kamloops and District Alzheimer’s Society identified a need for education and support groups for caregivers in their community. After submitting a community grant application in collaboration with the local Continuing Care Division of the

B.C. Ministry of Health and the local University College School of Nursing, this group successfully received Ministry of Health funding to develop and provide local educational and support groups for caregivers caring for family members with dementia at home.

Just as this local Kamloops group was organizing themselves into a working steering committee, they were invited by Ministry personnel to participate in a similar, but much larger program involving the Caregiver's Association of B.C. (CABC), the Alzheimer Society of B.C., and the University of Victoria School of Nursing. The latter three groups had received funding from the Ministry to collaboratively design, implement and evaluate an initiative aimed at supporting family caregivers in six under-serviced communities in B.C. After some initial meetings, the groups formed a coalition, and a decision was made by all partners to combine funding and resources to develop and implement a caregiver support initiative, which eventually became the province-wide "Supporting Caregivers in B.C." (SCBC) program.

#### Development and Description of the SCBC Program

After considerable consultation with numerous caregivers and organizations serving caregivers about how caregivers might best be supported in

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their roles, the project steering committee decided to focus on the establishment of caregiver education and support groups. In addition, a decision was made to establish these groups in communities in B.C. where few, if any, previous such groups existed. The groups were established in these communities in phases: seven communities (including a pilot community) in Phase I, and another 10 communities in Phase II of the project.

After an extensive review of other existing education and support group formats, a subgroup of the steering committee developed a ten week support and education group program entitled 'Supporting Caregivers in B.C.' (SCBC), the specific goals and content of which will be discussed in further detail in chapter three. The SCBC groups were developed so as to be facilitated by a trained lay or professional group facilitator, who would lead small groups (i.e., 6 - 15) of caregivers through ten weekly sessions of roughly two hours each. Each of the sessions entailed approximately one hour of education / discussion on a pre-determined topic (with opportunities for two optional topics determined by the group), and one hour of mutual group support. During the support component, participants were encouraged to share freely with each other whatever they felt important to share, such as the difficult emotions associated with caregiving. As the ten weeks progressed, shared leadership was encouraged and modeled, so as to allow a self-led and self-sustaining caregiver support group to emerge at the end

of the ten week facilitated period.

Underlying the whole SCBC program was a community development process, whereby a program community developer would visit each of the involved communities. The community developer helped to form local community development groups (local SCBC steering committees) that were responsible for raising community consciousness around caregiving, recruiting caregivers and facilitators for groups, supporting ongoing groups, and, in some cases, facilitating political action around caregiving issues.

There were some notable differences between Phase I and Phase II of the SCBC program. While the establishment of caregiver education and support groups (the focus of this dissertation) remained the central focus in both phases, phase II involved more communities (ten) than phase I (six). Phase II also targeted caregivers caring for *any* kind of care-recipient, whereas Phase I primarily targeted caregivers of the frail elderly with mental health concerns (e.g., dementia). Finally, Phase II involved four additional evaluation components (e.g., the evaluation of caregiver facilitator training workshops) that were outside of the focus contained within this dissertation research.

More detailed information regarding both the SCBC program and the community development process will be presented in chapter three.

### Purpose of the Study

The purpose of this dissertation is to provide a systematic analysis of specific data collected during the evaluation of the “Supporting Caregivers in British Columbia” initiative, and to discuss the research findings in light of current research and relevant literature.

### Significance of the Study

#### Theoretical Significance

Given the realization of the importance of family caregivers and the considerable stress and burden they experience in their roles (Braithwaite, 1996), there has been growing interest in using existing caregiving stress theories to evaluate popular caregiver interventions such as support groups (Gonyea, 1989; Knight, Lutzky & Macofsky-Urban, 1993). As a consequence, numerous instruments have been developed to measure such constructs as caregiver burden and stress (Pearlin, Mullan, Semple, & Skaff, 1990). These quantitative instruments have been the primary means by which to evaluate whether support group interventions for caregivers are deemed to be effective (Toseland &

Rossiter, 1989; Lavoie, 1995).

Yet, as will be discussed further in chapter two, the results of these theoretically-driven quantitative evaluations have been equivocal at best, and disappointing at worst. Despite caregiver participants repeatedly stating how helpful support groups are to them, the quantitative research predominantly fails to mirror caregivers' reports of these groups (Callahan, 1989; Zarit, 1990; Biegel, Sales & Schulz, 1991). Noting this discrepancy, Lavoie (1995) has critiqued the existing evaluation research on support groups for caregivers, and has concluded that the present outcome variables are inadequate, and that a need exists for greater use of qualitative methods. It has also been noted elsewhere (Chesler, 1991; Tebes & Kraemer, 1991) that qualitative and/or participatory methodologies are perhaps the most appropriate choice for evaluating self-help/mutual aid initiatives, since they are more in keeping with the principles of self-help and mutual aid. However, only one published qualitative evaluation of a caregiver support group initiative could be found by this author (Wilner, 1988). Therefore this study, by incorporating both quantitative and more qualitative and participatory methodologies, stands to make a valuable contribution to the evaluation literature on caregiver support groups, and support groups in general.

Furthermore, this study may offer valuable contributions to our understanding of the process and outcomes of government-sponsored community

development initiatives. Hume (1993) for example, in her review of government-sponsored community development initiatives in B.C., notes that little is known about the long-term viability of such initiatives, or ways in which a community development initiative can be both empowering and government-sponsored at the same time.

Finally, while there is some initial evidence as to the moderating influence community service usage may have on negative caregiving consequences (Bass, Noelker & Rechlin, 1996), less is known about ways to increase caregivers' notoriously low usage of such services. Thus, this evaluation of the SCBC program -- which had among its primary goals to increase the knowledge and use of community services by its caregiver participants-- will hopefully shed light on the success of this kind of approach to increasing service use.

### Practical Significance

Nurses, particularly community health nurses, are being increasingly called upon to adopt a "community development" approach to their work. Yet much of the nursing literature on community development is theoretical, with little practical discussion as to how nurses might actually implement community development in their practice. This study, with the insights it will provide on the

process and outcomes of community development with family caregivers, should prove valuable to nurses wanting to take more of a community development approach with their clients in the community, particularly with family caregivers. The study should also provide valuable information about the process of working with caregiver support groups, and strategies to maximize such groups' chances for long-term viability.

## The Research Questions

### Origin of the Questions

The questions chosen for this dissertation were both theoretically and pragmatically driven. The questions were theoretically driven in the sense that questions emerged from gaps in the existing literature; gaps in what we know about caregiver support groups, how they are evaluated, and the kinds of outcomes for caregivers we can realistically expect as a result of participation in such groups.

However, large pragmatic elements also came into play with the development of the questions. The nurse researchers conducting this evaluation (including the author), were only one sub-group of a larger team and steering committee which included representatives from the project funders (Ministry of

Health, Continuing Care Division), the Alzheimer's Society of British Columbia, and the Caregivers' Association of B.C. (CABC). Thus, all decisions regarding the SCBC project, including decisions around evaluation, were made collaboratively. As a result, different stakeholders around the table wanted different interests reflected in the evaluation. For example, Ministry of Health representatives wanted information on use of community services, CABC representatives wanted feedback on group process and structure, and the nurse researchers wanted information on caregiver's social support. Furthermore, because the SCBC evaluation was intended to be as participatory as possible, efforts were made to frequently include caregiver participant feedback into the research and evaluation questions. For example, feedback from Phase I participants was used to plan the evaluation of Phase II of the SCBC project.

Finally, it should be noted that the author had negotiated with the project steering committee that much of the data he was collecting as a researcher / evaluator would ultimately be incorporated into this dissertation. While some of the data presented in this dissertation has been included in smaller detail in reports written for the project steering committee (Gallagher, 1996; Gallagher & Hagen, 1995), this dissertation presents the data in considerably more detail and includes questions and data not included in the original evaluation reports.

### Levels of Research Questions

Given the multiple research questions, a framework was needed to organize and integrate them. Ultimately, a framework similar to the ‘Continuum of Empowering Strategies’ presented by the Registered Nurses Association of B.C. (1992) was used. This framework organizes the research questions concerning the SCBC project at the level of the individual participant, the small group, the community, and at the level of health care services. This organizing framework reflects the reality that community development projects (such as the SCBC project) have wide-reaching effects, and impact people in communities at numerous and inter-related levels. For example, a caregiver support group may have such a strong impact among its’ individual members, that several of the members form a small group to start a petition and/or letter writing campaign directed at local politicians. Such lobbying / political action may ultimately result in a change in the health care system, such as the amount of respite or home care services offered in their community.

The level of “individual caregiver” refers to impacts the SCBC program had on individual caregiver participants. The “small group” level refers to the small groups (from 6 to 15 members) which were formed during the SCBC program, and how they were affected as the program progressed. The “community” level refers to influences the SCBC program had on each of the

communities which hosted the program, and in turn how the community may have affected the delivery of the SCBC program. Finally, the “health care services” level includes how the use of government-sponsored health related services, and the propensity of caregivers to place their loved ones in long-term care facilities were potentially affected by the program.

For ease of visual clarity, all of the research questions, along with their corresponding levels of questions, are presented in Table 1.

#### Evaluation Questions at the Level of the Individual Caregiver

1. What did the caregivers perceive as the main benefits of the SCBC program? That is, how did the SCBC affect participants’ day-to-day experience of caregiving?
2. To what degree was the SCBC program successful in increasing caregivers’ support?
3. To what extent did the SCBC program affect caregivers’ perceptions of powerlessness / powerfulness?

Table 1: Research Questions

Level of Question	Research Question	Methodology	Participants	N =
Level 1: Individual Caregiver	1. What did the caregivers perceive as the main benefits of the SCBC program?	Qualitative focus group interviews (Appendix 1: question 1)	Phase 1 caregiver groups	6 caregiver groups <i>(average of 8.2 caregivers / group)</i>
	2. To what degree was the SCBC program successful in increasing caregiver's support?	Pre and post program surveys (App. 2: questions 5 & 6, and App. 3: questions 4 & 5)	Phase 1 group members	48
	3. To what extent did the SCBC program affect caregivers' perceptions of powerlessness / powerfulness?	Pre and post program surveys (Appendix 4: questions 15 & 16).	Phase 2 group members	28
Level 2: Small Group	4. What did caregivers feel would help the long-term sustainability of their groups?	Qualitative focus group interviews (Appendix 1: question 3)	Phase 1 caregiver groups	6 caregiver groups
	5. What aspects of each support group's process was particularly beneficial for participants?	Qualitative focus group interviews (Appendix 1: question 4)	Phase 1 caregiver groups	6 caregiver groups

Table 1

Table 1: Research Questions (continued)

Level of Question	Research Question	Methodology	Participants	N =
Level 3: Community	6. What unique community characteristics influenced the SCBC project's outcome as a community development initiative?	Qualitative focus group interviews (Appendix 5: question 3).	Phase 1 community steering committees.	6 committees <i>(average of 7.5 members / committee)</i>
	7. Which elements of the comm. dev'p process in each of the communities were important to the outcomes of the project?	Qualitative focus group interviews (Appendix 5: question 4).	Phase 1 community steering committees.	6 committees
Level 4: Health Care Services	8. To what degree did the SCBC program influence the knowledge / use of community health services by program participants?	Pre and post program surveys (Appendix 2: question 20, and Appendix 3: question 11).	Phase 1 caregiver participants.	48
	9. To what extent did the program influence the propensity of caregivers to place care-receivers?	Pre and post program surveys (Appendix 4: questions 14)	Phase 2 caregiver participants	28

Evaluation Questions at the Level of the Small Group:

4. What did caregivers feel would help the long-term sustainability of their groups?
5. What aspects of each support group's structure and/or process was particularly beneficial for participants?

Evaluation Questions at the Level of the Community:

6. What unique elements of each community influenced the SCBC project's outcome as a community development initiative?
7. Which elements of the community development process occurring in each of the communities were particularly important to the outcomes of the SCBC project?

Evaluation Questions at the Level of Health Care Services:

8. To what degree did the SCBC program influence the knowledge and/or use of community health services by participants in the

program?

9. To what extent did the SCBC program influence the propensity of caregiver participants to place their care receiver in a long-term care facility?

### Statement of Assumptions and Beliefs

#### Assumptions

1. The first assumption is that when researching community development and/or self-help initiatives, one needs to use research methodologies that are in keeping with the philosophical underpinnings of these kinds of initiatives. Thus, participatory and qualitative methodologies should be employed wherever possible and practical, but may be triangulated with quantitative methods, if done in a manner which is respectful and empowering of research participants.
2. Not all research questions are theory based. That is, in the real-world practice of evaluating programs (such as the SCBC initiative), the political realities of collaboration and the need for answers to concrete and practical questions, requires that some

research questions and methods be allowed to originate without rigid concerns for epistemological purity (Patton, 1990).

### Beliefs

1. The stories of caregivers and their caregiving are often full of courage, grace, and great love, and the researcher is in a position of rare privilege to bear witness to these stories. As caregivers are giving great gifts of themselves by participating in research, the researcher in the field of caregiving needs to treat research participants with great respect, and needs to ensure that the research experience is as positive and supportive as possible.
  2. Participants' own reports of their experiences are often the best source of information when researching community development / self-help initiatives such as the SCBC project, and it is not always necessary (or desirable) to quantify things to determine if a particular project is helpful. For example, if participants state that a program was "extremely helpful" or "a waste of time," it is the belief of this author that we may safely presume that the program *was* indeed probably extremely helpful (or a waste of time) --
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without necessarily having to second guess the honesty, motives, or sophistication of the respondents.

## Definition of Terms

### Family Caregiver

“Family caregiver” is an individual providing care, support and assistance with activities of daily living (A.D.L.’s) and/or instrumental activities of daily living (I.A.D.L.’s) for an older family member. The caregiver may or may not live in the same household as the older family member requiring care.

### Self-Help

“Self-help” is defined in this dissertation as a process whereby individuals who share a common condition, situation, heritage, symptom or experience seek each other out for mutual support and assistance. Typically, these individuals will form self-regulating and self-governing “groups” (of varying formality) which will offer face-to-face or phone-to-phone fellowship/networks, which may or may not rely on external funding and/or support.

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### Community

Within the context of this dissertation research, 'community' is defined simply as "...a group of people (who) form a social unit based on common location..." (Fellin, 1995, p. 114); in this case, an identified town or city such as Hope or Coquitlam. This admittedly simplified definition of community defines it in a "where" sense (Panzetta, 1971), which allowed local steering committees to focus on a particular geographic area during their community development activities.

### Community Development

'Community development' is defined here using Labonte's (1993) definition, which is: "...the process of supporting community groups in identifying their health issues, planning and acting upon their strategies of social action / social change and gaining increased self-reliance and decision-making power as a result of the activities" (p. 92).

### Supporting Caregivers in B.C. (SCBC)

The name for a 10 week, facilitator-led process whereby caregivers in local communities were brought together weekly for education, self-help and mutual aid, for the purposes of support and encouraging self-sustaining and ongoing caregiver support groups.

### Stakeholder

Any individual / group of individuals who had decision-making capabilities within the SCBC project, or would be influenced by the project. This included caregivers, elderly care-receivers, local community steering committees, local community group facilitators, the Long-term Care division of the Ministry of Health, the SCBC project steering committee, the Caregivers Association of B.C. (CABC), the Alzheimer Association of B.C., the Kamloops and District Alzheimer Association, and the University of Victoria School of Nursing.

### Empowerment

This dissertation will use a definition offered by Wallerstein (1992), which

describes empowerment as a:

..multi-level construct that involves people assuming control and mastery over their lives in the context of their social and political environment; they gain a sense of control and purposefulness to exert political power as they participate in the democratic life of their community for social change (p. 198).

As Wallerstein notes, empowerment is a *multi-level* construct, and can mean different things in different situations. While political power and social change are seen as important end-points of the process of empowerment, the process itself can take many forms, a point which will be further explored in chapter two.

### Social Support

A plethora of definitions for social support exist (Chappell, 1992; Stewart, 1993). For the purposes of this dissertation, 'social support' shall be defined using Gottlieb's (1983) definition: "...verbal and/or non-verbal information of advice, tangible aid, or action that is proffered by social intimates or inferred by their presence and has beneficial emotional or behavioral effects on the recipient" (pp. 28-29).

### Caregiver Group

A group of caregivers who have come together in face-to-face groups for the purposes of education and/or mutual support. The groups may be either be led by a facilitator or self-led.

### Overview of Research Methodology

This dissertation utilizes a combination of quantitative and qualitative evaluation methodologies. The quantitative methodology used is primarily survey research methodology; including both descriptive (e.g., service-use profiles of caregivers) and analytic (e.g., changes in service use before and after the SCBC program) use of data from the surveys. The qualitative methodology include focus group interviews using semi-structured interview guides, with a focus on both process (e.g., process of community development) and outcome (e.g., impact of SCBC program on caregiver's experience of caregiving) evaluation. Surveys were primarily self-administered by caregivers, while focus group interviews were conducted by trained research assistants.

## CHAPTER TWO: REVIEW OF RELEVANT LITERATURE

This dissertation addresses the evaluation of a province-wide government sponsored set of initiatives to offer local family caregivers of frail older persons opportunities for group education and support, using a community development model. Obviously, such a topic could encompass a broad range of themes and concepts from the available academic literature. The theoretical and philosophical underpinnings most germane to this project are imbedded in literature pertaining to:

- 1) Community development and empowerment
- 2) Self-help / mutual-aid groups
- 3) Caregiving groups, and the evaluation thereof
- 4) Factors affecting Canadian caregiver policy.

Community development was important as a major theme since the project partners wanted each of the stakeholders involved to have equal authority and power, and wanted to leave a legacy in place whereby local communities would feel empowered to continue on in efforts to support family caregivers.

Self-help is also often discussed as an important component of community development initiatives, and it follows logically from the process of community development. Self-help also formed the basis of the service model which was implemented and was the main explanatory model for the eventual benefits that

caregivers received from the program.

The third theme, caregiving groups, includes an overview of the nature of such groups, and reviews the evaluation of such groups to date. It was important to examine previous efforts to evaluate the impact of these groups because as will be shown, a slightly new approach was called for given the results of such efforts.

The fourth area of literature deals with Canadian public policy regarding family caregiving. In particular, the factors contributing to the significant shortcomings in Canadian caregiver public policy will be reviewed. As will be seen, these same factors prevent such programs as the SCBC program from being as successful as they might otherwise be.

### Community Development and Empowerment

The SCBC initiative, the evaluation of which is the focus of this dissertation, was envisioned by the key stakeholders to be a community development project. Therefore, in order to complete a thorough evaluation of this project, it seemed appropriate to examine the community development literature, and review the essential components. Thus, in this section, the definitions and characteristics of community development will be briefly examined. As will be shown, the concept of empowerment is closely related to the idea of community development. Indeed, the framework that was ultimately chosen for this dissertation is a continuum of 'empowerment strategies' (RNABC,

1992), which includes community development as one of several important strategies of empowerment.

### Community Development Defined

Although the term “community development” is used with increasing frequency nowadays, there is no one definitive meaning for the term, and many other similar terms -- including ‘community organization,’ ‘community intervention,’ ‘locality development,’ and ‘community work’ -- exist and create a confusing picture (Rothman, 1995). Lassiter (1992) has defined community development as “a process of working in collaboration with community members to assess the collective needs and desires for health change and to address these priority needs through problem solving, utilization of local talent, resource development and management” (p. 30). Ultimately, the goal of community development is “...to build self-help, community capability and integration” (Ibid., p. 31). Similarly, Labonte (1993) emphasizes community groups in his definition of community development, stating it is “...the process of supporting community groups in identifying their health issues, planning and acting upon their strategies of social action / social change and gaining increased self-reliance and decision-making power as a result of the activities” (p.92).

Dominelli (1989) has described community development as “...the ongoing process of developing self reliance, both in terms of personal and social

group capacities.” (p. 82). Dominelli goes on to stress that the hallmarks of community development include its egalitarian nature, its emphasis on process as opposed to ends, and indigenous leadership that the community (group) must have to control the pace and nature of any outside intervention. Rothman (1974) notes that community development is similar to what he calls locality development, where community change is pursued through broad participation of a wide spectrum of people at the local community level. The themes emerging from all of the above definitions were similar to those articulated by those involved in the caregiver group project: that is, it was envisioned the project would reach out to groups of family caregivers in the community, work with them in an egalitarian process to get their health concerns identified, and respond to those concerns in a manner that would encourage self-reliance and resource-building.

All community development projects, regardless of the subtle nuances of how they might be defined, need to be initiated by someone, and generally need to be funded somehow. Some level of government often funds a community group and/or community non-profit organization (NPO) to do the job of community development. And herein lies the rub of community development: there are important doubts and questions about the ability of government sponsored and government controlled community development projects to actually achieve the aims of community development. This is a point that experienced community developers such as Labonte (1993), McKnight (1989), Dixon (1989) and Rothman(1974) have repeatedly raised. That is, goals such as self-reliance and egalitarian relationships and processes seem difficult to attain when the

government funders—and those employed by the funders to achieve their goals and objectives—retain most of the potential power and decision-making ability in the overall project. Thus, with such potential power differentials, the importance of trying to keep the community development project as empowering for participants as possible is an important, and often difficult, aim.

### Community Development and Empowerment

When reading the community development literature, one is struck by the similarities and inter-connectedness between the concepts of community development and empowerment. Grace (1991), for example, notes that empowerment is “...the notion of people having power to take action to control and enhance their own lives, and the processes of enabling them to do so,” (p. 330), and notes that “...the notion of empowerment has a strong link with the tradition of ‘community development’” (p. 330). Similarly, Wallerstein (1992) defines empowerment as a

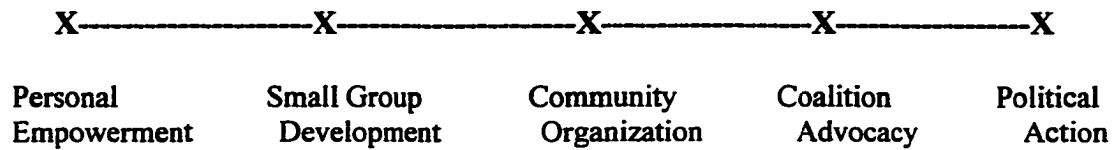
..multi-level construct that involves people assuming control and mastery over their lives in the context of their social and political environment; they gain a sense of control and purposefulness to exert political power as they participate in the democratic life of their community for social change

(p. 198).

Empowerment seems like an important idea for community development project with groups such as family caregivers, not only because there is a real danger of the “managers” of the project having too much power compared to the actual participants / benefactors of the project (Labonte, 1989a), but also for the simple reason that caregivers themselves are typically isolated elderly women; people with traditionally very little power in our society. Thus, the importance of “offering” such projects in an empowering manner—a manner in which the caregivers might be able to re-claim some power and control in their chaotic lives—seems of utmost importance.

#### Empowerment Strategies: Origins of the Evaluation Framework

Given the conceptual links between empowerment and community development, a framework was fashioned for the SCBC evaluation out of a nursing model that highlights the importance of both ideas. The final evaluation framework was adapted from a model for nursing practice articulated by the Registered Nurses Association of B.C. (RNABC, 1992), known as a “Continuum of Empowering Strategies,” which “...depicts a set of empowering strategies that can be used by professionals and their organizations” (RNABC, 1992, p. 9). The RNABC model is depicted as follows:



This model is virtually identical to Labonte’s (1993) Empowerment Holosphere, which has the same five basic strategies (although he uses the term “personal care” rather than “personal empowerment”), but places the strategies in a “holosphere,” (overlapping circles) rather than along a continuum. Either way, this basic model states that no one person (or project) can realistically work towards all empowerment strategies, but that it is the responsibility of a health agency or network of agencies to provide all empowering actions together. Furthermore, the model states that all strategies are important for an individual’s or group’s empowerment; that no strategy in and of itself is sufficient. For example, it can be seen that community development (called “community organization” in the RNABC framework) is considered one of *several* important empowerment strategies that a nurse might use during a project such as the SCBC program.

Each of the five empowering strategies along the continuum will now be discussed in further detail.

### Personal Care

The first of these empowering strategies, personal care, involves “...the

venue of direct service” (RNABC, 1992, p. 56). For example, this would include services that caregivers may need and/or want to help them in their role as caregivers, such as education about various caregiver issues (e.g., legal issues) and community services, respite care, and home support services. As Labonte (1993) notes, these kinds of professionally offered services can be potentially empowering if they are offered in a supportive, respectful and non-controlling way, and if these services are offered in conjunction with other resources, such as small group development.

### Small Group Development

Small group development is a common empowerment strategy used in many community development projects; where groups of people with a similar identity (e.g., family caregivers) are brought together for mutual support and a sense of connectedness. Bringing people in community together—such as family caregivers—in small groups often helps to alleviate their isolation and begins a process of personal and group empowerment, in the sense that:

...only in interacting with others do we gain those healthful characteristics essential to empowerment: control, capacity, coherence and connectedness. The power of the group is in creating that connectedness; the healing of the group is validating that we’re not alone” (Labonte, 1993,

p. 58).

The RNABC (1992) also notes that small groups are where “...individuals together begin to normalize their experiences of distress, disease or powerlessness by discovering that they are not alone in their problems” (p. 11), and that small groups “...also helps to break down isolation and self-blame, and to provide reinforcement for healthful behavior changes” (p. 12). For many community members, such groups can become “more important than family,” and a place where they can gain a sense of connectedness, control and power in their lives. For others, the process of telling and listening to stories in small groups can begin a process of critical reflection and action—of challenging of some aspects of their taken-for-grantedness:

...liberation is a dialectical process of action and reflection. The core of reflection is demystification: critical, penetrating questioning of the taken-for-granted aspects of particular circumstances. Through this process the oppressed taken what is unquestioned and tear away its veneer, renaming it from their own perspective (Stevens and Hall, 1992, p. 3).

Wallerstein and Bernstein (1994) also describe this process of “community empowerment”—where *the group becomes the community*—which can occur in many groups, noting the similarity to Friere’s (1970) ideas on emancipatory education:

To Friere, community empowerment starts when people listen to each other, engage in participatory / liberatory dialogue, identify their commonalities, and construct new strategies for change. Through dialogue, we can learn from one another's perspective and discover new ways of looking at problems (Wallerstein and Bernstein, 1994, p. 143).

### Community Organization

Once again, small group development—like any empowerment strategy—is incomplete in itself, and the RNABC model suggests that nurses should also use 'community organization' as an empowerment strategy. Labonte (1993) -- whose work the RNABC model is based upon -- describes community organization as "...the process of organizing people around problems or issues that are larger than group members' own immediate concerns" (p. 61). Although one can get bogged down easily in semantics, the RNABC appears to use the phrase 'community organization' in much the same manner that several authors -- such as Lassister (1992) and Labonte (1993) -- would use the phrase 'community development.' Indeed, Labonte (1993) uses the phrases 'community development' and 'community organizing' interchangeably. While such use of these terms by the RNABC (1992) and Labonte (1993) might be challenged by Rothman (1995) -- who sees a clear distinction between community organization

and community development -- for the sake of simplicity and clarity (if not theoretical purity) the terms will be considered similar enough to be used interchangeably for the purposes of this discussion.

As an example of community organizing/development, SCBC community steering committees were formed for the express purpose of not only getting caregiver groups up and running, but to also raise the profile of caregiving issues in their community, and to take whatever steps they felt were in their power to address those issues. Both professionals and laypersons (including caregivers) were on these community steering committees, and the extent to which these groups organized their communities around caregiving issues varied from community to community.

Yet despite the importance that many authors place on community organization/development, the reality is that it can be extremely difficult to foster any extensive involvement and participation in community development projects from community members, particularly those who traditionally have no real voice (e.g., minorities, the elderly, the mentally ill, etc.). Even for those members in communities who traditionally participate in community projects, a common complaint heard by community organizers is that citizens are too busy or too tired to participate in yet another worth-while community project. This theme was an important one that Hume (1993) discovered during her review of all government sponsored community development initiatives in B.C. between 1988 and 1993. She notes that:

It is one of the dilemmas of intensive interest in communities that residents are feeling “consulted to death.” The researcher {Hume} was warned over and over not to bother approaching community participants because they were tired of being consulted and studied, that their desire was to be left alone to get on with their work. In smaller communities, the problem of being over consulted, studied or “committee’d to death” is even more acute as the same pool of people is drawn upon to participate in community activities (p. 6).

This inability of community developers to successfully garner extensive involvement of non-professionals in community development projects has led some writers such as Labonte (1993), to argue that “...community self-sufficiency may be a myth” (p. 66), and that community members can only be realistically expected to participate in community development projects to a relatively small extent.

#### Coalition Advocacy and Political Action

Coalition advocacy and political action—the fourth and fifth empowerment strategies mentioned in the RNABC empowerment model, tend to be seen much less in government-sponsored community development projects. Both these strategies tend to focus on making long-term transformative changes,

particularly at the policy and/or political level, to the broader socio-environmental factors which limit the amount of power and control certain groups (e.g., caregivers) have. Political action, in particular, concerns itself with change at the social movement level, such as found in the women's movement and the peace movement (RNABC, 1992).

In general, although community development projects may help community participants cope with their current situation, rarely are participants given real opportunities to address and challenge the fundamental assumptions, values and hegemony of our society which create disadvantaged situations to begin with (for example, the fact that women are usually the ones who do family caregiving). The difficulty lies in convincing government funding agencies to fund initiatives that may well make community members angry, dissatisfied, vocal and militant about the ways things currently are. Government bureaucracies, by their very nature, tend to be conservative and preserving of the status quo, and not particularly eager agents of real social change. Yet, as Dixon (1989) notes:

Unless community development is redefined, so that it approximates political action, or unless community group sponsored projects establish themselves....the sponsorship arrangements and the necessary ingredients of parochialism and self-interest will repeatedly doom community development to disappoint in terms of fundamental social change (p. 90).

Similarly, not only do many government-sponsored community development projects turn a blind eye to political action issues, many of them also tend to disregard gender issues. As Hume (1993) notes in her analysis of community development projects in B.C.:

Many feminists note the gendered nature of community development work. The work in many communities falls to women who are not employed outside the home and who work part time, the elderly (both segments of the population who are low on the hierarchy of power) and to those who can afford to take the time from work and those who are paid to be there because they represent their professional or organization. Right away that sets up many inequities that are not addressed by any of the initiatives (p. 46).

Dominelli (1989) too, has noted the over-reliance on women to do community work, stating that "...community development models draw heavily on women to provide the grassroots support and resources a project requires during its implementation" (p. 11). Yet this "women's work" is often entirely taken-for-granted and assumed to be free (i.e., not paid) by most government sponsors of community development.

Thus, although the concept community development holds some great promise for enabling community members to help themselves, promote their own health and gain control over their lives, there need to be careful safeguards put on

the process, so it does not just become another means by which government can “dump” more demands on women. As Labonte (1989b) writes about a self-help group community development project:

Self-help groups can be empowering and health-enhancing, but there is no recognition in documents such as *Achieving Health for All* that self-help primarily taps the volunteer energies of women, society’s ‘traditional’ care-providers. Will government support and professional co-ordination of self-help simply increase volunteerism, at the expense of women? (p. 88).

Having reviewed the area of community development, empowerment, and community work, this discussion will now turn towards the theme of self-help and mutual aid, a key component of the SCBC project.

### Self-Help / Mutual-Aid Groups

As the focus of this dissertation is on the evaluation of an initiative to develop self-sustaining caregiver self-help/mutual aid groups (the SCBC project), it seems important to review the literature on self-help / mutual aid groups. In particular, I will focus on the definition of self-help groups, the benefits of self-help groups, and how and why people join self-help groups. In this discussion I

will also review some of the proposed helping mechanisms that seem to be operating in self-help groups -- that is, the key ingredients that seem to make self-help groups so helpful. Finally, a brief discussion of how self-help groups might be influencing the health care system and health policy will be offered.

### Self-Help Groups Defined

For the purposes of this review, I will use a definition of self-help groups as offered by Lieberman (1986), who describes them as:

....composed of members who share a common condition, situation, heritage, symptom or experience. They are largely self-governing and self-regulating. They emphasize self-reliance and generally offer a face-to-face or phone-to-phone fellowship network, available and accessible without charge. They tend to be self-supporting rather than dependent on external funding (p. 745).

Romeder (1990) also emphasizes that the primary purpose of self-help groups is to alleviate suffering by offering mutual aid to each other in the form of social support, and the sharing of experience, information and ways of coping. Due to their emphasis on mutual aid and support, self-help groups are also often referred to as mutual aid groups. The literature makes a distinction, however, between

self-help / mutual aid groups and other group experiences such as group psychotherapy, and support groups—which tend to be professionally led, more time-limited than self-help groups, and generally offer fewer opportunities for self-reliance and self-governance. However, these distinctions between “true” self-help groups and “other” groups are often more clear-cut in the literature than in reality, and groups (such as the SCBC groups) can and do move between being professionally-led and self-led.

There are many different types of self-help groups, reflecting almost every facet of the human condition. There are self-help groups for addiction problems, long-term psychological problems (e.g., depression), life crises (e.g., death of a spouse), chronic physical illnesses (e.g., lupus), family problems (e.g., adult children of alcoholics), social rejection (e.g., groups for gays), and consciousness raising (e.g., women’s and men’s groups) (Lavoie, 1990). There are literally self-help groups for everyone, including former professional athletes having difficulty adjusting to their loss of notoriety, and all-but-thesis doctoral students! There is obviously a broad spectrum of self-help groups, reflecting the wide variation in members’ life situations. However, all self-help groups offer the same important ingredient to their members: mutual support and aid for their members experiencing the same difficulty or condition.

### The History and Growth of Self-Help Groups

While collective and personal mutual aid are old as humanity itself, the

idea of organized mutual aid was initially born in the 19th and early 20th centuries to deal with the stresses of industrialization. Out of this period came the first trade unions, consumer cooperatives, ethnically-based immigrant associations, and so-called "Friendly Societies" (Borkman, 1990; Katz & Bender, 1990a; Romeder, 1990). However, it was not until the 1930's when the first true self-help groups emerged; Alcoholics Anonymous being initiated in 1935, and Recovery Inc. -- a self-help group aimed at assisting former mental patients -- arriving on the scene in 1937. Following on the heels of these two main self-help groups, parents of sick or handicapped children with mental or physical problems became the next people to form self-help groups. In the 1950s and later, self-help groups for all kinds of people with various diseases (e.g., diabetes, cancer), life transitions (e.g., widow-hood), medical treatments (e.g., colostomies) and stigmatized conditions (e.g. ex-offenders) began to spring up (Borkman, 1990). This has led to a crescendo of self-help groups emerging for almost every aspect of the human condition imaginable; a trend that continues well into the 1990s.

The quiet, small and local nature of many self-help groups belies the staggering magnitude of overall use and growth of self-help groups. While precise membership is hard to assess accurately, it has been suggested that between three and six percent of people currently belong to a self-help group. This translates into approximately 6.25 million American and several hundred thousand Canadian active self-help group members (Jacobs & Goodman, 1989; Lieberman, 1989; Borkman; 1990; Romeder, 1990). The growth of self-help groups is equally as impressive: mental health problem self-help groups have a 42.5% growth rate, bereavement-terminal illness groups have a 37.8% growth

rate, and membership in even larger, established groups such as Alcoholics Anonymous has increased by an annual average of 7 to 11% percent worldwide (Kurtz, 1990; Manton, Leventhal, Madara & Julien, 1990). Agencies or clearinghouses that keep lists of local available self-help groups typically have anywhere from 150 to 400 groups in their self-help directories, ranging in maturity from newly established groups struggling for viability, to organizationally mature, international groups such as Alcoholics Anonymous (Jacobs & Goodman, 1989; E. Woollard, personal communication, July 30th, 1996). Increasingly, these self-help groups are offering not only face-to-face fellowship, but are connecting through other methods and technologies, such as by telephone and home computer networks (Madara, 1987; Lavoie, 1990).

Growth and membership in self-help groups, however, is not necessarily uniform throughout the population. With the exception of Alcoholics Anonymous, membership of most self-help groups has traditionally been predominantly female -- and white middle class females at that. Minorities, lower or working class people, men, and the elderly are significantly under-represented in self-help groups, although this situation seems to be slowly changing (Borkman, 1990; Levy, 1976; Lieberman, 1989).

#### Factors Affecting the Growth of Self-Help Groups

There are a number of indications that self-help groups are not just a passing fad which will disappear in a few years. In fact, there are a number of forces at work in our society that point towards self-help groups continuing to be

an increasingly important part of our health care system. These include:

- 1) **Volunteerism.** Mutual aid and self-help groups are voluntary activities, and volunteerism continues to burgeon in our society as we approach the end of the twentieth century. A Canadian study done in 1987 showed that 27% of the adult population -- more than five million Canadians -- volunteer their time and their skills to community groups and organizations (Romeder, 1990). This continued trend towards volunteerism guarantees a steady supply of people willing to commit their time and energy for self-help groups.
- 2) **A shift in disease patterns from acute to chronic illness.** Medical advances in the past few decades have not so much succeeded in "curing" illness, as they have dramatically increased the number of people struggling with chronic physical illnesses and their psychological consequences (Rachlis & Kushner, 1989). Since medical science offers no "cure" for chronic illnesses, many people have turned to self-help groups as an important means by which to deal with such illnesses.
- 3) **Erosion of traditional support networks.** As both a consequence of the erosion of the traditional extended family, and our highly mobile society, people have less extensive and enduring social support networks to turn to at times of crisis or illness. Self-help groups successfully help to fill this void.
- 4) **Less public confidence in the major institutions in our country.** In the past few years, people have becomingly mistrustful of previous "sacred cows," such as the medical profession. People have become more assertive with traditional power figures such as physicians, and have begun to seek more personal control over their own health care. Self-help groups encourage this "questioning of

authority," and put control and power back in the hands of ordinary citizens.

5) Unavailability of needed mental health services. This is the most frequently cited reason for joining self-help groups (Jacobs & Goodman, 1989).

As increasing numbers of people continue to be frustrated either with the lack of affordable traditional mental health services -- or their efficacy -- more people turn to self-help groups, and find them an economical and effective way to maintain psychological and emotional well-being.

6) The media's dramatization and documentation of self-help groups. The media -- along with word of mouth -- are the primary ways that people find out about self-help groups (Madara, 1987; Borkman, 1990). Widely-viewed television shows as Donahue and Oprah have profiled self-help groups a great deal, effectively advertising the existence and effectiveness of a wide variety of self-help groups.

7) Governmental and professional support. Particularly as governments continue their efforts to restrict their health and human service expenditures, governments at many different levels have supported self-help groups as an attractive alternative (and affordable) treatment model. In the United States, the self-help movement got a boost in 1987, when the Surgeon general at the time, C. Everett Koop, held a national self-help workshop (Reissman & Gartner, 1987; Borkman, 1990). Emerging out of the workshop were many ideas and concrete actions to support self-help groups, including the establishment of self-help clearinghouses (see below). There have been similar Canadian meetings and workshops, albeit on a smaller scale, to plan how governments might best support the Canadian self-help movement (Borkman, 1990; Katz & Bender, 1990b).

8) Clearinghouses. Self-help clearinghouses are organizations / centers which collate information on available self-help groups, and provide information and referral service (Lieberman, 1986; Madara, 1987; Manton, Leventhal, Madara & Julien, 1990; Borman, 1992). There are currently more than 70 clearinghouses in North America, the most famous one of which is the computerized New Jersey Self-Help Clearinghouse, which fields over 10,000 calls/referrals a year (Madara, 1987). Clearinghouses operate in most major Canadian cities, such as Vancouver and Toronto (Borkman, 1990; Woollard, 1996), and provide an important means for people to connect with self-help groups.

9) Self-help groups are helpful. While it may stand to reason, people keep joining and going to self-help groups because they find them so helpful. While the very nature of self-help groups makes them difficult (and inappropriate) to prove their benefit with "scientific proof," participants in self-help groups know their groups work, and often consider them nothing short of life-saving (Levy, 1976; Lavoie, 1990).

10) Technology in the home. Advances in telephone and home computer technology has enabled people to receive a self-help group experience, even when they are unable to meet face-to-face. These technologies are proving particularly helpful for the elderly -- or their family members providing them care -- who are unable to normally get out and attend normal meetings (Brennan, Moore, & Smyth, 1992; Gallienne, Moore & Brennan, 1993; Smyth & Harris, 1993).

11) Paradigm shifts in society. The growth of self-help groups also reflects a larger but subtle shift in societal thinking about health, where health is seen to be less of a medical idea, and more of a social idea (Lavoie, 1990). That is, people

are increasingly seeing the importance of the social, psychological, emotional and spiritual dimensions of health, the very dimensions that self-help groups address so very well.

### Benefits of Self-Help Groups

We are social creatures, and our ability to connect with others is an important determinant of health. In fact, research has shown that people with strong social relationships have mortality rates that are half those of people with weaker social relationships (Katz & Bender, 1990b; Romeder, 1990). People experiencing illness or adversity -- who may often feel isolated and ostracized -- particularly need these vital life-giving social relationships.

Herein lies the tremendous power and benefits of self-help groups. That is, self-help groups are deliberately comprised of persons with the same difficulty or experience — persons who recognize the need to listen, to connect, to give, and to receive. In particular, persons in difficulty or suffering who are making the self-help transition from a state of isolation and disconnectedness, to one of acceptance, understanding and connectedness, generally describe their groups as nothing short of life-saving (Jacobs and Goodman, 1989; Romeder, 1990). A variety of evaluations have documented the benefits of self-help groups for participants. These include: better adjustment to illness/trauma; better coping; higher self-esteem; less depression; greater life-satisfaction; improved relationships; improved knowledge; less passiveness; and less dependence on

professionals (Lieberman, 1986; Trojan, 1989; Kurtz, 1990; Lavoie, 1990).

### Joining Self-Help Groups

People seek out self-help groups for a wide variety of reasons (Lieberman, 1979), but the usual factor that gets people to seek out and join self-help groups is some common difficulty or experience (Romedor, 1990). Furthermore, people will generally only join a self-help groups when they have come to a point in their suffering where they acknowledge—and at some level accept—their situation enough to recognize the similarity between themselves and other members within the self-help group (Silverman, 1992). For example, parents with a severely handicapped child would generally only seek out help in the form of a self-help groups once they have comes to terms (at least initially) with the fact that their identify includes being the parent of such a child, and are ready to seek out other individuals with similar identities. Needless to say, denial of one's situation usually precludes membership to a self-help group.

Once people have accepted their identity based on some difficulty or situation, they may deliberately try to find a self-help group or the group may somehow find them. People may learn of self-help groups through the media, through a self-help clearinghouse, or may be referred to a group by a friend, family member, or professional. Some persons may be invited and welcomed into a group by a sponsorship or “buddy” relationship (such as in Alcoholics Anonymous), a method of joining self-help groups that works particularly well for

dealing with difficulties arising from a blow to one's identity, such as with loss of a breast, job, or spouse (Medvene, 1985; Lavoie, 1990). Or, if no self-help groups exists in one's community, certain individuals with initiative may simply start a group, with or without some kind of professional assistance (Hill, 1983; Madara, 1987).

Less is known about people who decide not to join or seek out self-help groups. In a review of what research has been done in this area, Lieberman (1989) notes that some non-joiners decline invitations into self-help groups because they do not wish to be associated with a group whose central focus emphasizes a status or identity based on some affliction. For example, a widow may not want to join a group whose main common identity is the status of widowhood. Furthermore, it has been found that non-joiners perceive their normal social networks to be more effective and helpful than those of people who join self-help groups. Finally, it appears that non-joiners are generally far less active consumers of services overall when compared with members of self-help groups, who tend to be high service users to begin with (Lieberman, 1986).

### Helping Mechanisms of Self-Help Groups

There is no one simple description of how self-help groups actually help, and the very nature of self-help groups means that each group helps its members in a unique manner. However, the following is offered as a summary of what appear to be the more important helping mechanisms of self help groups discussed in the literature.

### Disclosure of Emotions / Emotional Support

For many people in crisis or distress, self-help groups are one of the few places where they can freely express the powerful and difficult emotions that often accompany illness or tragedy. It is often this opportunity to express emotions—and to receive support in turn for these emotions—that self-help group members claim is the most helpful component of their groups (Lieberman, 1989; Lavoie, 1990). The opportunity for people in suffering to tell their own story—to give their own humanity a voice in the company of other people who truly understand—is one of the powerful mechanisms that self-help groups offer that allow people to move through their pain, and begin the process of coping and/or healing (Jacobs & Goodman, 1989; Lavoie, 1990; Romeder, 1990).

### Helper-Therapy Principle

What makes self-help groups particularly unique among all the ways that people receive help in self-help groups during times of distress is what has been called the “the helper-therapy principle” (Romeder, 1990). That is, people in self-help groups learn very quickly that one of the most powerful means of receiving help is through the act of helping others; self help group process consists largely of members simultaneously giving and receiving help. This process is decidedly different from the process of counseling or group therapy, where the roles for

giving help (professional) and receiving it (client) are more rigid and unidirectional in nature.

While at first new members primarily receive help and support from other group members, they usually quickly discover their own inherent capacity for helping and gain a sense of equality with other members. This discovered ability to assist others not only leads to an increased sense of self-esteem and self-worth, but often starts an important process whereby a person can begin to find an all-important sense of meaning in an otherwise meaningless disease, affliction or tragedy. With this sense of meaning comes all important hope, and the ability to embrace what the future may hold (Romedor, 1990).

#### Creating a New Social World / Identity

Self-help groups offer participants the opportunity to form new bonds with persons like themselves. For example, in a study examining self-help groups for persons who had experienced the death of a spouse, it was found that the creation of these new social bonds was the most important helping factor in these groups (Lieberman & Videka-Sherman, 1986). Due to the high degree of perceived similarity among members, and the strong feelings of a “refuge” that self-help groups engender, this new social world often begins to feel very “family-like” for participants. This social world and family now serves as a new reference group for members, a reference group in which previously stigmatized conditions can become normalized and one can be accepted by the group as being “okay.” This

experience can be very powerful and transformative, as Jacobs and Goodman (1989) note:

The new member, who frequently has felt stigmatized and criticized (or at the very least isolated and not understood), frequently finds immediate acceptance as a member of the group. That sometimes stunning experience seems to be a vital step toward making the cognitive, emotional, and behavioral changes necessary for more effective functioning and improved quality of life (pg. 538).

### Role Modeling and Problem Solving

Self-help groups offer a valuable problem-solving resource for members. Self-help groups members have the opportunity to discuss their problems and try out new solutions—and are generally encouraged to deal with just one problem at a time, helping to reduce feelings of being overwhelmed and confused by their problems (Lavoie, 1990). In addition, relative newcomers in groups get to watch more veteran members, who can serve as role models, to see how they struggle and cope with their problems. This sharing of experiences with problems—which is the basis for the regular ritual of personal testimonials in such self-help groups such as Alcoholics Anonymous—reflect a healthy process of social comparison, whereby members come to believe that “if he/she can do it, then I can too” (Katz

& Bender, 1990b).

### Sharing of Information and Knowledge

Self-help group members are able to offer each other information of various types, such as information on available services and how to access them, practical information such as where to buy Velcro shoes for family members unable to tie their shoes, or even a widow finding out it is normal to hallucinate about her deceased husband (Lavoie, 1990; Silverman, 1992). Importantly, self-help groups specialize in providing their members with the very kind of information they need the most—concrete information that enables them to get on with their day to day lives.

This process of information sharing reflects the importance of experiential knowledge in self-help groups. Experiential knowledge—as opposed to professional knowledge (based on theory, education and credentials) -- is knowledge and information gained by personal, first hand experience with a given situation (Borkman, 1976). While our society has traditionally placed more value upon professional (and/or scientific) knowledge than upon experiential knowledge, it is precisely this transmission of experiential knowledge in self-help groups that makes them so powerful. People feel valued and empowered when other group members seek the knowledge they have gained as a result of their unique experiences, and group members gain insight into their problems. As Borkman (1976) notes:

By pooling the experiences of a number of people, the common elements of the problem and attempts to cope with it emerge, while simultaneously highlighting the uniqueness of each individual's situation. Consequently, the individual learns how his problem is both similar to and different from that of others, which forces him to utilize the knowledge selectively to fit his situation (p. 450).

This learning and change that occurs from the sharing of experiential knowledge can be quite enduring, as individuals learn to trust their own experience and the wisdom within their own stories—as opposed to relying on professionals with “expert” knowledge to help them cope with their problems. Thus, the sharing of experiential knowledge in self-help groups not only feeds people's need for support and assistance with their problems, but also feeds their ongoing need for personal autonomy, independence, and mastery of their own situation (Romedor, 1990).

### Ideologies / Belief Systems

People in suffering have always struggled to make meaning and sense out of that suffering, as the Old Testament story of Job powerfully illustrates. What each self-help group offers—and each self-help group is unique and different—is an ideology, belief system, or philosophy to help members make meaning of

whatever affliction has brought the group members together. This belief system may be implicit and very subtle, or it may be explicit and reinforced at every meeting. For example, a large component of the ideology that Alcoholics Anonymous offers is the belief in a higher power—that group members do not have complete control over their lives (Lavoie, 1990; Romeder, 1990). In contrast, Recovery Inc., a self-help group for former mental patients, encourages the belief in self-power and the control of psychological symptoms through will-power training (Medvene, 1985).

Whatever the belief system a particular self-help group offers, there is generally a fairly powerful pressure the group exerts for members to adopt the existing ideology. Members who find the group's belief system to be unworkable or unsatisfactory will usually drop out of the group quite quickly. For those however, who do find the belief system workable, those beliefs are the glue that holds the group together, and offer members an important interpretation of their common suffering, which often has profound and lasting effects.

### Assistance Through Transitions

Silverman (1992) makes the important point that people in suffering—whether they be a newly diagnosed AIDS patient, a cocaine addict that has just hit bottom, or someone who has just lost their spouse of 25 years—experience that suffering in phases and transitions. Therefore, an important helping mechanism that occurs in self-help groups is group members helping each other through those

transitions, or as Silverman describes, enabling each other "...to get here to there...from one sense of self to another" (p. 80).

While every individual and circumstance is unique, people tend to experience trauma in three general phases. The first phase or transition is impact, where people are trying to take in the full reality of what has happened to them, such as being diagnosed with a life-threatening illness. People in this phase may feel disconnected and as if they are in a bad dream, and attending a group with other people in the same situation may not be helpful. The second phase is recoil, where people slowly begin to take in their new status and identity, and begin to allow themselves to feel the pain and anxiety they may have. A group at this point can offer individuals tremendous support by legitimizing their feelings and offering role models of people who are coping with their affliction. Finally, people may move through the third phase, accommodation, where they start to live differently according to their new identity. At this point, the group can not only offer an individual emotional support as they form their new identity, but the individual may now be receptive to other's needs, and assume the meaning-giving role of helper to others (Silverman, 1992). This is the magic of self-help groups: that many individuals within a group may be at many different phases and transitions within a group, but groups are able to negotiate a dance of reciprocity and balance whereby people receive when they need to receive, and give when they need to give.

### Self-Help Groups: Their Impact on the Health Care System

Self-help groups, in their quiet—and often not so quiet—way, are having a significant impact on the current health care system, and the way our health care system might look in the future. For example, Rouse (1987) outlines from her own experience how self-help groups can help to humanize public health both for provider and consumer alike, as well as making it more effective and capable of reaching hard-to-reach groups. There has been much written and discussed in the past few years how our health care system needs to move towards one that better embraces the principles of health, health promotion, prevention and empowerment (Epp, 1986; RNABC, 1992; Labonte, 1993), yet there are many internal sources of resistance to these changes. However, as a “critical mass” of the populace gets a taste of the kind of autonomy, empowerment and health-promotion that self-help groups offer, the demand for change in the health care system may ultimately come from consumers of that system.

Furthermore, as the support that self-help groups offer may often also include advocacy and political/social action, self-help groups are a fertile “training ground” for health care consumers to learn how to work towards change in the system. For example, Zola (1987) describes how women’s self-help groups were key in establishing the first women’s health clinics, and how disability self-help groups helped to establish the first independent living centers. Thus, self-help groups, through their action in the political arena, are very capable of bringing about legislative and social change.

Finally, Jacobs and Goodman (1989) make a convincing argument that self-help groups will become a major component of the health care system—particularly the mental health care system—for the important reasons of economics and cost-effectiveness. That is, the authors reason that as health care falls increasingly under the scrutiny of cost-conscious corporate managers, these managers will not fail to notice—unlike the physicians who traditionally managed health care before them—that the status quo is expensive and ineffective.

For example, the authors cite statistics which note that 60% of physician visits are not medically necessary, and an estimated 19 to 25% of hospital visits are inappropriate. The cost-containment motive alone may well start to drive managers to take a look at more economical and effective “treatments” such as self-help groups, particularly as health-care managers increasingly examine the mind-body connection, and realize the “cost-containing” effects of tending to people’s social, emotional and psychological needs. As evidence of this trend, Jacobs and Goodman point towards the rapidly rising use of self-help groups in corporate-run health maintenance organizations (HMO’s) and corporate employee assistance programs (EAPs) -- initial proof that modern corporate health care managers see the emotional/psychological/social support that self-help groups offer as a very wise and economical investment.

#### Self-Help Groups: Roles for Nurses

Current trends in the self-help group movement would indicate that nurses, particularly community health nurses, could well increase their roles and

scope of practice with self-help groups in the community. Yet a knowledge barrier exists for many nurses: despite self-help groups being such a popular and increasingly important part of our health care system, very few nurses have adequate knowledge of self-help groups. Professional training courses or workplace inservices on self-help groups are rare and sporadic (Stewart, 1989; Borkman, 1990; Kurtz, 1990). Lack of nurses' awareness or understanding about self-help groups corresponds with the failure to refer appropriate clients / patients to them. Thus, nursing students need to be exposed to self-help groups in basic nursing curriculum, and trained nurses need to be offered inservice educational sessions on self-help groups, such as the ones offered by the Self-Help Resource Association of B.C. in Vancouver (Wollard, personal communication, July, 1996).

Given further education, there are several broader roles that nurses could play with regards to self-help groups. The most important of these include the roles of referrer, resource person, and group member.

### Referrer

One of the most important, and probably the simplest role the nurse can assume is that of referrer. Nurses in both acute and community care settings are continually working with clients who are suffering from a variety of physical and psychological afflictions, and could benefit from involvement with a self-help group. In fact, Madara (1987) goes as far to suggest that the simple act of referring a client to a self help group is an ethical and professional obligation:

Just as it would be unethical for a physician to withhold medication that he or she knew would help a patient, with the increasing amount of research that indicates the value of social support, we must ask ourselves if there isn't a similar obligation or provide a patient with a referral to a self-help group, knowing that it can both reduce suffering and promote recovery or rehabilitation (p. 29).

In order for a nurse to refer a client to a self-help group, she or he needs to be aware of self-help groups in the community. Information about self-help groups is usually only a phone call away: if one is in a larger urban center like Vancouver or Toronto, self-help clearinghouses exist that will happily provide the names of self-help groups and contact persons. Otherwise, local crisis lines, mental health offices, or social services offices will usually provide this information.

Often simply providing a client with the name and telephone number of a self-help group, along with a bit of encouragement to call, is sufficient. The decision to call or not is then left in the hands of that person. Some people, however, are more likely to attend a group meeting if they receive a personal invitation from someone in the group (Gilbey, 1989). In this case, the nurse can ask for the client's permission to have them receive a phone call from a person in the self-help group itself. Either way, the important thing is that the nurse has made the client aware of the existence of the self-help group and what they offer. After that, the nurse must assume to a certain extent that the client will eventually connect with the group if he or she was meant to. Some nursing authors (Newton,

1984; Alley & Foster, 1990) suggest rather complicated processes of assessing whether groups are appropriate for clients or not. However, these kinds of approaches assume the nurse knows what is best for the client; a possibly condescending approach that hinders the client's ability to know what is best for him or herself. Generally, it is likely the best thing to do is to let clients explore groups on their own, and decide for themselves whether a particular group seems helpful or not.

#### Resource person

Another role that a nurse can play is to act as a resource person for a self-help group (Orr, 1987). This may be as simple as giving a guest talk on care of colostomies to a colostomy self-help group, or may be as involved as helping a group of people with a similar problem come together and form a self-help group (Gilbey, 1987). Or, as Quarrington (1992) describes with her experience on an inpatient psychiatric unit, nurses may be involved in starting and facilitating self-help groups. Such groups may or may not go on to assume self-leadership and continue on without nurse involvement (Wilson, 1992). No matter what particular role the nurse may assume as resource person, it is important that the nurse's involvement does not endanger the group's own ability to empower themselves, provide their own leadership, and retain their autonomy. As Borman (cited in Madara, 1987) is often quoted as saying, the professional must stay "on tap, not on top" (p. 28).

### Group Member

One final important role that nurses can play in supporting self-help groups (and themselves) is that of actual group member. There are actually many examples of nurses forming their own self-help groups. Cullinan (1992), for example, describes the powerful impact that a self-help group had on the ability of a group of nurses to deal with the excessive amount of death they were having to cope with as part of their work. She notes that as a result of the self-help group they formed, the nurses noticed:

(the) emphasis has switched from "doing nursing" to "helping patients die well" or "accompanying them on their way." Staff turnover has diminished as has the incidence of sick days; group members have come in on days off just to participate in the group (p. 102).

Whether a nurse belongs to a self-help group of other nurses, or a group of any other people with some common difficulty or identity, she or he gains a new appreciation and empathy for the tremendous healing powers tapped within self-help groups, and is more likely to support or refer to other self-help in the future.

### Caregiver Support Groups

As this dissertation focuses on the evaluation of a caregiver support and

education group initiative, it is appropriate to only briefly review some of the literature pertaining to caregiving. This review will focus primarily on a particular intervention for family caregivers: caregiver support/education groups.

### The Increasing Recognition of the Need to Support Family Caregivers

In the province of British Columbia, there has been a growing realization of the importance that family caregivers play in the health care system in B.C., and the overall health of British Columbians. As the percentage of the population that is aged 65 and over has been projected to increase by nearly 66% between 1991 and 2011, and the population aged 80 and over will increase during the same period by 135% (Gutman, Gee, Bojanowski & Mottet, 1995), the accompanying projected increases in demands for health care and continuing care cause many policy makers to wonder how better to support family caregivers of the frail elderly in B.C. (Forbes, Jackson & Kraus, 1987). Also, many of the baby-boomer generation are now caring for their aging parents (Brody, 1985), and wish to continue to do so as long as possible (Shanas, 1979a). Indeed, a recent telephone survey by the Center on Aging at the University of Victoria suggests that seven percent of B.C.'s population is caring for someone at home, usually a frail elderly family member (Chapell & Litkenhaus, 1995). These nearly two hundred and fifty thousand caregivers in B.C. represent not only a massive contribution to the health care of B.C.'s elderly, but also a potent political voice that is likely to become increasingly more vocal about the importance of supporting family

caregivers.

Having apparently recognized the potential economic and political benefits of assisting people to receive more of their health care "closer to home," and having identified seniors as a group that has not always been well served by the existing health care system, the B.C. Ministry of Health and Ministry Responsible for Seniors has begun a major health care reform initiative entitled "New Directions for a Healthy British Columbia" (Ministry of Health and Ministry Responsible for Seniors, 1993). A main thrust of this initiative is to develop means by which to shift the focus of care of B.C.'s elderly from institutions to the community.

Realizing that this shift cannot occur without the support of family caregivers in the community, the provincial Ministry of Health has recently begun to recognize the important care that family caregivers do provide (Shanas, 1979b; Brody, 1985), and is now considering beneficial and cost-effective ways of supporting family caregivers in the community. While there are numerous ways to support family caregivers -- such as offering them respite from the demands of caregiving (Lawton, Brody & Saperstein, 1989) -- bringing caregivers together in groups for education and mutual support has been a popular and successful means of caregiver support.

### Caregiver Groups

Different types of caregiver support groups have been in existence for

some time (Barusch, 1991). Recently, however, various levels of government in Canada are interested in playing a more active role in promoting caregiver support groups, as they are seen increasingly as a "cost-effective" potential way of assisting family members to keep their loved ones out of expensive institutional care for longer periods of time. Bringing caregivers together in groups is also in keeping with the principles of health promotion, which various Health Ministries across Canada (including B.C.) are advocating more strongly with the passage of time (Ministry of Health and Ministry Responsible for Seniors, 1993).

Caregiver support groups are also seen as noteworthy examples of the development of small groups in the community, which is a means of empowering people to take greater control over and responsibility for their own health (Epp, 1986; Labonte, 1989; Lord & Farlow, 1990; RNABC, 1990; RNABC, 1992). Indeed, as noted earlier in this review, the whole self-help group phenomenon -- people helping each other in small community groups -- has seen tremendous growth and success in the U.S., where it has been called "the other system," soon to assume primary responsibility for disease prevention and health promotion (Abdellah, 1990; Borkman, 1990; George & Gwyther, 1988; Jacobs and Goodman, 1989). For community health care professionals such as nurses, working with caregivers to establish and maintain support groups provides exciting opportunities to forge new client-provider relationships that are collaborative, egalitarian, health-promoting and community developing (RNABC, 1992), and help to expand the social networks of caregivers (Fudge, Neufeld, & Harrison, 1997).

### Evaluation Issues: Caregiver Support / Education Groups

A number of authors have undertaken reviews of published evaluations of group interventions for caregivers of "frail" elderly (Biegel, Sales & Schulz, 1991; Gallagher, 1985; Knight, Lutksy & Macofsky-Urban, 1993; Toseland & Rossiter, 1989; Zarit, 1990) and elderly persons with dementia (Collins, Given & Given, 1994; Kuhlman, Skodol-Wilson, Hutchinson, & Wallhagen, 1991). The overall conclusions of these reviews (many of which would only include evaluation articles if they were experimental or quasi-experimental studies, that is, if they used comparison or control groups), can be summarized as follows: (i) more evaluation studies, particularly empirical ones, are needed; (ii) there is considerable variation among the evaluation studies in terms of the nature of the group intervention and the measures used, making comparisons difficult; (iii) when asked about their experiences, caregiver group participants usually appear very satisfied with their group experience and report a number of benefits as a result of their experience; and (iv) when "objective" and standardized instruments are used to assess the effects of the groups on a variety of measures (e.g., depression, anxiety, burden) the effects of group interventions appear to be marginal and highly equivocal, although some authors have found that some form of group participation results in lower rates of institutionalization when compared with control groups (Greene & Monahan, 1987; Mittleman, Ferris, Steinberg et al., 1993; Mohide, Pringle, Streiner, et al., 1990).

### The Paradox of Existing Evaluations

An interesting paradox emerging from these reviews is the notion that, although caregivers give consistently favorable reports of support group experiences and indicate what a powerful and positive impact group participation has had on them, the objective, empiricist and quantitative evaluations of caregiver groups by and large conclude that in reality such groups do not have any statistically significant effect on caregivers. Tebes and Kraemer (1991) have noted this apparent contradiction, stating:

...members of a mutual support group frequently describe profound personal changes which result from membership, avow their satisfaction with the group, and attest to the group's meaning in their lives.

Researchers, however, who study the same participants in either a controlled or nonequivalent control group design, often fail to observe significant differences between the two groups on various health and psychosocial measures. Wherein lies scientific 'truth' given these conflicting perspectives? (p. 743).

Most traditional quantitative researchers would still say it is their perspective, and not that of the group members, that is closer to this elusive "truth." For example, it has been suggested that such factors as selection bias

"...suggest that there is little point in measuring or reporting consumer satisfaction in intervention evaluations" (Knight, Lutzky, & Macofsky-Urban, 1993, p. 244). Or, that caregiver satisfaction is in large part due to caregivers merely feeling "...grateful that someone pays attention to their needs and shows interest in their problems," and that caregivers might just "... feel positive about the agency/organization sponsoring the group, or they may like and appreciate the professional staff working with the group" (Biegel, Sales & Schulz, 1991, p. 224). Callahan (1989) also notes that although family caregivers may be highly satisfied with certain programs "...more than use, liking and satisfaction as a rationale will be required" for services to be made available (p. 6). Rather, Callahan argues that "...more sophisticated program design and continued analysis of outcomes" (p. 6) are needed, supposedly to elucidate the truth about whether these programs actually do anything for caregivers. Then and only then, Callahan argues, will policy makers presumably be able to make some responsible decisions regarding these programs.

#### Critique of the Traditional Paradigm for Evaluating Groups

The views reflected in the traditional quantitative evaluation research reviewed above reflect a basic philosophical stance that is essentially mis-trustful of caregivers' ability to "accurately" describe their own experience. That is, it is a philosophical stance that essentially favors professional and expert knowledge over people's own experiential knowledge (Borkman, 1976), and one that

believes that it is only the expert professionals, with all their traditional scientific wherewithal, who can be trusted to tell us what's really best for people.

This traditional expert approach to evaluating mutual support groups (such as caregiver groups) has been criticized elsewhere on at least six counts. Firstly, it has been noted that experimental procedures (such as random assignment, delayed interventions, placebo controls, and the administration of lengthy inventories and scales) over-control and objectify group members, and are antithetical to the values and goals of self-help groups such as member participation in the design and operation of activities, local grass-roots orientation, consciousness raising, and empowerment (Chesler, 1991; Tebes & Kraemer, 1991). As Chesler has noted, alternative paradigms of evaluation such as participatory action research are much more in keeping with the spirit of mutual support groups.

Secondly, as caregiver groups are predominantly comprised of women (Aronson, 1991), traditional methodologies that over-emphasize control, manipulation and objectivity are inappropriate for evaluating caregiving mutual support groups (Barnsley & Ellis, 1992; Harding, 1987; Olesen, 1994). Field-Belenky et al. (1986) have noted that many women have rejected the traditional scientific approach as "alien expertise," due to its patent devaluing of subjectivity, inner experience, morality, internal knowledge and emotionality. Caregivers (again, most of them women) are struggling with tremendously difficult and important feelings and inner experiences, and do not need to be told by some "scientific" evaluator (often a man) that such experiences and feelings are unimportant to the matter at hand.

Thirdly, traditional evaluation methods ignore or minimize the

considerable impact that evaluations may have on already tremendously burdened caregivers. Subjecting already stressed caregivers to attempts at measuring and/or controlling them (such as randomization, waiting lists and lengthy scales and inventories) is unsupportive at best and harmful at worst. Evaluators should assume that they will have an impact on the caregivers involved (Collins, Given & Berry, 1989; Lather, 1986; Rubin & Mitchell, 1976), and plan an evaluation that is as respectful and supportive as possible.

Fourthly, as Chesler (1991) has observed, both the structure and process of self-help groups make the realities of groups impossible to predict and replicate, and standardized or highly controlled research designs "...overlook or inappropriately squeeze group realities into oversimplified models" (p. 764). The benefits that arise from group participation are highly context-bound and unique to each group, and results from one group are not necessarily generalizable to other groups.

Fifthly, many of the benefits resulting from group participation are of an emotional and even spiritual, nature. While group members report that these kinds of benefits are extremely powerful and significant to them as caregivers (Hills, 1992; Wilner, 1988), traditional quantitative evaluators have often seen these kinds of benefits as measureless and hence inconsequential, because these benefits cannot be given a numeric score on a paper and pencil test. What attempts there have been to numerically quantify such highly subjective and personal experiences such as "spirituality" (Kaye & Robinson, 1994) and "loss of self" (Skaff & Pearlin, 1992) among caregivers seem patently wrong-headed and inane reductionistic.

Finally, the basic epistemology and values of quantitative inquiry have been called into serious question. While a complete review of these critiques is beyond the scope of this discussion, the arguments for more qualitative and participatory models of inquiry and evaluation (Freire, 1970; Greene, 1994; Guba & Lincoln, 1989; Lather, 1986; Patton, 1990) appear to be particularly relevant for evaluating support groups (Chesler, 1991; Tebes & Kraemer, 1991).

#### Alternative Models of Evaluating Caregiver Support Groups

Within the caregiving literature itself, there has been a gradual increase in the use of qualitative methodology to study caregiving (Neufeld & Harrison, 1995; Rutman, 1995). However, despite calls for increased use of qualitative and/or participatory style of evaluations methods to evaluate supportive group initiatives (Chesler, 1991; Tebes & Kraemer, 1991), at the time of writing this author was able to find only one qualitative evaluation of a caregiver group support initiative (Wilner, 1988). In her grounded theory of twelve caregivers of relatives with Alzheimer's disease participating in a caregiver support group, Wilner found that the most common reason for caregivers to join and use the groups was to "...transcend their position of being neglected and rejected by societal institutions" (p. 149). Members also felt a profound lack of support from other family members and friends. Wilner's evaluation showed that the prime outcomes of support group participation were prevention of premature institutional placement of the care-receiver, increased support, increase knowledge of support services, and smoother transitions to institutional care if

and when it was necessary.

Therefore, although Wilner's evaluation contributes important qualitative information to our understanding of how support groups might benefit caregivers of frail elderly relatives, more qualitative evaluation studies -- particularly studies that blend both qualitative and some quantitative methods -- will go a long ways towards shedding light on the equivocal quantitative evaluation results. Further such studies will also enable us to evaluate caregiver interventions in a manner which is supportive of caregivers and in keeping with the principles of mutual aid and community development. It is with these thoughts in mind that the evaluation of the SCBC program, the topic of this dissertation, was planned and conducted.

#### Canadian Public Policy on Family Caregiving: Reasons for Failure

Canadian society is on the brink of having to restructure itself in many ways to accommodate the impact of the aging "baby boomers" (Foot & Stoffman, 1996). As a result of these demographic shifts, the demand for caregiving is exhibiting -- and will continue to exhibit -- dramatic increases. Yet despite these current and projected demands, current Canadian public policies regarding family caregiving are inadequate to meet either present or future needs (McDaniel & Gee, 1993). Services available to assist caregivers vary greatly from province to province, and year to year. Reflecting a generalized lack of coherent policy -- at

any level of government -- regarding caregiving, those services that do exist for caregivers tend to be fragmented, disjointed, poorly coordinated, hard to access, and susceptible to funding disruptions. While a program such as the SCBC program is a noteworthy example of a level of government (B.C. provincial) attempting to support family caregivers, it too suffers the fate of most such programs: lack of ongoing funding and lack of clear policy support.

There are numerous contributing factors to the lack of clear Canadian (Federal or Provincial) policy and programming for family caregivers. This discussion will review the most important factors: myths society has about caring for the elderly; Canadian health-care funding structures; the new Conservation; and the gendered nature of caregiving.

### Myths About Elder Care

In our society, a number of myths about caring for the elderly exist, that have allowed our public policy to fall woefully behind the actual realities. One of the most pervasive and stubborn myths is the myth of family abandonment; that caregiving is actually on the decline and that families do not care for their older members the way they used to “in the good old days.” This myth perpetuates despite ample evidence to the contrary (Brody, 1985; Gilliland & Havir, 1990;

Hortensine Brackely, 1994). This myth, held both by the general public and government policy makers, has a considerable impact on public policy. Policy makers, influenced by this myth, express widespread fear that any publicly sponsored elder-care programs -- or any program that might be seen to give family caregivers a "break" -- will encourage caregivers to abandon their elderly relatives at even faster rates than they supposedly are now. Obviously, this kind of myth-generated public policy has disastrous consequences for the countless number of people who are caring dutifully for elderly family members.

A second related myth is the "come out of the woodwork" myth (Gilliland & Havir, 1990). That is, it is feared that once families get wise to any elder-care services which might be available to them, they will "come out of the woodwork" to demand more and more such services, until such services are swamped and overloaded. Policy makers reason that the only way to curtail these unlimited demands for more publicly sponsored services, is to severely limit benefits and services. The reality that nearly all family caregivers need to be persuaded and cajoled into using *any* services to supplement their own considerable caregiving labor, is lost to most policy makers.

A third myth is the myth of intergenerational inequity. This myth portrays the elderly as the fabulously wealthy, getting rich from entitlement programs and seniors's discounts, and who are "...robbing the young, stripping the economy and

plunging the nation into debt” (Binney & Estes, 1988, p. 90). This myth promotes intergenerational conflict, by using such powerful terms as “old age dependency ratios,” and suggesting that the money and benefits siphoned by the affluent elderly would otherwise go to needy and hungry children (Gilland & Havir, 1990). Thus, any additional money that might be directed towards the elderly, even if it was used to support family caregivers, is often perceived as just more grain to an already fattened calf. Yet, as some authors such as McQuag (1995) might argue, the real reasons for rising fiscal deficits are such factors as rising interest rates on national debts, tax cuts to corporations, and military spending increases (in the US). Thus, the real ‘truth’ may lay hidden behind the myths and rhetoric of elder care, along with the many hidden elderly (especially women) who live below the poverty line.

### Barriers Within the Canadian Health Care System

In addition to the above myths influencing the Canadian public and policy makers, there are unique aspects of the Canadian health care system that severely hamper its ability to respond effectively to the challenges of elder care. McDaniel and Gee (1993), in their review of Canadian public policy regarding family caregiving, give a clear description of these “Canadian contradictions.” For

example, since the Canadian Health care system was first established by giving priority to funding acute care -- that is, hospitals and physicians -- the system became a health care system for the *young*. Once hospitals and doctors became entrenched in their hierarchies of power and influence, the resistance to changing the health care system to be more receptive to the needs of the elderly has been -- and continues to be -- firm.

In addition, the Canadian health care system, although one of the best in the world, is plagued by the nebulous assignment of responsibilities between federal and provincial governments. The historical basis for provincial jurisdiction over health care, combined with the shifting nature of transfer payments between governments, results in elder care programs and policies that vary greatly from province to province. As McDaniel and Gee (1993) point out, "...policies concerning the aged and caregiving have developed in an ad hoc fashion and are fraught with internal contradictions" (p. 62). Using respite care as an example, they note that: "...in some places, respite care is provided under provincial government long-term care policy; in others, it is available only from for-profit organizations for persons willing and/or able to pay" (Ibid, p. 64).

Even in provinces where elder care policy may be more innovative or progressive than others (e.g., British Columbia), the programs, services, eligibility criteria, and funding sources are confusing, disjointed and constantly changing.

The situation is similar for policy and funding related to community development.

As Hume (1993) notes,

...the sheer numbers (of funding sources) makes it difficult for communities and even other government employees to keep track of what is available. The short-term nature of the funding and restricted funding criteria limit the usefulness to well defined projects rather than ongoing processes that may evolve as the needs of the community evolve (p. 50).

As no exception to this trend, the SCBC program itself came from a number of confusing funding sources, all of which were short term and no longer available after the completion of the program. Unfortunately, such is the current nature of public policy regarding family caregiving.

### The New Conservatism

Another contributing factor to sluggish public policy regarding caregiving is the new political climate of Conservatism, at the core of which is heated debate over the role of government in the “private” aspects of people’s lives. As “the new conservatism” has dominated the political landscape throughout the 1980’s and 1990’s, increasing responsibility has been transferred to the family and the individual, and away from the state. This transfer of responsibility has certainly

influenced care of the elderly. Although much of this transfer of responsibility has been motivated by economic factors -- the belief that family care of the elderly is "cheaper" than care offered by the government, many of the arguments also contain moral overtones. That is, family care or "community care" of the elderly is often promoted alongside the ideologies of self-help, empowerment, austerity, self-sufficiency, individualism, and family responsibility (Binney & Estes, 1988; Hooyman, 1990; Kapp, 1991; Skelton, 1994).

Although these ideologies are laudable in and of themselves, they are no justification for public policy that targets family members (predominantly women) as cheap sources of labor, with no regard to the associated financial, physical and emotional burdens of caregiving (Binney & Estes, 1988). As Hooyman (1990) suggests:

...such public demands for filial responsibility mask social irresponsibility. They label adults, primarily women, as unloving deviants if they institutionalize their relatives, scapegoat them for the escalating long-term care costs, and place the legitimate needs of generations in conflict with one another (p. 233).

Hogan (1990) notes that the current conservative political climate and associated policies may backfire. As she notes, "...if the state continues to place burdens on

families to increase their caregiving activities, the effect will undermine the very family that is currently giving the majority of the informal care to the elderly” (p. 16). Thus, although governments may neglect the issue of caregiver well-being and support in the short term, the long-term effects of prolonged caregiving on individuals and society may be considerable, and cannot be ignored (Hooyman, 1990; McDaniel & Gee, 1993).

### The Gendered Nature of Caregiving Work

One final possible contributing factor to the current caregiving policy directions is that caregiving is almost exclusively women’s work. As Ward (1990) has noted, “family care” is really a euphemism for “women’s care,” as not all members of the family share equally in the work of caregiving. Since the majority of caregivers are women, and the majority of policy makers are men (or traditionally have been men), it is unfortunate, but not altogether surprising, that current caregiving policy perpetuates the gender inequities of caregiving work. For example, current home care policy in Canada, which strives to maintain elderly persons at home for as long as possible, has minimal impact on men, but places tremendous burden squarely on the shoulders of Canadian wives, daughters and daughter-in-laws (McDaniel & Gee, 1993).

When men in society are allowed to avoid the actual work of caregiving, caregiving becomes “invisible” to them (including male policy makers), as do the long-term consequences of caregiving work. For example, all the years women spend out of the full-time work force to care for others are not compensated by pensions or social security in Canada. This deepens the “feminization of poverty” many women experience, particularly in old age. As Ward (1990) notes,

...if women caregivers have to reduce work hours, forego promotions, and/or risk their own retirement funds by changing or leaving work, they risk impoverishment and the likelihood that their own daughters will face the same dilemma (p. 233).

Until real political change occurs, public policies which perpetuate these gender inequities in caregiving are unfortunately likely to continue.

### Summary and Conclusions

In summary, after reviewing selected aspects of the relevant literature on community development, self-help, the evaluation of caregiver support groups, and forces shaping Canadian public policy on caregiving, several points can be noted. First, it has been seen that the traditional ways of evaluating caregiver support groups are antithetical to the very principles upon which such groups are

founded. In an over-zealous quest for scientific rigor, evaluators have also overlooked the importance of utilizing evaluation methods that empower, encourage the telling of stories, and recognize the value of the experiential knowledge that caregivers possess. Furthermore, more information is needed about both the process and outcomes of government sponsored community development projects that involve the establishment of small groups / support groups. There is also the issue of balance in such projects: the possible pitfalls of co-opting and over-involvement by professionals need to be weighed carefully against placing unrealistic demands and expectations on community members, particularly when involving already heavily burdened groups, such as family caregivers. Finally, there are a number of forces at work in Canadian society that have resulted in generally inadequate policy to support the growing number of family caregivers. These forces are important considerations when trying to implement and evaluate government sponsored caregiver programs such as the SCBC program.

## CHAPTER THREE: METHODOLOGY

### Purpose and Scope of Chapter Three

The purpose of this chapter is to introduce the methodology for this dissertation. This chapter will include a detailed outline of the SCBC program, and a discussion of the participants, research methods and procedures, ethical considerations, and data analysis plan. The data were collected as part of a large collaborative research project. As co-principle investigator, the author played a major role in the development of surveys and interview guides, coordination of the evaluation, and in the collection of data.

### The Supporting Caregivers in B.C. (SCBC) Program

#### Timelines and Phases of the Program

The SCBC project consisted of two phases. Phase I -- which included an initial pilot of the program in Kamloops -- was undertaken from February, 1994 until March 1995, and focused on providing a program primarily for persons caring for an older family member with Alzheimer's or other mental health

disorder. During phase I, two support-group facilitator training workshops were held, and caregiver support groups were established in six under-serviced communities throughout B.C., using the 10-week facilitator led model discussed below.

Phase II officially began in June, 1995, and ended in August, 1996. In phase II, a decision was made to broaden the target audience of caregivers to include anyone caregiving for an older adult. Facilitator training workshops were again conducted, and ten additional communities throughout B.C. were targeted for the establishment of caregiver support groups. As with phase I, the phase II caregiver groups were established using the 10 week facilitator-led education and support group model.

#### Content of the Program

As will be discussed in more detail later in this chapter, a steering committee representing several stakeholders was formed to oversee the development and delivery of the SCBC program. To develop the content of the SCBC program, a subgroup of the steering committee was formed. After an extensive review of other education and support group formats, this subgroup developed a ten-week education and support group program. The program was

developed so as to be facilitated by either a lay or a professional group facilitator, who would lead small groups (i.e., 6 - 15) of caregivers through ten weekly sessions of roughly two hours each. Each of the sessions entailed approximately one hour of education / discussion on a pre-determined topic (with room for two optional topics to be determined by the group), and one hour of mutual group support, where participants were encouraged to share freely whatever they felt important to share. Although a pre-set agenda was available, group facilitators were encouraged to be adaptable, and flexible to the particular needs of their group as they arose. The topics comprising the educational component included the following:

- \* Meeting the group and group expectations / goals.
- \* Communication: within the group and between caregiver and care-receiver.
- \* How to cope with difficult behaviors.
- \* What about me?: Support, assertiveness and self-care.
- \* Accessing and using local community resources.
- \* Dealing with potential legal and financial problems.
- \* Coping with caregiver stress.
- \* Two optional sessions: individual group decides.

- \* Where to from here? Planning future goals of the group.

### Goals of the Program

The SCBC steering committee had decided that the overall goal of the SCBC program should be to develop caregiver education and support groups in communities of B.C., which had identified themselves as lacking support for family caregivers of the frail elderly. Goals of the SCBC project varied slightly from phase I to phase II. The specific goals of phase I were as follows:

- \* To provide an opportunity for family caregivers to experience being in a support group.
- \* To provide caregivers with an opportunity to learn more about issues affecting caregiving.
- \* To provide caregivers with the experience of being supported in their roles.
- \* To enhance caregivers knowledge about and access to other community services.
- \* To examine the need for local respite care for caregivers.
- \* To provide opportunities to assess ongoing needs for support which could

lead to the development of support networks and other forms of service in the community.

Phase II goals were similar, but were modified slightly, based on the experience of phase I. The goals of phase II included:

- \* To enhance caregivers' knowledge and use of formal and informal services available in the community through:
  - informing and encouraging them to use appropriate services,
  - assisting them in linking with needed services.
- \* To introduce caregivers to the empowerment potential of small groups through participation in an SCBC support/education group.
- \* To enhance day-to-day caregiving abilities and satisfaction, and potentially reduce premature institutionalization through:
  - sharing of effective problem-solving strategies,
  - informing them about caregiving strategies, through use of carefully selected videos, guest speakers and printed materials,
  - attending to issues relevant to self-care of the caregiver,
  - understanding their family's need for respite and the variety of options available.

- \* To encourage on-going, self-sustaining support groups and other creative support mechanisms through:
  - establishing a long-term commitment for someone or some agency to assume the responsibility for overseeing caregiver issues in each community,
  - encouraging interagency partnerships to address ongoing caregiver issues,
  - forming networks with other support groups in the community and throughout the province to establish a resource base and become more powerful in effecting change.

### The Community Development Process

#### Initial Selection of Partners.

A somewhat unique partnership was formed to oversee the SCBC project and its subsequent evaluation. Largely due to the vision and persistence of some individuals in the Continuing Care Division of the B.C. Ministry of Health, a partnership was formed including representatives from the Caregivers Association of B.C. (CABC), the Alzheimer Society of B.C., the Kamloops District Alzheimer Association, and the University of Victoria School of Nursing (including the

author). By bringing together groups who all had the similar and overlapping objective of supporting family caregivers, resources were pooled, bridges built between community organizations, and duplication of services reduced. This task was not easy however, as there existed a historic turf war between CABC and the Alzheimers Society of B.C. Both of these groups were involved in caregiver advocacy, and saw themselves in direct competition with each other for scarce government and private funding. Furthermore, personality differences between the representatives of these two groups made collaboration extremely difficult, and the partnership was threatened at numerous points along the process. Partners from the University of Victoria (School of Nursing) played a large diplomatic and “peace-keeping” role, and the overall project funders (Continuing Care Division, Ministry of Health) made it clear that successful project and agency funding depended upon the partners’ abilities to work effectively with each other.

Representatives from these community groups formed an overall SCBC project steering committee which, among other things, was responsible for overseeing the project budget, hiring a project coordinator/community developer, developing the SCBC program, and conducting the project evaluation.

#### Participation of Caregivers in Decision Making Process.

From the outset, there was a shared realization among all partners that the

SCBC project needed to embrace community development principles, and efforts were made to maximize caregiver input into the project, and avoid a situation whereby an expert steering committee would merely make decisions in a “top down” manner. Yet there was also an equal realization that the average caregiver in the community was heavily burdened, and would likely have neither the time or the energy to attend regular steering committee meetings.

This dilemma was resolved in several ways. To begin with, it was ensured that at least half of the steering committee were former caregivers, and the project coordinator / community developer (who sat on the steering committee) had extensive recent experience as a caregiver. Second, each of the community groups represented on the steering committee had frequent contact with family caregivers, and input from caregivers was continually channeled to the committee through these various connections. Thirdly, the SCBC project itself was actually implemented in three phases: pilot phase, phase I and phase II. Each phase of the project solicited extensive caregiver feedback through the evaluations, so each subsequent phase was modified as caregiver feedback was received. Thus, with a combination of all these measures, the steering committee felt more confident that caregivers still ultimately “owned” the overall SCBC project, even though no active caregivers actually sat on the committee itself.

### Selection of Community Sites.

Kamloops, the community where the SCBC project was offered as a pilot, was chosen due to its original involvement in the SCBC grant application process, and its willingness to serve as a pilot development site. Once the program had been successfully piloted in Kamloops, the remaining 16 communities in B.C. were chosen for phase I and II. These communities were chosen by the steering committee on the basis of having been identified during a province-wide campaign of public forum meetings on caregiving in 1993 and 1994 (conducted by Caregiver's Association of B.C.) as having few, if any, existing caregiver support groups. An equitable distribution of communities throughout the province was also sought, both in terms of geographic location and population size.

### Selection of Community Steering Committees.

In most of the communities, recruitment of local steering committees began by holding a large community public "town hall" meeting of stakeholders, out of which emerged local steering committees. Membership on these committees varied, with members representing past and present caregivers, retirees, continuing care and home nursing personnel, social workers, mental

health workers, activity coordinators, and both hospital and extended care personnel. Their role was three-fold: to get the SCBC group program initiated; to recruit both facilitators and caregiver participants; and to assist the caregiver groups' long-term sustainability.

#### Recruitment and Training of Group Facilitators.

As the steering committee spoke to more and more caregivers, it became obvious that most caregivers did not feel comfortable about joining a caregiver education and support group that was “self-led.” That is, due to the tremendous pressures put on their time and energy, caregivers repeatedly stated that they wanted a group experience that was led by a facilitator who was familiar with the content being presented, knowledgeable about local resources, and comfortable with the intense emotions that can arise in caregiver support groups.

In response to this feedback, a decision was made to solicit and train facilitators to guide the caregivers through the initial 10 week program, with the hopes that this two and a half month experience would increase the skills and confidence of the groups sufficiently enough to become self-led and self-sustaining. The facilitators would thus guide each group through the process of becoming a self-led and self-sustaining group; a “true” self-help group.

Each of the local community steering committees took responsibility for recruiting, through advertising and word of mouth, suitable group facilitators for their local group of caregivers. The group facilitators varied in experience and background, although several were either nurses or social workers (some retired). Their ages ranged from early 20's to early 70's, and all were female. A small honorarium was given to the facilitators for their services. For each of the groups, a less experienced co-facilitator was also recruited on a volunteer basis. These co-facilitators, whose role was primarily a support for the facilitator, were typically persons who wanted some volunteer experience with caregivers, but felt uncomfortable with the role of primary facilitator.

To train both the facilitators and co-facilitators, two-day facilitator training workshops were offered at the Naramata Center, near Penticton, B.C., and in central Vancouver Island. Facilitated by a local caregiving counselor and group process expert, the training workshops familiarized participants with caregiver group facilitation skills, the SCBC program, and the facilitator's guide which outlined the 10 week program. By the end of phase II of the SCBC project, a total of six facilitator training workshops had been conducted, providing groups and communities with a rich resource of persons trained in conducting and facilitating caregiver support groups in their communities. The author attended the first two workshops as a participant in order to fully understand the process and content of

the program, and to introduce the evaluation plan to the group facilitators.

### Community Awareness and Development.

In the SCBC project, community steering committees were formed not only for the purpose of getting the caregiver groups running, but also to raise the profile of caregiving issues in their community, and to initiate efforts to address those issues. Many community steering committees had newspapers run human interest stories on caregiving, raising the profile in the community of not only the SCBC program, but of caregivers in general. As steering committee members furthered their recruitment campaigns by targeting banks, business, churches, senior's centers, etc., community awareness of caregivers continued to grow.

The program coordinator / community developer remained in ongoing contact with each of the community steering committees - and would pay visits when useful -- in order to share other communities' experiences and help committees brainstorm around community development issues. With some communities, community development took the form of political action, whereby caregiver participants and/or community steering committee members began to lobby varying levels of government for change. Lobbying objectives included increased home care hours, additional funding for future facilitators, better access

to respite care, and increases in long-term care facility beds.

## Participants

### Recruitment of Communities and Participants

The communities selected for phase I of this project were: Kamloops (pilot), Quesnel, Hope, East Vancouver, Terrace, Coquitlam and Castlegar. Phase II communities included: 100 Mile House, Campbell River, Comox Valley, Delta/Tsawwassen, Fort St. John, Revelstoke, Richmond, Salmon Arm, Trail and Golden. The communities were purposefully diverse in size, ranging from 5,000 to 500,00 in population, and were identified and chosen by steering committee members (after a CABC-sponsored province-wide series of public meetings of caregiving) as having few, if any, existing generic caregiver support groups.

Recruitment of caregiver participants was one of the tasks of the local steering committees. Although each steering committee went about this job a little differently, some common methods of client recruitment existed. These included:

- Distribution of brochures and posters to churches, pharmacies, banks, physician's offices, senior's centers, grocery stores, home care agencies,

Continuing Care, health units, and long-term care facilities.

- Meetings with long-term care and continuing care assessors and home nursing coordinators, to make them aware of the program and to encourage appropriate referrals.
- Advertising in radio, T.V., and newspaper.
- Publication of “human interest” stories on caregiving in the local newspapers, including information on the SCBC program -- and, of course,
- Word of mouth.

Each local steering committee continued their recruitment activities until such time it was felt enough caregivers existed to form a group, generally anywhere from 5 to 12 caregivers.

### Characteristics of Participants

#### Caregiver Participants.

A total number of 166 caregivers participated in the SCBC program; 56 in phase I, and 110 in phase II. Table 2 summarizes the participation of caregivers in various levels of the evaluation for both phase I and phase II. As Table 2

Table 2: Caregivers by Participation in SCBC Evaluation

	Phase I		Phase II		Combined (I & II)
<b>Total Caregivers in SCBC Program</b>	56		110		166
<b>Did not participate in Evaluation</b>	5% (N = 3)		40% (N = 44)		28% (N = 47)
<b>Did participate in SCBC Evaluation</b>	<b>Completed at least Time 1 Survey</b>	<b>Completed Both Time 1 and 2 Surveys</b>	<b>Completed at least Time 1 Survey</b>	<b>Completed Both Time 1 and 2 Surveys</b>	72% (N = 119)
	95% (N = 53)	88% (N = 49)	60% (N = 66)	25% (N = 28)	

Table 2

demonstrates, eighty eight percent of the 56 caregivers in phase I ( $N = 49$ ) completed both the pre and post-program components of the program evaluation. In contrast, only 25% of the 110 caregivers in phase II ( $N = 28$ ) completed both components of the evaluation, although 66 of the phase II caregivers (60%) completed at least the pre-program survey (and thus giving demographic information). The lower rate of evaluation completion in phase II was likely due to phase II caregivers being sent their post-program surveys by mail only, whereas phase I caregivers had their completed surveys picked up by researchers at a special meeting called for each caregiver group in their community. This less desirable means of collecting surveys in Phase II was due to budgetary restrictions, as less money was available in the evaluation budget for traveling to the various sites in Phase II.

Table 3 summarizes the demographic data on caregivers participating in the SCBC evaluation. As Table 3 illustrates, the majority of caregivers were women (between 82% and 95% of all participants), whose average age was approximately 60 years. Most caregivers were only caring for one person -- generally their spouse -- and had been providing care for approximately six years on average. A high majority of caregivers were married, and were either retired or homemakers. Roughly three quarters of caregivers were of European descent.

Table 3: Sociodemographic Characteristics of SCBC Caregiver Participants

<b>Age</b>	$\bar{X} = 57.9$ years	$\bar{X} = 61.6$ years
<b># of Persons Cared For</b>	$\bar{X} = 1.18$ persons	$\bar{X} = 1.14$ persons
<b>Length of Time Caregiving</b>	$\bar{X} = 6.2$ years	$\bar{X} = 5.4$ years
<b>Gender</b>		
Female	95.3% (N = 41)	81.8% (N = 54)
Male	4.7% (N = 2)	18.2% (N = 12)
<b>Relationship to care-receiver</b>		
Spouse	50.0% (N = 21)	59.1% (N = 39)
Daughter	35.7% (N = 15)	25.8% (N = 17)
Other	14.3% (N = 6)	15.1% (N = 9)
<b>Marital Status</b>		
Single	2.3% (N = 1)	0% (N = 0)
Married	63.3% (N = 31)	92.4% (N = 61)
Widowed	4.1% (N = 2)	3% (N = 2)
Divorced	12.2% (N = 6)	3% (N = 2)
Separated	6.1% (N = 3)	1.5% (N = 1)
<b>Employment Status</b>		
Full-time	18.6% (N = 8)	12.1% (N = 8)
Part-time	14.0% (N = 6)	15.2% (N = 10)
Seeking work	7.0% (N = 3)	1.5% (N = 1)
Homemaker	20.9% (N = 9)	28.8% (N = 19)
Retired	37.2% (N = 16)	42.4% (N = 28)
WBC	2.3% (N = 1)	0% (N = 0)
<b>Able to Meet Basic Financial Needs?</b>		
Meet all of needs	56.1% (N = 23)	N/A
Meet most of needs	29.3% (N = 12)	N/A
Can barely meet needs	14.6% (N = 6)	N/A
<b>Ethnic Background</b>		
European	70% (N = 28)	84% (N = 47)
Canadian	10% (N = 4)	3.6% (N = 2)
Slavic / Russian	12.5% (N = 5)	5.4% (N = 3)
China / Pacific Rim	5% (N = 2)	3.6% (N = 2)
Other	2.5% (N = 1)	1.8% (N = 1)
Native Canadian	0% (N = 0)	3.6% (N = 2)
<b>Previous Experience with Support Groups?</b>		
Yes	18.6% (N = 8)	N/A
No	81.4% (N = 35)	N/A

Finally, data from the phase I participants indicated that most (85.4%, N = 35) caregivers could meet all or most of their financial needs, and only 18.6% (N = 8) had any previous experience with support groups.

Table 4 summarizes the sociodemographic information available for the persons that caregivers in the SCBC program were caring for. As table 4 illustrates, the average age of care-receivers was 73.4 years, and care-receivers were split closely between females and males. As with caregivers, most care-receivers were married, and were living with the caregiver (again, usually their spouse) in their home. Finally, data from phase I indicated that slightly more than half (54.8%, N = 23) of the care-receivers were suffering from a dementia such as Alzheimers disease. The remainder suffered from a wide variety of conditions including strokes, Parkinson's disease, osteoporosis, arthritis and cancer. No data were collected on the conditions requiring care for the care-receives in phase II of the SCBC program.

Table 4: Sociodemographic Characteristics of Care-Recipients

<b>Age</b>	$\bar{X} = 73.4$ years	$\bar{X} = 73.4$ years
<b>Gender</b>		
Female	48.8% (N = 21)	42.4% (N = 28)
Male	51.2% (N = 22)	57.6% (N = 38)
<b>Marital Status</b>		
Married	67.5% (N = 27)	92.4% (N = 61)
Widowed	30% (N = 12)	3% (N = 2)
Divorced	2.5% (N = 1)	3% (N = 2)
Separated	0% (N = 0)	1.5% (N = 1)
<b>Living Arrangements</b>		
In Caregiver's home	57.1% (N = 24)	72.7% (N = 48)
Alone	16.7% (N = 7)	7.5% (N = 5)
In own home, with others	14.3% (N = 6)	12.1% (N = 8)
Long-term care facility	7.1% (N = 3)	7.6% (N = 5)
In own home, with caregiver	4.8% (N = 2)	0% (N = 0)
<b>Condition Requiring Care</b>		
Dementia (e.g., Alzheimers)	54.8% (N = 23)	N/A
Other conditions	45.2% (N = 19)	N/A

Community Steering Committee Participants.

The community steering committees varied widely in membership. A breakdown of their membership for phase I is as follows:

**Vancouver:** 10 members: one director of care of a local intermediate care facility; two mental health nurses; two continuing care staff; two home support staff; two caregivers; three provincial disease-specific organization representatives, and the SCBC project coordinator.

**Terrace:** 8 members: two psychiatric nurses; one long-term care facility nurse; one home support administrator; one long-term care assessor; one past caregiver, and two local seniors.

**Quesnel:** 7 members: one head nurse of a long-term care facility; one nurse from an hospital extended care; one adult day care administrator; one home support administrator; one seniors' counselor; one Alzheimer support group leader, and a volunteer senior.

**Hope:** 6 members: one adult day care director; one head nurse of a hospital extended care; one hospital social worker; one mental health nurse; one retired long-term care assessor; and a caregiver.

**Coquitlam:** 9 members: one assessor from continuing care; one mental health nurse; one administrator from home support; two hospital social workers; one activity director from a seniors' center; one activities coordinator from a disabled young adults center; one retired caregiver support group leader, and the SCBC project coordinator.

**Castlegar:** 5 members: two caregivers; one local senior (non-caregiver); one long-term care assessor; one nurse from a long-term care facility.

Data were not available for the composition of steering committees in the communities participating in phase II of the SCBC project, although they were similar in size and makeup to committees in phase I of the project. For the purposes of this dissertation, data was only obtained from steering committees involved in phase I of the project.

## Research Methods and Procedures

### Overview of Methodological Approaches

This dissertation incorporates a number of methodological approaches,

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including participatory action research (Barnsley & Ellis, 1992), qualitative evaluation research (Patton, 1990), and survey research methods (Burns & Grove, 1993). A mix of methodologies was chosen not only to overcome the shortcomings of traditional evaluations of caregiver support group initiatives outlined in chapter two, but to also accommodate the wide-ranging needs which various stakeholders had of the evaluation.

Aspects of participatory action research are reflected in the considerable input and decision-making influence steering committee members and community caregivers had in the research, and in the extent to which research findings can and will be used to influence the change process. Qualitative evaluation research was reflected in the focus group interviews which took place with caregivers in their groups, and community steering committees. Finally, survey research methods were reflected in the survey questionnaires which were administered to individual caregiver participants.

A description of the methods, procedures and data analysis associated with the dissertation research will now be presented. The methods and procedures are discussed for each research question, as per the four levels of evaluation introduced in chapter one.

Level One: Questions, Methods and Procedures at the Level of the Individual

Question 1: What did the caregivers perceive as the main benefits of the SCBC program?

Method.

Focus group qualitative interviews with caregivers, meeting in their usual caregiving groups.

Procedure.

Six caregiver groups from phase I of the SCBC project, all in different communities, were interviewed in a focus group setting by nurse research assistants (and the author) three months after the end of the official 10 week SCBC program. The interviews were conducted using a semi-structured interview guide (see Appendix 1) and tape recorded. As can be seen in Appendix 1, question #1 relates to the first research question regarding perceived benefits of the caregiver support groups. All interviews were held in the usual locations of the support group meetings, lasted approximately 60 minutes, and were followed by a “tea social.”

### Data analysis.

The audiotapes from each of the focus group interviews were transcribed in their entirety. The transcripts were reviewed numerous times to get a sense of the whole (Sandelowski, 1995), and analyzed using NUDIST qualitative analysis computer software (Richards & Richards, 1990). Data analysis entailed reasonably straightforward content analysis (Patton, 1990), as the author was merely looking for themes in the qualitative data which summarized group members' responses to each of the questions contained within the focus group interview guide. That is, each transcribed focus group interview contained various sections of responses which pertained to each of the questions asked in the interview guide, and data analysis consisted primarily of easily locating and summarizing the responses of focus group participants. Emergent themes and concepts pertaining to the interview / research question were categorized and reviewed with NUDIST software, using the participants' own words and descriptions wherever possible (Patton, 1990). Memos and analytical notes were kept (using NUDIST) to record the process of developing themes and categories, until such point that no new themes developed from the data (Sandelowski, 1986; Tesch, 1987; Tesch, 1990).

In order to help establish the credibility of analysis throughout the process

of content and data analysis (Lincoln and Guba, 1985; Sandelowski, 1986), several techniques were used. To begin with, “member checking” (Lincoln & Guba, 1985) was used to the extent that each focus group interviewer “played back” the main themes arising from the focus group interview to the group members at the end of each interview, and invited comments and reactions. This immediate form of checking allowed the opportunity for respondents to assess the correctness of the information the interviewer had collected. Although this immediate form of member checking was possible, subsequent member checking -- once the data analysis had been completed -- was not possible due to the inability to re-visit the sites throughout the province. The themes emerging from data analysis were, however, checked by reviewing them with members of the overall steering committee, many of who were former caregivers.

The author also used “peer debriefing” (Lincoln and Guba, 1985) as a means of ensuring the credibility of data analysis. The author was able to debrief the process of data analysis and seek validation of the emerging themes with: the two research assistants which had also (along with the author) conducted focus group interviews; two other research assistants who had transcribed the focus group interviews (both experienced with NUDIST software); and the co-investigator of the SCBC evaluation. This process of peer debriefing included elements of an “audit trail” (Lincoln & Guba, 1985), such as sharing of the raw

data, data reduction and analysis process (e.g., categorical notes), data reconstruction and synthesis products (e.g., the structure of categories, definition of themes), and process notes. Through this process of peer debriefing, the author was able to gain considerable confidence that the resulting themes did indeed accurately reflect the focus group participants' responses during the interviews.

Question 2: To what degree was the SCBC program successful in increasing caregivers' support?

#### Method.

Pre and post-program survey questionnaires, administered to caregivers in phase I of the project, were used to address this question. The pre-program survey is seen in Appendix 2, and the post-program survey in Appendix 3. It can be seen that questions #5 & 6 in the pre-program survey, and questions #4 and 5 in the post-program survey, deal with the second research question regarding caregivers' experience of support. Although the importance of social support for family caregivers has been well recognized (Biegel, Shore & Gordon, 1984; Chappell, 1992), there is no one accepted means by which to assess the level and/or type of social support caregivers receive. Therefore, the social support questions in appendix 2 & 3 were developed after a review of the literature on

caregiving and social support and existing caregiver social support measures (for example, Chase-Goodman, 1991; Hannappel, Calsyn & Allen, 1993).

The social support questions were developed primarily as a means to simply and easily measure both the kinds and quantity of social support that caregivers received, and an additional question was added to assess caregiver's overall satisfaction with the support they received from others. The resulting social support questions are very similar to the social support measure used by Hannappel, Calsyn and Allen (1993) in their study of social support and caregiver depression. That is, both their study and this dissertation measured *structural social* support (the people in their support network), *functional social* support (the types of social support provided), and *satisfaction with social support*.

Although the social support questions used in this dissertation offer good face validity, and were previewed by other researchers familiar with the caregiving literature, no other tests of validity or reliability (e.g., Chronbach's alpha) were performed, as the questions were primarily a means to measure the overall quantity and type of support caregivers received.

#### Procedure.

The 56 caregivers participating in phase I were given survey questionnaires to complete at the first session of the SCBC program (pre-program

survey: see Appendix 2), and again three months after the last of the 10 weekly sessions (post-program survey: see Appendix 3). Pre-program surveys were handed out by the group facilitators during the first session for caregivers to fill out on their own at home, and collected at the beginning of the second session the following week. Post-program surveys were completed by caregivers at a meeting that was called for group members (facilitated by one of the four nurse research assistants), three months after the official 10 week program had ended. Of the 56 caregiver participants, 49 actually completed both pre and post-program surveys.

#### Data analysis.

To begin with, descriptive statistics were generated to present a portrait of the overall level and nature of social support experienced by caregivers. That is, average support scores were generated for each of the six different aspects of social support, as well as for total sum social support scores (the sum of all six aspects of social support). Then, using SPSS, t-tests for dependent samples were performed, to test for (statistically significant) differences in the quantity of and satisfaction with social support between Time I (pre-program) and time II (3 months post-program) surveys.

Question 3: To what extent did the SCBC program affect caregivers' perceptions of powerlessness and powerfulness?

Method.

Pre and post-program survey questionnaires, given to caregivers in phase II of the project, were used to address this question. The pre and post-program survey is seen in Appendix 4. It can be seen that questions #15 and 16 deal with the third research question regarding caregivers' perceptions of powerlessness and powerfulness. Again, although the traditional powerlessness of caregivers has been documented (Rutman, 1995; 1996), and although the SCBC project aimed to increase caregivers' perceptions of power, the evaluation team was unable to locate a suitable means by which to measure feelings of powerfulness and powerlessness. Therefore, questions were designed based on Rutman's (1995, 1996) work and incorporated into the caregiver survey. Again, prior to statistical analysis of this data, Chronbach's alpha coefficient (Burns & Grove, 1993) was calculated, to determine the questions' reliability. Although it could be argued that these questions also have good face validity, and were previewed by other researchers familiar with the caregiving literature, no other tests of validity were performed.

### Procedure.

A total of 66 caregivers in phase II completed the pre-program survey questionnaire pertaining to this question (Appendix 4), which was self-administered by caregivers at the first session of the SCBC program. When asked to complete and return the same questionnaire which was mailed to them three months after the end of the 10 week program, a total of 28 caregivers returned their completed surveys. Caregivers were contacted by telephone once to encourage the completion of their questionnaires if they had not been received within 30 days of mailing.

### Data analysis.

As per the analysis of data on social support, data collected on caregivers' perceptions of powerlessness and powerfulness was summarized in descriptive statistics. Again, differences in perceptions between time I and time II surveys were tested for statistical significance using t-tests for dependent samples. That is, total mean scores for powerlessness and powerfulness (sums of all of the nine questions) were compared between time I and time II.

Level Two: Questions, Methods and Procedures at the Level of the Small Group

Question 4: What did caregivers feel would help the long-term sustainability of their caregiving groups?

Method.

Focus group qualitative interviews with individual caregiver groups were used to address this question.

Procedure.

Six caregiver groups from phase I of the SCBC project, all in different communities, were interviewed in a focus group setting by a nurse research assistant three months after the end of the official 10 week SCBC program. The interviews were conducted using a semi-structured interview guide (see Appendix 1), and tape recorded. As can be seen in appendix 1, question # 3 in the interview guide relates to the fourth research question regarding long-term sustainability of these caregiver support groups, and was developed in consultation with steering committee members. All interviews lasted approximately 60 minutes, and were followed by a “tea social.”

### Data analysis.

The audiotapes from each of the focus group interviews were transcribed in their entirety. The transcripts were reviewed numerous times to get a sense of the whole (Sandelowski, 1995), and analyzed using NUDIST qualitative analysis computer software (Richards & Richards, 1990). Emergent themes and concepts pertaining to the research question were categorized and reviewed, using the participants' own words and descriptions wherever possible (Patton, 1990). Memos and analytical notes were kept to record the process of developing themes and categories, until such point that no new themes developed from the data (Sandelowski, 1986; Tesch, 1987; Tesch, 1990). For more information on the qualitative data analysis process, the author encourages the reader to refer to the previous data analysis section for question #1 (pages 105 - 107)

Question 5: What aspects of each support group's structure and/or process was particularly beneficial for participants?

### Method.

To address this question, focus group qualitative interviews with individual caregiver groups were conducted.

### Procedure.

Six caregiver groups from phase I of the SCBC project, all in different communities, were interviewed in a focus group setting by a nurse research assistant three months after the end of the official 10 week SCBC program. The interviews were tape-recorded, and conducted using a semi-structured interview guide (see Appendix 1). As can be seen in appendix 1, question #4 in the interview guide addresses the fifth research question on group process and outcome. All interviews lasted approximately 60 minutes, and were followed by a “tea social.”

### Data analysis.

The audiotapes from each of the focus group interviews were transcribed in their entirety. The transcripts were reviewed numerous times to get a sense of the whole (Sandelowski, 1995), and analyzed using NUDIST qualitative analysis computer software (Richards & Richards, 1990). Emergent themes and concepts pertaining to the research question were categorized and reviewed, using the participants’ own words and descriptions wherever possible (Patton, 1990).

Memos and analytical notes were kept to record the process of developing themes and categories, until such point that no new themes developed from the data (Sandelowski, 1986; Tesch, 1987; Tesch, 1990). For more information on the qualitative data analysis process, the author encourages the reader to refer to the previous data analysis section for question #1 (pages 105 - 107)

Level Three: Questions, Methods and Procedures at the Community Level

Question 6: What unique elements of each community determined the SCBC project's success as a community development initiative?

Method.

Focus group qualitative interviews with community steering committees.

Procedure.

Six community steering committees from phase I of the SCBC project, all in different communities, were interviewed in a focus group setting by a nurse research assistant three months after the end of the official 10 week SCBC

program. The interviews were tape-recorded, and conducted using a semi-structured interview guide (see Appendix 5). As can be seen in appendix 5, question # 3 of the interview guide pertains to the sixth research question related to community development. Again, all interviews lasted approximately 60 minutes.

#### Data analysis.

The audiotapes from each of the focus group interviews were transcribed in their entirety. The transcripts were reviewed numerous times to get a sense of the whole (Sandelowski, 1995), and analyzed using NUDIST qualitative analysis computer software (Richards & Richards, 1990). Emergent themes and concepts pertaining to the research question were categorized and reviewed, using the participants' own words and descriptions wherever possible (Patton, 1990). Memos and analytical notes were kept to record the process of developing themes and categories, until such point that no new themes developed from the data (Sandelowski, 1986; Tesch, 1987; Tesch, 1990). For more information on the qualitative data analysis process, the author encourages the reader to refer to the previous data analysis section for question #1 (pages 105 - 107)

Question 7: Which elements of the community development process occurring in each of the communities were particularly important to the outcomes of the SCBC project?

Method.

Focus group qualitative interviews with community steering committees were conducted to address this question.

Procedure.

Six community steering committees from phase I of the SCBC project, all in different communities, were interviewed in a focus group setting by a nurse research assistant three months after the end of the official 10 week SCBC program. The interviews were tape-recorded, and conducted using a semi-structured interview guide (see Appendix 5). As can be seen in appendix 5, question # 4 in the interview guide pertains to the seventh research question regarding community development. All interviews lasted approximately 60 minutes.

### Data analysis.

The audiotapes from each of the focus group interviews were transcribed in their entirety. The transcripts were reviewed numerous times to get a sense of the whole (Sandelowski, 1995), and analyzed using NUDIST qualitative analysis computer software (Richards & Richards, 1990). Emergent themes and concepts pertaining to the research question were categorized and reviewed, using the participants' own words and descriptions wherever possible (Patton, 1990). Memos and analytical notes were kept to record the process of developing themes and categories, until such point that no new themes developed from the data (Sandelowski, 1986; Tesch, 1987; Tesch, 1990). For more information on the qualitative data analysis process, the author encourages the reader to refer to the previous data analysis section for question #1 (pages 105 - 107)

### Level Four: Questions, Methods and Procedures at the Level of the Health Care Services

Question #8: To What degree did the SCBC program influence the knowledge and use of community health services by participants in the program?

### Method.

Pre and post-program survey questionnaires were used to address this question. .

### Procedure.

49 caregivers from phase I were given survey questionnaires to complete the first session of the SCBC program (pre-program survey: see Appendix 2), and again three months after the last of the 10 sessions (post-program survey: see Appendix 3). Questions # 20 and #11 in appendices 2 & 3 (respectively) pertain to the eighth research question on service usage. Pre-program surveys were handed out by the group facilitators during the first session for caregivers to fill out on their own at home, and collected at the beginning of the second session the following week. Post-program surveys were completed by caregivers at a meeting that was called for group members (facilitated by one of the four nurse research assistants), three months after the official 10 week program had ended.

### Data analysis.

To begin with, descriptive statistics were generated to present a portrait of

overall knowledge and use of community services by care-receivers. A decision was made to limit analysis to care-receivers, as anecdotal evidence and cursory analysis showed that it was the care-receivers that were using the overwhelming majority of the services. Using SPSS, t-tests for dependent samples were performed, to test for (statistically significant) differences between knowledge and total use of community services between Time I (pre-program) and time II (3 months post-program) surveys. In addition, to determine whether differences exist for both nominal (e.g., length of caregiving) and interval (e.g. relationship to care-receiver) caregiver characteristics and either the knowledge or use of community services, chi-square and ANOVA analysis were performed (Hazard-Munro & Batten-Page, 1993) using SPSS.

Question #9: To what extent did the SCBC program influence the propensity of caregiver participants to place their care-recipient in a long-term care facility?

Method.

Pre and post-program survey questionnaires were used to address this question.

### Procedure.

A total of 66 caregivers in phase II completed the pre-program survey questionnaire (Time 1 survey) pertaining to this question (Appendix 4), which was self-administered by caregivers at the first session of the SCBC program. Questions # 14 in appendix 4 pertains to the ninth research question regarding caregivers' propensity to institutionalize their loved one. When asked to complete and return the same questionnaire which was mailed to them three months after the end of the 10 week program (Time 2 survey), a total of 28 caregivers returned their completed surveys. Caregivers were contacted by telephone once to encourage the completion of their questionnaires if they had not been received within 30 days of mailing.

### Data analysis.

As the data are ordinal data between two dependent groups, the Wilcoxon matched-pairs signed-ranks test (Burns & Grove, 1993) was used to test for statistically significant differences (using SPSS) between caregivers' propensity to institutionalize their loved ones between time I and time II.

### Limitations of Methodology

This dissertation possesses a number of potential methodological limitations. To begin with, many of the research questions and corresponding methods were developed collaboratively by a committee reflecting varying vested interests in the research, and varying levels of experience with research. Therefore, the questions and methods presented here are a reflection of compromises and political realities, as much as they are a reflection of concerns over rigor and methodological purity. The author believes, however, that this is an accurate reflection of the world of program evaluation, particularly program evaluation conducted collaboratively with different stakeholders.

In terms of overall design, some critics might charge that the dissertation lacks sufficient scientific rigor to determine, for example, any causal links between changes in time one and time two survey data, and the actual SCBC program itself. That is, the methodology lacks certain features of experimental control, such as randomization to experimental and control groups. Even if such measures had been desirable -- and it has been argued in chapter two of this proposal that such measures are *not* necessarily desirable due to their conflict with the overall principles of self-help and community development -- such measures were not feasible given the nature of the SCBC program, particularly the manner

in which the various groups were to be established in the different communities. The overall intent of this dissertation, however, was not so much to determine causality, as it was to conduct a comprehensive evaluation of the impact and experience of the SCBC program, using both quantitative and qualitative data, in a manner which was both supportive of caregivers, and keeping as true as possible to the principles of self-help and community development.

Finally, it is acknowledged that several of the surveys used to collect quantitative data were established expressly for this study, and have no established reliability or validity statistics yet associated with them.

### Ethical Considerations

All research outlined in this dissertation was granted approval by the Human Subjects Review Committee, at the University of Victoria. All potential ethical issues, including such things as voluntary participation, confidentiality, and anonymity, were addressed in the process of ethical review. Appendix 6 is a copy of the approved request for approval of proposed research involving human subjects form for the University of Victoria.

## CHAPTER FOUR: RESULTS

The purpose of this chapter is to present the results of the data analysis pertaining to the research questions underlying this dissertation. The findings will be presented in order of the four levels of questions: level of the individual caregiver, level of the small group, level of the community, and level of health care services. Out of the large volume of data collected, I have selected those results which shed the greatest light on the nine research questions posed in this dissertation.

### Level One Questions: Level of the Individual Caregiver

#### Question One: What Did the Caregivers Perceive as the Main Benefits of the SCBC Program?

During the focus group interviews with each of the six Phase I caregiver groups, caregivers were asked to describe how they had experienced the 10 week SCBC program. Overall, most caregivers enthusiastically recounted what a positive impact their involvement with the caregiver groups had on their

experience as caregivers. The focus group format seemed like a particularly good means to collect information and stories on the impact of the program, as the caregivers were not only able to give their own accounts, but fellow group members also often commented on how they felt the group had benefited others within the group. This kind of sharing back and forth within the group offered a rich taste of how caregiver group members felt the group had benefited themselves and fellow group members.

Four major themes emerged from the analysis of the text of the focus groups. The four major themes pertain to what caregivers perceived as the main benefits of the SCBC program: learning they were not alone; learning about resources and the system; learning not to feel guilty; and being able to care for loved ones longer. Each are presented below, with examples of verbatim text for illustration purposes.

#### Learning That They Were Not Alone

Numerous caregivers mentioned that finding out that there were others "in the same boat" was extremely beneficial in making their caregiving seem easier.

As one participant noted:

It's kind of nice too if you come to the meetings and you're all confused

and you feel like (you're) all alone out there and then you come and....it's always easier to know there is someone else with the same problems. So you can go home with a little bit of self esteem....and by the time you go home you have a little different perspective on things.

For some, it was helpful to gain a different perspective; for others, this "same boat" outcome helped them to "keep their sanity":

Well, I know the groups' been good for me. It's helped me to keep my sanity. It's very important to find other people with similar problems; it's nice to know that you are not alone.

It also became important for caregivers to not only know that they weren't the only ones dealing with difficult behaviors in their loved ones, but to also know that others were having to deal with their own emotional reactions, which would often be upsetting or frightening. As one woman looking after her husband explained, "I found out that I wasn't the only person that got really mad and yelled at him!" Caregivers repeatedly stated that it was this sense of being connected with others experiencing similar difficulties that was the main perceived benefit of their involvement with the SCBC program.

### Learning About Resources and the System

The majority of caregivers came into the caregiver group to learn more about available resources and how to negotiate the long-term care / health care system, which was often described as "a maze." Participants stated they got what they needed in this department:

What I really got out of this group was to find out the resources in town and to compare with people who are gathering this information....there is no coordination of these services, you know -- one place where people can go and get all the information you need. This group helped so I didn't have to be so much of a detective to find out things. It's terrible, the lack of coordination between doctors, between nurses -- the home care nurses and the homemakers and the homemakers and the nursing providers -- you talk in the middle of all this commotion; it's frustrating.

Participants also learned how to successfully modify the way they were dealing with the system. Several women in one group learned by sharing and encouraging that they could have more luck negotiating "red tape" if they tried the "diplomatic" approach:

This group helped me to remember that you don't get very far by being

pushy. You get a lot further by being nice with these people.

And,

They (the group members) reminded me that if one person, like, doesn't help you, there's no use getting nasty with her. You're better off wanting to be nice to somebody else (laughs) and working through the back door, you know? There are things you learn in this group!

### Learning Not to Feel Guilty

Many caregivers stated that despite the tremendous time and energy they devote to caregiving, they were still often plagued with feelings of guilt -- feelings which only add to the difficulty of caregiving. In particular, despite the importance of caregivers taking care of themselves, many caregivers reported feeling tremendous guilt when they did something to take care of themselves -- that self-care was somehow indicative of not properly caring for the care-receiver. According to these participants, involvement in a support group helped to combat those feelings of guilt:

Another thing is from this group I learned not to feel guilty about wanting to have my own time or not feeling guilty about my feelings about what has happened. That was a big thing for me.

Similarly,

Let's face it, it was the guilt for me all the time. Anytime I used to think of myself I used to think how selfish I was. And he [her husband) would make me feel that way too. He had a great way of making me feel guilty. You girls [fellow participants] have been great in making sure I don't feel that way anymore.

Again, by helping participants to shed the guilt they felt about caring for themselves, many of them began to feel like caregiving was no longer driving them crazy:

Yeah, this (the group) is the way you keep you sanity, because with the guilt and things like that, I was driving myself insane -- which doesn't help me and it doesn't help my husband.

#### Able to Care for Loved Ones Longer

Another important outcome arising from this support group experience -- from both the caregivers' perspective and the perspective of funders/policy makers interested in supporting informal family caregivers -- was that most participants felt they could care for their family members longer, largely as a result of now knowing how to better take care of themselves. While some caregivers realized that taking better care of themselves might mean placement of their loved one in a long-term care facility, most felt that this 'taking better care' was compatible with

ongoing in-home care, as long as they received support such as they had found in the SCBC program. As one older woman caring for her husband described how she perceived the group helping her:

Well, if you help yourself, then it is easier to help someone else. But someone has to help us help ourselves, like in this group. If they don't, they'll have two people instead of one. That's what I keep saying. They're going to have both of us there [a nursing home] because there is no one else to look after him if I go.

Question Two: To What Degree was the SCBC Program Successful in Increasing Caregiver's Support?

As was discussed under the results for question one, the simple act of joining and belonging to a caregiver support group automatically increased the number of people in their support network and opportunities for support. The data and themes presented in question one documented the benefits felt were due to their experiences with this new-found social support network.

Answering this second question, however, took a more quantitative approach, and involved trying to measure the quantity and quality of social support both before and after caregiver's involvement in phase 1 of the SCBC

group program. As can be seen in Appendix two (question five), caregivers were asked to estimate the amount of support (0 = not at all, 1 = rarely, 2 = on occasion, 3 = often, 4 = very frequently) they received from persons in their support network, in the areas of emotional support, advice, companionship, and practical help. By adding up each of the “scores” for each of the four different kinds of social support these received from persons in their network, a composite score was created for the total sum social support caregivers received. Caregivers were also asked to indicate how satisfied they were overall with the support they received from others (question six in appendix two) on a five point Likert scale (1 = very unsatisfied, 2 = somewhat unsatisfied, 3 = neutral, 4 = somewhat satisfied, 5 = very satisfied).

The results of this data are presented in Table 2. It shows, for example, that the biggest form of social support from others, both in time one and time two, was in the form of emotional support, followed (in decreasing order) by companionship, practical help, and advice. Caregivers at time one averaged 3.4 persons in their social support network (range from 1 to 6), and they were generally somewhat satisfied with the support they received from others. There was a weak but statistically significant positive correlation between the total number of people in caregivers’ social support network, and the degree of satisfaction with the support they received ( $r(38) = .275, p < .05$ ).

Table 5:

**Average Caregiver Scores – Aspects of Social Support at  
Time 1 and Time 2**

Aspect of Social Support	Time 1	Time 2	T-test and significance
Emotional support	9.4348 (N = 23)	11.4783 (N = 23)	t = -1.186 p = .248
Informational support	5.2857 (N = 21)	7.1429 (N = 21)	t = -1.961 p = .064
Companionship	7.1739 (N = 23)	9.000 (N = 23)	t = -1.284 p = .212
Instrumental help	6.5652 (N = 23)	7.3478 (N = 23)	t = -.739 p = .468
Satisfaction with support from others	3.60 (N = 25)	3.64 (N = 25)	t = -.108 p = .915
Number of people who provide support	3.38 (N = 24)	3.96 (N = 24)	t = -1.534 p = .139
Total sum social support scores	27.13 (N = 23)	34.96 (N = 23)	t = -2.229 p = .036

Table 2 also shows that caregivers experienced an modest increase between time one and time two in all of the various types of social support they received. As a group, the caregivers also demonstrated a small increase in the number of persons listed in their support network from time one to time two, from an average of 3.38 persons at time one to 3.96 persons at time two. Neither this modest increase in the number of persons in their network, or the increases in the four individual types of social support were found to be statistically significant. However, a statistically significant difference was found in caregivers' total sum social support scores between time one and time two, which increased from a score of 27.13 in time one to 34.96 in time two,  $t = -2.229$ ,  $df = 22$ ,  $p < .036$ . The increase in total social support scores was greatest for spousal caregivers; their scores increasing by an average of 5.68 points, as compared with only 0.31 for daughters, or 3.17 for other caregivers (sons, friends, etc.). While the overall amount of social support increased for caregivers between time one and time two, the satisfaction caregivers expressed with the social support they received remained unchanged from time one (mean of 3.60) to time two (a mean of 3.64).

Finally, some nonsignificant gender differences were noted with the time one social support data. While males reported higher overall satisfaction with the report they received (mean of 4.50) than female caregivers (mean of 3.62), this difference was not statistically significant ( $t = -1.029$ ,  $df = 37$ ,  $p < .310$ ) due likely

in part to the low number of males in the sample ( $N = 2$ ). While the overall number of persons in their support networks did not vary significantly between males (mean of 3.00,  $N = 2$ ) and females (mean of 3.22,  $N = 37$ ), female caregivers averaged total sum support scores approximately 150 percent higher than their male counterparts (means of 28.00 versus 17.00, respectively). Again, due likely to the low number of males in the sample, this difference was not statistically significant ( $t = .916$ ,  $df = 37$ ,  $p < .366$ ).

Question Three: To What Extent Did the SCBC Program Affect Caregiver's Perceptions of Powerlessness / Powerfulness?

As can be seen in Appendix 4, caregivers in phase II were asked to rate how often they had experienced various feelings of “powerlessness” (question 15 in Appendix 4) and “powerfulness,” (question 16 in Appendix 4) on a scale of one to five, with the increments representing:

- 1 = “I never feel this way”
- 2 = “I occasionally feel this way”
- 3 = “I feel this way about half of the time”
- 4 = “I feel this way fairly often”
- 5 = “I feel this way most of the time.”

As these scales, based on Rutman's (1995, 1996) work on caregivers' experience of powerlessness and powerfulness, had never been used before, reliability was

determined with the use of Cronbach's alpha coefficient, a measure of internal consistency (Burns & Grove, 1993). Using the data from the phase II caregiver group members ( $N = 28$ ), it was determined that the Cronbach's alpha coefficients for the two scales were as follows:

Powerlessness Scale: Alpha = .6936

Powerfulness Scale: Alpha = .7849

The results for both the powerlessness and powerfulness scales are presented in Tables 3 and 4, respectively. First, it can be noticed that although all the items in the powerlessness scale, with only two exceptions, indicated a downward trend (i.e., toward less feelings of powerlessness) from time one to time two, only the downward trend in the sum total powerlessness score was statistically significant using a t-test for dependent samples, dropping from an average score of 21.43 at time one to 18.43 at time two ( $t = 3.396$ ,  $df = 13$ ,  $p < .005$ ).

In terms of powerfulness, all the items in the powerfulness scale, with the exception of three items, indicated an upward trend (i.e., toward increased feelings of powerfulness) between time one and two. Again, only the change in sum total powerfulness score achieved statistical significance, increasing from an average score of 25.25 at time one to 31.42 at time two ( $t = -.3450$ ,  $df = 11$ ,  $p < .005$ ).

Table 6

**Caregiver's Feelings of Powerlessness: Time 1 and Time 2**

	Time 1		Time 2		Change	Sig. of t-test
	Valid N	Mean	Valid N	Mean		
<b>Feeling uncertain about the future</b>	26	3.269	26	2.885	↘	.218
<b>Person's illness (e.g. Dementia) is in control instead of you</b>	22	3.182	22	2.636	↘	.090
<b>Lacking freedom to express emotions</b>	19	2.789	19	2.579	↘	.480
<b>Alone, stranded with no support</b>	19	2.789	19	2.368	↘	.088
<b>Unable to protect care recipient from harm</b>	16	2.313	16	2.125	↘	.594
<b>Others don't believe or trust your judgment</b>	16	1.750	16	1.688	↘	.751
<b>Lacking skills or confidence in caregiving role</b>	15	2.000	15	1.800	↘	.334
<b>Too few respite opportunities</b>	21	2.476	21	2.810	↗	.149
<b>Lack of respect from professionals</b>	18	1.778	18	1.94	↗	.528
<b>Average sum total powerlessness scores</b>	14	21.43	14	18.43	↘	t = 3.396 p = .005

Table 7

**Caregiver's Feelings of Powerfulness: Time 1 and Time 2**

	Time 1		Time 2		Change	Sig. of t-test
	Pre-Program		Post-Program			
Type of feeling of Powerfulness	Valid N	Mean	Valid N	Mean		
Feels confident in caregiving abilities	22	3.500	22	3.636	↗	.701
Assertive in expressing own ideas	18	3.333	18	2.944	↗	.168
Feels respected by professionals	19	2.947	19	3.579	↗	.235
Feels fulfilled in caregiving work	15	2.867	15	3.133	↗	.512
Feelings adequately rewarded as caregiver	14	3.000	14	3.429	↗	.551
Confident in caregiving knowledge	17	2.647	17	3.235	↗	.181
Had made positive changes in care recipient's life	19	3.263	19	3.053	↘	.607
Recognizes and attends to own needs	23	3.261	23	3.043	↘	.565
Able to cope with difficult situations	24	3.292	24	3.292	none	1.000
<b>Average sum-total powerfulness scores</b>	12	<b>25.25</b>	12	<b>31.42</b>	↗	<b>t=3.450</b> <b>p=.005</b>

Taken together, it would appear that caregivers expressed less feelings of powerlessness, and more feelings of powerfulness, three months after the official SCBC program had ended, compared with just prior to their involvement with the program. Of these two statistically significant trends, the increases in feelings of powerfulness were the most pronounced, increasing in average score by roughly 25 percent.

In addition, some gender differences in feelings of powerlessness and powerfulness were found. As can be seen in Table 5, male caregivers at Time one scored lower in feelings of powerlessness and higher in feelings of powerfulness in comparison with their female counterparts. By time two, however, even though male caregivers still reported lower levels of powerlessness, feelings of powerfulness had equaled out between the two genders. Thus, comparatively speaking, female caregivers had greater increases in feelings of powerfulness between time one (pre-program) and time two (three months subsequent to end of program). However, only the gender differences in feelings of powerlessness achieved statistical significance using a t-test for independent samples, both for time one ( $t = 2.60$ ,  $df = 12.99$ ,  $p < .022$ ) and time two ( $t = 3.20$ ,  $df = 13.79$ ,  $p < .007$ ).

Table 8

## Feelings of Powerlessness, Powerfulness, and Gender

	Mean Sum Scores Feelings of Powerlessness		Mean Sum Scores Feelings of Powerfulness	
	<u>Time 1</u>	<u>Time 2</u>	<u>Time 1</u>	<u>Time 2</u>
<b>Male Caregivers</b>	17.75 (N = 8)	14.67 (N = 3)	28.50 (N = 8)	31.25 (N = 4)
<b>Female Caregivers</b>	22.32 (N = 38)	20.84 (N = 19)	24.94 (N = 35)	32.0 (N = 18)
<b>Significance of differences (df = t, p)</b>	$t = 2.60,$ (df = 12.99), $p < .022$	$t = 3.20,$ (df = 13.79), $p < .007$	$t = -1.51,$ (df = 11.08), $p < .16$	$t = -.030,$ (df = 3.77), $p < .98$

## Level Two Questions: Questions at the Level of the Small Group

### Question Four: What Did Caregivers Feel Would Help the Long-Term Sustainability of Their Caregiver Support Groups?

Question #3 in the caregiver focus group interview guide asked caregivers in phase I of the SCBC program to address the long-term viability of their caregiver support group (see Appendix 1). As this focus group interview took place three months after the end of the official ten week program (during which each group had a trained and paid facilitator) caregivers were called together for a group interview to find out if they were still meeting regularly, and what factors were influencing their survival as a group.

At the time of the focus group interviews, five out of the six phase I groups were still meeting regularly (most of them weekly) as active caregiving support groups. Of these five active groups, three continued to be led by the original paid facilitator on a volunteer basis. The other two groups had become essentially self-led, with little or no involvement of the original facilitator. All of the five existing groups were in various stages of looking for sources of funding to pay for future facilitators similar to the one(s) they enjoyed during the 10 week long SCBC program. Furthermore, it was found that after ten months had

elapsed since the official end of the SCBC program, four out of the six original community support groups were still meeting regularly, with a variety of funding and/or facilitator arrangements (Schell, 1996).

Regarding factors affecting group sustainability, three prominent themes emerged out of the focus group interview data: planning for new members; seeking another facilitator; and political action.

### Planning for New Members

When discussing the future of their caregiver groups, participants stated they realized they were feeling the need to think about the issue of new members, if their groups were going to survive over the long-term. Participants felt an understandable dilemma: they were very comfortable and "cozy" with each other, and were wary of "outsiders," but also realized that they would need to seek new members as established group members left. Individual groups had different "marketing" ideas as to how to go about getting new members, but all groups felt they were going to have to accept new members sooner or later. One caregiver noted:

We'll need new members, just not a great number at one time. I think we need to sort of incorporate people two or three at a time. And you have to do it to keep the group going too I think.

Participants also indicated that they felt their groups should continue to be "generic" ones; that is, the groups should be open to *all* caregivers, not just caregivers of people with a specific condition (e.g., dementia). Most groups also expressed a desire to consciously seek out more male caregivers to join their groups.

### Seeking Another Facilitator

All six groups had been led by paid trained facilitators who had only committed themselves to facilitating each of their groups through the ten week program. All of the groups expressed the view that finding money to pay for another group facilitator was vital to the long-term viability of the group. While one of the aims of each facilitator was to try and prepare the group for self-leadership (i.e., self-led, with no facilitator) at the end of the ten week period, only two of the six groups had gone on to become truly self-sustaining at the time of the follow-up focus group interview. However, even these two groups saw self-leadership as a temporary measure, until such time when they could find funds to pay for another facilitator.

Caregivers expressed with a common voice their belief that a paid facilitator -- and not a volunteer caregiver -- was the right person to lead and sustain an effective caregiver support group. One caregiver spoke of her previous

experience with a group of caregivers unsuccessfully trying to organize a group with just their own resources and leadership:

Well see I have been three times before. They had tried getting this going here and it just did not work because of the leadership....these people just had no idea how to be a group leader. One fellow tried getting it going and it didn't work under him and then we had another lady and then we had another lady and then we had Jill and it just did not work. I can't tell you why, but I think it's that leadership thing. Maybe it wasn't organised because I do think you have to have some organisation. You have to have something in mind that is going to come up that day, you know, to be planned for, a topic or something.....But Agnes (the group's facilitator) encouraged us to say how we felt and everything whereas the other they thought they had to entertain us. I just didn't get the help I needed [in the previous group], and I thought, "God, what am I doing here?"

Most caregivers agreed with this woman that a skilled and trained facilitator was paramount to the long-term survival of a caregiver support group. Contrary to feeling "disempowered" by the idea of being supposedly dependent on a facilitator to lead their group, most felt that self-leadership was only a temporary option at best. Thus, seeking some kind of funding to pay for an ongoing trained facilitator became a prominent focus for each group after the end of the official three month

program.

### Political Action

Most participants seemed to have experienced an awakening of consciousness in terms of caregiver issues as a result of their involvement with their caregiver group. Such consciousness-raising often led to the feeling that each group should engage in some caregiver lobbying and political action, in whatever form. These feelings seemed to be based in the belief that each caregiver group had to “fight” if it was going to survive. For example, one of the caregiver groups had devoted one of their entire meetings to a letter-writing blitz, writing to as many politicians as they could think of about the need for support services for caregivers. For many of the participants, the search for funding to continue having a facilitator was the beginning of a bigger political process. As one participant put it:

We have to do something about making sure they (politicians) hear us.

Like we have to become activist to a degree. Whether it is letters, or, somehow that we are recognized.

One group had decided that the social work staff at a local hospital needed to hear about the plight of caregivers, and a few members arranged to have a

meeting with the staff. They were quite pleased at the results, and their new-found "power" as caregiver activists:

We got some action from the social workers. When we went to Burnaby General we were only supposed to have fifteen minutes and we took the whole meeting time (laughter). They just kept asking us more questions.

Another group ensured that the local community TV and radio stations did some kind of piece on raising community awareness about the plight of caregivers, with the hopes that other people would begin to lobby politicians about the issue.

Another participant had a unique idea about how to get a local politician's attention about caregiving:

Well, we'll just take all the people we are looking after and go sit in his office for a while. We'll do a little sit-in. Better yet, leave them all there for an hour or so -- let him look after them for a change!

These caregivers -- all of them women except for two -- were also starting to realize that caregiving was a women's issue as well as a political one. As one woman described with the difficulty she had getting the system to be flexible regarding her need for respite,

Men's aren't caregivers, yet men are still basically the ones that make up all the rules in the hospitals and the nursing home. They need to know what

it's like, because a man isn't going to speak up for us, that's for sure!

Thus, participants were eager to get political, and educate local politicians what it was like to care for the kinds of people they were caring for. However, the reality was that many of these participants were extremely burdened and stressed, and had little time and energy to attend a weekly support meeting, let alone to be politically active.

Question Five: What Aspects of Each Support Group's Process Was Particularly Beneficial for Participants?

The caregiver participants (Phase I) were very eager to discuss what actually occurred in their caregiver support group. This category includes their descriptions of the group "mechanisms" -- the process that the caregivers felt helped to produce the positive outcomes they experienced. The major themes emerging from data related to group process included: opportunities to laugh at themselves; feeling cared for and caring for others; venting of difficult emotions; confidential interaction; and the ability to discuss and process loss.

Opportunity to Laugh at Themselves

Participants stressed the important role that laughter played in their caregiver support groups; that these groups were a place where "we could laugh at

ourselves and our situation." As one participant stated simply, "If you can't laugh, you go under." One participant recounted how when she became particularly angry at her mother whom she was caring for, she would go into the bathroom, turn on all the taps with running water, and swear long and loud until she got the anger out of her system! She and the group were able to have a good laugh as she told this story, and the group used this story as an example of how important it was to have contact with fellow caregivers, who could appreciate the "gallows" humor that caregiving sometimes engenders. The ability to laugh was seen as an important stress release which allowed caregivers to go back into their difficult environments a little renewed and recharged.

#### Feeling Cared for and Caring for Others

With caring so much for others, many caregivers found the experience of being *cared for* particularly rewarding and valuable. While participants quickly realized in their groups that it was important for each of the individuals to take care of themselves, many were surprised by the extent to which they would become cared for by other members of the group. As one woman stated to the other women in her group during the interview:

This group came just at the right time for me, definitely. I don't think I could have gone through what I went through without the help and support of all you ladies, and knowing that you all cared.

As many caregivers felt that their caregiving situations at home always demanded *one-way* caring, the ability to experience *reciprocal* caring in the groups was seen to be a particularly important way of taking care of themselves.

### Venting of Strong Emotions

Caregiving evokes many strong emotions such as profound sadness and anger; emotions which the participants said most of their non-caregiving friends and family were too uncomfortable to hear. Yet in a group of fellow-caregivers, participants felt they had the permission and understanding to finally vent emotions which were "eating away at them." While the venting of sadness was a prominent theme, the ability to vent anger also seemed to be particularly important to participants:

What was really important for me was probably everyone understanding that I get really frustrated and angry.....angry when I don't have my own space or I'm always expected to be there sort of thing.

and,

This group was the only place that seemed to listen and understand. I haven't come across any other situation yet where anyone has really cared about me. I remember when I rang up almost screaming on the phone to

them (the hospital) saying "look what is going to happen to this man?  
I'm feeling ill and I don't know what to do and I can't go -- you know if I  
just walk out and leave him what is going to happen what are you going to  
do?!!

Having permission finally to be as mad as they needed to be (in their groups) seemed to give caregivers the ability to "make a home" for their anger, without it becoming destructive or potentially leading to abuse of their family member. As one woman put it, "we've learned it's all right to be angry as long as you don't let that eat you up."

### Confidential Interaction

Another aspect of group process which the participants mentioned as being important was the *confidential* nature of the interaction. Group facilitators stressed throughout the sessions the importance of confidentiality, and participants stated the confidentiality helped to create a place that was "safe" and where they could really bare their souls. Two participants relate:

...the confidentiality that we knew was there was extremely important. In the group, if we let ourselves down completely, we knew that it was going to stay with the ladies here,

and,

I know definitely that you wouldn't say what you really felt unless we were confident it was going to stay between us.

While confidentiality may seem an "obvious" aspect of any support group process, the participants stated it was important to remind themselves of it each week, and that group confidentiality was vital for the groups producing the positive outcomes that they did.

#### Discussing and Processing Loss

A final theme emerging out of the interview data was the idea of discussing and processing loss. All the participants were experiencing loss, some more profound than others, and all needed a safe place where they could begin to grieve and work through their losses. The groups appeared to be just that kind of place for most participants. As one woman, contemplating eventually losing her husband to Alzheimer's disease, described to her group:

....it's not just a loss to death, but a loss of a way of life. I think that this is one thing I really chewed on. I had a way of life until something came and "whoof," and I think everybody else did too. You couldn't do what you wanted to do, you couldn't do what you had dreamed of doing at a certain

state and it was difficult adjusting to that -- yeah you -- when you reached 60 or 65 that things are going to be a certain way and they don't turn out that way.

As caregivers met and shared their losses in the groups, it appeared that this enabled a process of "moving on" -- which involved the realization and acceptance that this *was* the way that their lives had turned out -- appeared to make caregiving a little more tolerable.

#### Level Three Questions: Questions at the Level of the Community

#### Question Six: What Unique Community Characteristics Influenced the SCBC Project's Outcome as a Community Development Initiative?

The analysis of data from the Phase I steering committee focus group interviews revealed two sets of themes. The first was characteristics of each community which helped the SCBC project in their community; the second was community characteristics which hindered the project.

#### Community Characteristics Which Helped the SCBC Project

The themes of community characteristics which helped the project

included: having a local community senior's center; a centralized, accessible and coordinated health unit; and a safe place to meet with good transportation.

Having a local community senior's center.

One community's steering committee, whose caregiver group was a particular success, credited their results to the local community senior's center. This center was particularly active, and served as a magnet for seniors throughout the community. In addition to offering the caregiver group space and facilities, they were described by a steering committee member as being :

...very willing to accommodate us in any way we asked. You know they were flexible and would provide whatever we needed, photocopying, Xeroxing, refreshments....and to me that was just unheard of, you know. Anywhere else to go you have to beg and plead -- but they seemed to recognize the need in the community for what we were doing and they accepted it and supported us.

Thus, for this steering committee, being able to plug into such a vibrant and caring senior's center proved central to their success.

A centralized, accessible and coordinated health unit.

Two steering committees mentioned that it was their good fortune to have access to a central and well-coordinated local health unit in their community.

This was seen to make their job much easier:

...actually, I think what made a major difference too, is that the health unit is pivotal here. Where it is now it's right in the middle of the community. So when you are looking for support or information of where caregivers are or who needs help you just phone the health unit and say "listen, what's going on out there in the community?" And they basically have their finger on the pulse.

Another steering committee described what a pleasure it was to work with their particular health unit, stating:

All the agencies, home support, continuing care, long term care, daycare -- they are all integrated. They support each other....yeah, so then they know, like they are very close knit and they work closely together. They have monthly meetings but they are on the phone to each other a lot more. So they see a lot of each other personally and over the phone.

This kind of coordination at the health unit level was seen to be unique to their community, and an important reason why their job as a steering committee went much more smoothly.

A safe place to meet with good transportation.

In one large urban community (East Vancouver), an important characteristic of their community vital to success was a safe place to meet -- for both steering committee members and caregivers -- that was easily accessible by public transportation. Participants stated that had they not had their safe facility with good bus access, the project would have simply failed due to people's concerns for physical safety, particularly during the evening.

Community Characteristics Which Hindered the SCBC Project

This theme reflected participant's perceptions of unique characteristics of their own community which made their community development job particularly difficult. These included: overwhelmed community members; turf wars; cultural / language barriers, community size; and weather/season.

Overwhelmed community members.

While people being overworked was a consistent sub-theme for all communities, some communities seemed to particularly suffer from the problem

of "overwhelmed" community members / volunteers. This seemed to be a concern especially in smaller communities, where the pool of available volunteers was smaller:

....the down side is that because there are so many things going on here, there probably just aren't enough people around who have the energy -- to sit down and say "okay, this works, let's try to keep it going, right?"

and,

We have a very small pool of people in the community who will volunteer to be on committees. It's like after a while, you can only ask so much of people. People do burn out, you know, and it always seems to be here that the same people do the same things.

Bigger communities, on the other hand, seemed to have a large pool of potential volunteers to draw upon, without having to call on the same small group of dedicated persons over and over again.

#### Turf wars.

Again, while all communities experienced the phenomenon of territorialism to some degree, it seemed to be particularly pronounced in two of the communities. In one community, a woman who was already running some

caregiver support groups came to an SCBC public information meeting, and proceeded to heckle and harass the project coordinator while she conducted the meeting. It appeared that somehow the woman believed that "new" caregiver groups in her community would threaten the existing groups she was running.

In another community, a local Alzheimer's group was "boycotting" the SCBC project, as a result of being offended that a rival non-profit group was given signing authority for the project budget. Thus, while this community's Alzheimer's society came into contact with many caregivers who could have potentially benefited from the caregiver education and support groups, they refused to support the project, and did not refer any local caregivers to it.

#### Cultural / language barriers.

Two communities, due to their unique ethnic mixes, experienced some barriers related to culture and language. According to steering committee members, most of these centered around the difficulty of "...not being able to provide materials and advertising in all of the community's languages" (due to budget restrictions). Cultural differences related to care of the elderly also came up in the communities, adding to the challenge of marketing and designing caregiver groups that would have broad appeal in the community.

#### Community size.

Like the story of Goldilocks, some communities were perceived to be *just*

right in size; others were perceived to be either too big or too small. In the largest community (East Vancouver), the large size of the community was seen to be a barrier in getting an accurate "feel" of the community from a caregiving point of view:

...it was very difficult for us to get an idea of what was available because Vancouver is so big and there are so many resources...um, I don't know, even to get somebody to think about the resources was difficult. It made it all very cumbersome for us.

In other communities, their small size was seen to be an impediment, as there were too few volunteers to go around and people were feeling overwhelmed, as mentioned earlier.

Weather / season.

Finally, one Northern community was quick to point out that establishing projects in the North is very difficult, due to the narrow "window of opportunity" the climate presents for citizens to be involved in community activities. That is, Northern winter conditions make it too difficult and unpredictable for participants to drive to activities in the winter. Then, when Spring and summer do arrive, many community members are busy taking advantage of the short summer months to do necessary work around their homes. Thus, only the Fall months are seen to be plausible months to try and involve Northern citizens in community

development projects, making planning and delivery of these projects much more awkward and difficult.

Question Seven: Which Elements of the Community Development Process Occurring in Each of the Communities Were Particularly Important to the Outcomes of the SCBC Project?

This theme included Phase I interview data which described factors that steering committee participants believed were responsible for their success as an effective group working on community development with caregivers. The sub-themes included: getting a wide variety of people and "fire lighters" involved; working well together and commitment; soliciting support of local business and media; facilitating word of mouth; and having courage.

Having a Wide Variety of People and "Fire Lighters" Involved

All steering committees mentioned the importance of having as broad a base of involved people as possible -- not only on the steering committee itself, but with any community contacts the steering committee was making. Participants maintained this was important not only to ensure that many different areas and agencies were represented, but also to help avoid any individual -- or small group of individuals -- from "burning out" as a result of taking on too much.

Participants were quick to point out, however, that not just *any* person would necessarily do. In particular, participants mentioned it was vital to identify and involved those people who had reputations in their communities as being "fire lighters" -- people who could "light fires" under others in the community and get things done.

### Working Well Together and Being Committed

Two of the more successful steering committees stressed that once you got a broad base of people involved, the next important ingredient was working well as a group together, and being completely committed to the group and their community. As one participant put it:

...one of the successes was the fact that the people here were committed to the project so that in spite of all the frustration and anxiety, that they were committed to it...because if you are not committed then it's just too easy to say "I'm out of here."

Another participant described what she perceived to be the reason why her steering committee worked together so well:

....yeah, and we all worked really well together. We all took on jobs and were able to do them, so it was really good. And we did keep in touch with each other -- we didn't have any secret or hidden agendas. We really

were able to communicate with each other so that was really nice also. We kept track of what we were doing....it was great to have people assigned to jobs and then to have us report back.

### Soliciting Support of Local Business and Media

All groups accredited much of their success with actively soliciting the support of their local media and/or businesses. When business were approached (e.g., pharmacies), most proved to be extremely supportive and generous with facilities, supplies and money. Media contacts were especially valuable in the eyes of steering committee participants:

The media gave good coverage the way they presented it was really a big part of the success -- the profile and everything. I think the way we worked with the media was the key to the success of the whole thing getting off the ground.

and,

It's vital to continue with the media involvement in the process. The issue in *The Vancouver Echo* kept the caregiving issues before everybody in their minds, and then any advocacy you did at the regional health level,

you've got a contact in the media that you can take with you to the meeting when you do the advocacy work. You must keep those media relationships open and active!

Thus, steering committee members who had some kind of connections with the media were seen to be particularly valuable assets to the group, as many steering committees participants were new at working with the media.

### Facilitating Word of Mouth

While participants were involved in a great deal of public relations and advertising work in order to raise awareness of their caregiver group project, there was a unanimous feeling that *word of mouth* was the most effective and meaningful way to get other community members involved in the project. This strategy worked particularly well in smaller communities, though all participants felt it was word of mouth -- that all important personal invitation to become involved -- that always got the best results, no matter what their particular task was.

### Having Courage

Finally, participants mentioned that individual steering committee members needed to have *courage*. In the words of a participant:

....I think the fact too, that people were willing to participate in a new venture and to have the courage to do that, that was part of the success of the group.

Several participants stated that the project coordinator played a vital role in instilling this courage to try new things -- to go out on a proverbial limb:

I think a big reason for our success was that people were willing -- with a bit of help from Joyce (the project coordinator) -- to explore areas that they had never traveled in before....and that was really, what made this all possible.

Using various ways to describe it, nearly all of the groups identified this phenomena of courage and willingness to take risks as being a key ingredient to a successful steering committee effort.

Level Four Questions: Questions at the Level of Health Care Services

Question Eight: To What Degree Did the SCBC Program Influence the Knowledge and Use of Community Health Services by Participants in the Program?

Data for this question related to how often Phase I caregivers (who arranged the care for their care-receivers) of the SCBC program were using various community health services prior to and after their involvement with the program, and how much they felt their awareness of such services had changed since the program. The community health services caregivers which caregivers were asked about are listed in Appendix 2 (question 20) and Appendix 3 (question 11).

The extent to which caregivers were aware of the various community health services prior to their involvement with the SCBC program is summarized in Table 6. It can be seen that for the most part, caregivers were reasonably aware of most community health services. At least 50 percent of caregivers were aware of two-thirds of the services mentioned. At least 70 percent of caregivers were aware of home-delivered meals (83.8%), home cleaning (80.6%) and personal care (72.2%). Less than half were aware of how occupational therapy (33.3%) or geriatric outreach teams (13.9) could assist their caregiving.

As the SCBC program provided caregivers with information on the community health services available to them, it is not surprising that caregivers reported the program helped them learn more about these services. When asked how much the program affected their awareness of services, only 21.2 percent of caregivers responded “not at all.” The remainder felt that the program had either

Table 9  
 Caregiver's Awareness of Community Health Services: Pre-Program

Type of Community Health Service	% of Caregivers <u>Aware</u> of How Service Could Help	% of Caregiver <u>Not Aware</u> of How Service Could Help
Respite/Wheelchair	83.8%	16.2%
Home Cleaning	80.6%	19.4%
Home Care	72.2%	27.8%
24-Hour Day Care	69.4%	30.6%
Adult Day Program	64.7%	35.3%
Home Respite	61.1%	38.9%
Senior's Center	60%	40%
Home Nursing	57.1%	42.9%
Handi-Care/Alone	55.6%	44.4%
Facility Respite Care	52.8%	47.2%
Adult Health Services	47.2%	52.8%
Disease-Specific Groups	45.7%	54.3%
Day-to-Evening Respite	45.7%	54.3%
Community Therapy	33.3%	66.7%
Geriatric Outreach	13.9%	86.1%

affected their awareness of community health services “somewhat” (30.3%) or “a great deal” (48.6%) (Figure 1).

Data regarding changes in actual use of community health services by care-receivers -- again, remembering that it was the caregivers who generally arranged the services for care-receivers -- between time one and time two indicated that some change took place. Overall, when caregivers were asked if their care-receivers were using any new community health services -- or were now wait-listed for services -- since the start of the SCBC program, 35.5 percent of caregivers reported “yes.” Four caregivers stated that their care-receivers were using (or wait-listed for) Day Care Services for the first time since they became involved in the SCBC program. One caregiver each reported using (or wait-listed for) the following services: Handibus; Respite Bed; Private Home Care; Extended Care Facility; Homemaker Services; and Geriatric Outreach.

The changes in care-receiver usage between time one and time two for specific community health services are presented in Table 7. The changes reflect a somewhat confused pattern: three of the services showed no change in use, while the remaining services were split fairly evenly between increases and decreases in service use. Nearly all of the changes were small in magnitude, and none of the changes approached statistical significance (at the .05 level) when analyzed using the t-test for dependent samples. Overall, the manner in which

**Figure 1:**  
**SCBC Program's Effect on Caregiver's Awareness of Services**

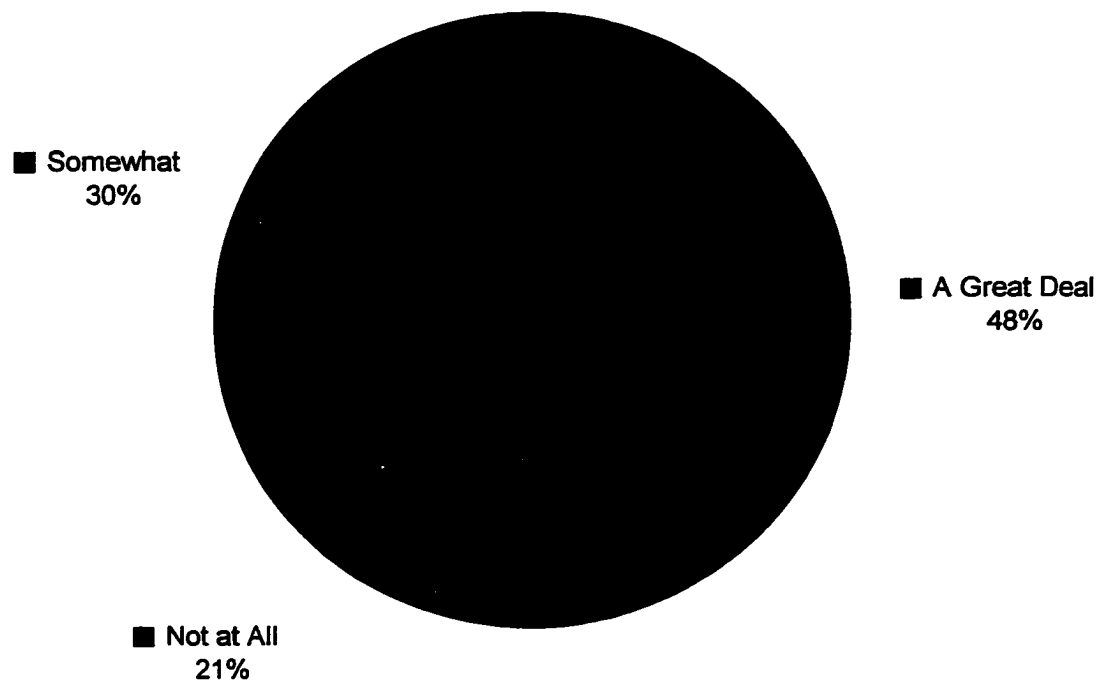


Table 10

## Changes in Caregiver/Care-Receiver Use of Community Health Services

Type of Community Health Service	Mean # of times used in past 3 months: Time 1	Mean # of times used in past 3 months: Time 2	Change in Service Use	T-test sig. (p=)
Adult Day Care	2.4	3.96	↗	.330
Day Care	7.25	11.75	↗	.253
Meal Preparation	0.0	3.91	↗	.328
Senior Center	1.22	2.65	↗	.387
Transportation	4.70	5.39	↗	.897
Physio/Rehabilitation	1.22	1.78	↗	.202
Personal Care	13.83	13.30	↘	.946
Home Care	2.74	2.09	↘	.801
Handicap/Taxi	1.50	.96	↘	.536
Medical Wheel	4.88	.48	↘	.179
Medical Bath Seat	.57	.04	↘	.328
Disease-Specific Groups	1.14	.86	↘	.768
Family/Caregiver Care	.10	.08	—	.788
Occupational Therapy	.04	.04	—	1.00
Community Center	.08	.08	—	1.00

services either increased or decreased in usage appeared to be random and governed by chance. The discrepancy between the four caregivers who reported that their care-receivers were now using (or wait-listed for) adult day care, and the lack of real change in usage of adult day care services reflected in Table 7, is likely due to the fact that most (if not all) of the four care-receivers may in fact have been placed on a waiting list for adult day care, something that would not be reflected in the data presented in Table 7.

Question Nine: To What Extent Did the SCBC Program Influence the Propensity of Caregivers to Place Their Care-Recipient in a Long-Term Care Facility?

Table 8 provides an overview of the various institutional placement decision-making stages the phase II caregivers were at for both time one and time two. Of note is the fact that at time one, only 24.6 per cent of the caregivers had either given institutional placement of their loved one serious thought, or had already requested/completed placement. Thus, of the caregivers entering the program, a full 75.4 per cent of caregivers had either not considered placement, or only given it some thought. This finding is important, in that caregiver program planners typically worry that caregivers only join support-type programs when they are near a crises or burn-out stage. These statistics reveal that the SCBC

Table 11

**Percentage Distribution of Caregivers According to Institutional Placement  
Decision-Making Stage**

<b>Institutional Placement Decision-Making Stage</b>	<b>Time 1</b>	<b>Time 2</b>
Not at all	44.6% (N = 29)	43.3% (N = 13)
From a little bit to some	30.8% (N = 20)	26.7% (N = 8)
From a little bit to a lot	7.7% (N = 5)	10% (N = 3)
Have requested placement	9.2% (N = 6)	10% (N = 3)
Have considered placement	7.7% (N = 5)	10% (N = 3)

program planners and local steering committees were successful in recruiting caregivers at a point in their caregiving career where a group support intervention might still prove beneficial, particularly in delaying institutional placement. As Table 8 also shows however, there were no real differences in caregiver's propensity to place their loved one between time one and time two. The percent of caregivers at various stages of their decision to place their loved ones in an institution remained essentially unchanged before and after the caregiver's involvement in the SCBC program. Indeed, when the Wilcoxon Matched Pairs Signed Ranks Test (used for two dependent groups with ordinal data) was applied to the data, no statistically significant changes were noted in caregiver's intentions about long-term care placement between time one and time two ( $Z = -1.069$ ,  $p = .285$ , 2-tailed).

## CHAPTER FIVE: DISCUSSION

The purpose of this chapter is to summarize and synthesize the main findings of this study, and to compare those findings to previous research and theory. This chapter will also review the relative strengths and limitations of the study, and discuss the main implications -- for public policy and nursing practice - - arising out of the results. Some overall recommendations for future research will conclude this chapter.

### Discussion of Findings

#### Level One: The Individual Caregiver Level

Caregivers participated in focus groups providing qualitative data about their perceptions of the main benefits of the SCBC program, and responded to a questionnaire that gave quantitative data on their level of social support, and perceptions of powerfulness and powerlessness. Each of these questions will now be discussed below.

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### The Main Benefits of the SCBC Program

Four major themes emerged from the focus group data pertaining to the perceived main benefits of the SCBC program: learning they were not alone; learning about resources and the system; learning not to feel guilty; and being able to care for loved ones longer.

*Learning they were not alone* was a prominent benefit mentioned by caregivers. Despite the importance of this decreased sense of aloneness or isolation to caregivers, few traditional evaluations of support group interventions include this aspect as an outcome (Gage & Kinney, 1995). Indeed, while the self-help literature has well documented this importance of “not alone-ness,” this author could only find one other published evaluation of caregiver support groups that mentioned this important benefit of finding “great comfort in knowing others shared the same situation” (Wilner, 1988, p. 154).

Caregivers also reported being *less guilt-ridden* about their caregiving after the SCBC program. This finding is similar to an evaluation of a caregiver support group evaluation by Toseland, Rossiter and Labrecque (1989), who found that caregivers in a support group intervention experienced less guilt than caregivers in a control condition. Reduction of guilt in caregivers is significant, as guilt can be a particularly debilitating and persistent emotion in caregivers,

making caregiving especially stressful and demoralizing. When unaddressed, guilt surrounding the quality of care given can prevail no matter how much of the caregiver's time and/or energy is devoted to caregiving (Schulz, 1990).

Women -- who traditionally provide the majority of caregiving in our society -- have been found to experience considerable guilt associated with caregiving. (Hooyman, 1990). This may be due to the way in which society has generally socialized women to internalize an injunction to care (Hooyman, 1990; Palo Stoller, 1990). If female caregivers assess their own worth by their ability to provide care, any decreases in the ability to provide that care, for whatever reason, often provokes feelings of guilt.

It would appear, however, that within the SCBC caregiver support groups, caregivers were able to effectively challenge each other about the unrealistic expectations they were up against, consequently reducing the guilt they felt as caregivers. This reduction of guilt and self-recrimination may go a long way to reducing caregivers' traditional feelings of powerlessness (Rutman, 1995), a point that will be discussed further in this chapter.

Caregivers also reported a major benefit of the SCBC program was their *learning about resources and the system*. At one level, caregivers simply learned what community resources and services were available to them as caregivers (this will also be addressed later on in this chapter in a section on knowledge and use of

community services). At another level, however, caregivers reported being more savvy about how to negotiate what is commonly known as “the system,” and no longer felt dominated by professions and bureaucracies (Trojan, 1989). That is, its one thing to know which services are available, but its an entirely different matter for caregivers to know how to confidently and assertively deal with health and social service providers, and to negotiate what can often seem like a maze of red tape and regulations. This is an important consideration when addressing the perceived problem of service under-utilization by caregivers consistently reported in the literature (Fortinsky & Hathaway, 1990). Furthermore, as these caregivers learned how to better deal with the system, they found themselves feeling less neglected, abandoned and rejected by the system (and even society as a whole), feelings that Wilner (1988) found were very prevalent in her qualitative evaluation of a caregiver support group.

Finally, the qualitative data indicated that caregivers felt a major benefit of the SCBC program was *the ability to care for loved ones longer at home*, primarily due to learning how to take better care of themselves. While some caregivers stated that “taking better care of themselves” meant initiating the process of placing their loved one in a long-term care facility, most caregivers felt that the SCBC program had offered them the skills and knowledge they needed to continue caring for their loved one at home for a longer period of time.

This finding is consistent with both other qualitative and quantitative evaluations of caregiver support groups, in which caregivers reported they were able to continue caring for their loved ones at home longer (hence avoiding institutional placement) as a result of support / education group participation (Feeney-Mohoney & Shippee-Rice, 1994; Mittleman, et al., 1993; Mohide et al., 1990; Wilner, 1988).

#### The SCBC Program and Caregiver's Support

Many studies on caregivers have documented the positive relationship between social support and caregiver well-being (Baille, Norbeck & Barnes, 1988; Bergman-Evans, 1994; Fiore, Coppel, Becker & Cox, 1986; Haley, Levine, Brown & Bartoucci, 1987). Two studies, however, have noted either a negative relationship, or no relationship at all, between social support and caregiver well-being (Hannappel, Calsyn & Allen, 1993; Cohen, Teresi, & Blum, 1994). Given what appears to be an important link between social support and caregiver well-being, it was hoped that the SCBC program -- with its focus both on connecting caregivers with each other and educating them about the importance of social support -- would have a positive impact on their experience of social support.

The research on social support, while conceptualized in various ways,

usually considers two aspects of social support: the number of available others one can turn to for assistance, and the satisfaction with the available support (Bergman-Evans, 1990). In addition to measuring these two aspects, this dissertation research also assessed the *type* of social support caregivers received from others. The results showed that at both the beginning and three months after the SCBC program, “emotional support” was the most common type of social support received, followed by “companionship.” Since emotional support is one of the most important forms of support to caregivers (Stephens, Kinney & Ogrochi, cited in Bergman-Evans, 1994), this sample of caregivers was fortunate to have emotional support as their most commonly received form of support.

The average number of persons in caregiver’s social networks did not change significantly between time one and time two. This is consistent with research by Toseland, Labrecque, Goebel & Whitney (1992) that found no change in social network size after a group program for spousal caregivers of elderly. Earlier research, however, found that both peer and professional led support groups for daughter caregivers significantly increased the social network size of group participants (Toseland, Rossiter & Labrecque, 1989).

For the phase one caregivers, their average total sum social support score, the sum of all forms of social support received, *did* rise after the SCBC program. Since the average number of people in their social support network did not

increase, this result means that the *amount* of assistance received from the person(s) already in their support network increased after the program. Thus, while the research design prevents stating conclusively that it was the SCBC program that *caused* the increase in support, it is encouraging to note that participation in the program was at least associated with increases in the amount of support caregivers received.

Participation in the SCBC program was not associated with any changes in caregiver satisfaction with their support. That is, caregiver self-reports of how satisfied they were with the social support they received from others did not change at all between time one and time two.

In terms of gender differences in social support, it has been found that female caregivers tend to have larger social networks than their male counterparts (Hibbard, Neufeld & Harrison, 1996). While the data from this dissertation found no differences in social network size between male and female caregivers, it was found that female caregivers had considerably higher average total sum social support scores than males. This would suggest that female caregivers are getting much more help than male caregivers from the people in their lives. This finding, however, along with the finding that male caregivers in this study reported greater satisfaction with the support they received, should be interpreted with great caution, due to the extremely small number of male caregivers ( $N = 2$ ) in this

sample.

In summary then, the data showed that participation in the SCBC program was associated with caregivers reporting an increase in the overall amount of support they received from their social support network. This reported increase was not accompanied by either a significant increase in the total number of persons of their social support, or by any changes in the satisfaction caregivers reported with the support they received from others. The dissertation's qualitative data, emerging from focus group interviews with the caregivers, suggests that the increase in the overall amount of support received was likely due to the help they received from support group members in feeling less guilty and learning to be more assertive. That is, caregivers gradually came to feel less guilty about asking for help from others, and more confident in making those requests.

#### The SCBC Program and Caregiver's Perceptions of Powerlessness and Powerfulness

Powerlessness has been described as the absence of empowerment; powerfulness, its presence (Rappaport, 1984). This dissertation research found that after involvement with the SCBC program, caregivers's self-reported feelings of powerlessness decreased, and feelings of powerfulness increased. Again, with

this kind of evaluation design, it can not be determined that the SCBC program *caused* these changes in caregiver feelings of powerlessness and powerfulness, merely that it was associated with them.

The use of caregivers's perceptions of their own powerlessness and powerfulness as outcome variables for the evaluation of caregiver education/support groups could not be found in the caregiving literature, in spite of Rutman's (1995) documentation of the importance of women caregivers' experiences of this phenomena. On the basis of her research, Rutman has suggested several sources of the powerlessness that women caregivers may experience. Her work offers an explanation of why involvement in the SCBC program may have been responsible for the reduction in feelings of powerlessness this dissertation research revealed.

For example, Rutman found that caregivers's feelings of powerlessness often stemmed from the lack of recognition or respect they received. Within the small caregiver groups of the SCBC program, caregivers gave and received much mutual recognition and respect, helping to reduce this particular source of powerlessness. Rutman also mentions the theme of "...powerlessness as feeling unable to express, or to control emotions" (1995, p. 33). Again, the caregivers in this dissertation research repeatedly stressed how often they used their caregiver groups as a safe forum to express and share the difficult emotions of caregiving.

This safe haven for caregivers would help to reduce this other potential source of powerlessness.

It is not surprising that decreases in feelings of powerlessness might be accompanied by increases in feelings of powerfulness. Again, Rutman's research sheds light on how the SCBC program may have been responsible for the increases in powerfulness that caregivers reported. As the *absence* of respect was related to feelings of powerlessness, so too was the *presence* of respect related to feelings of powerfulness. Thus, increases in feelings of powerfulness are not a surprising consequence of the respect and recognition caregivers found in their groups.

Rutman also found that caregivers in her research expressed a sense of powerfulness stemming from being more assertive with their care-receivers. Similarly, caregiver participants in the SCBC program reported that their group experience had made them more assertive in general, not only with their care receivers, but also with health care professionals and members of their families. In addition, caregivers in the SCBC program experienced another source of powerfulness found in Rutman's work. That is, caregivers experienced powerfulness when they "...took part in advocacy activities, and when they saw themselves as part of a collectivity or social movement of caregivers" (1995, p. 44). As will be discussed further in this chapter, most SCBC groups reported

some form of caregiver advocacy, such as writing letters as a group to local politicians. The caregivers were thus able to feel the sense of powerfulness that comes from belonging to a group and taking collective action (RNABC, 1992).

#### Summary of Findings at the Level of the Individual Caregiver

Overall, the findings from the first three research questions of this dissertation research indicate the SCBC program had an important impact at the level of individual caregiver participants. The qualitative data indicated that as a result of the program, caregivers felt less alone, were better able to utilize and negotiate the (health care) system, experienced less guilt as caregivers, and felt they were now able to care for their loved ones at home longer. The quantitative data revealed that participation in the SCBC program was associated with increases in the overall social support (total sum social support scores) caregivers received from others. Caregiver participants also experienced decreases in self-reported feelings of personal powerlessness, and increases in feelings of powerfulness.

Taken together, these findings would suggest that the SCBC program had numerous positive impacts on the lives of individual caregiver participants. The evaluation of the SCBC program at the second level, the level of small groups,

will now be discussed.

### Level Two: Level of the Small Group

The evaluation of the SCBC program at this level, the level of the small group, endeavored to determine: (1) the eventual fates of the SCBC caregiver groups once the official 10 week period was over -- and the factors determining long-term sustainability of the groups, and (2) a more detailed sense of the beneficial support group processes that caregivers experienced in their groups. Each of these questions will now be discussed in turn.

#### Factors Helping the Long-Term Sustainability of Caregiver Support Groups

Four out of the six caregiver groups in phase one of the SCBC program were still meeting regularly ten months after the program had officially ended (Schell, 1996). At three months post-program, when the focus groups with caregiver in their support groups were conducted, five out of the six groups were still intact. As the majority of caregivers had stated originally they were only interested in the ten scheduled (ten weeks) meetings, the fact that most groups were still meeting nearly one year later attests both to the extent to which

caregivers found these groups helpful, and to the ability of caregivers to sustain their groups over time.

When existing groups were asked at three months post-program about the factors determining their group's long-term sustainability, caregivers stressed the importance of: planning for new members; seeking an ongoing facilitator; and taking political action about caregiving. While these factors seemed intuitive and common sense to the caregivers, this author was unable to find sources in the literature addressing the issue of long-term sustainability or viability of caregiver support groups. The majority of published evaluations of caregiver group support initiatives report on time-limited (and usually facilitated) caregiver support groups, with no mention of the fate of these groups once the program ends. Nor is there a discussion of factors that might influence the long-term survival of these groups. Similarly, Hume (1993) has noted that with many community development initiatives, there is little or no thought given as to how communities can sustain action once official projects (i.e., funding) come to a close.

The developers of the SCBC program were aware of these potential pitfalls, and made attempts to address them. Thus, within the "curriculum" of the 10 week program, the issue of long-term sustainability of the group(s) was included, and each facilitator explored with their group how they would continue once the official 10 weeks ended. Facilitators also helped the groups to openly

address and brainstorm around such issues as recruiting new members, ongoing leadership (facilitator vs. member led) and fund raising / political action. It is no surprise then, that these are the very themes that came up in the focus group interviews at three months post-program, inquiring about the long-term sustainability of the caregiver groups

While no literature could be found specifically addressing the long-term sustainability of caregiver support groups, Lemberg (1984) discusses themes similar to the above findings in his article about what helps self-help groups to *fail*. For example, he notes that not recruiting new members, and not rotating leadership “helps” self-help groups to fail. Indeed, two of the six caregiver groups that failed to continue after 10 months were reported to have failed either due to dwindling numbers (failing to recruit) or an over-reliance on a single leader who ultimately could no longer facilitate (failure to rotate leadership).

While Lemberg did not mention the importance of political action as a factor affecting the ongoing survival of self-help groups, it is interesting that caregivers did mention this activity as central to the ongoing viability of their caregiver support groups. This finding stands to reason, however, in light of Rutman’s (1995) discussion of the importance of political action and advocacy to caregiver’s sense of powerfulness. That is, a caregiver support group, whose

members can both find and channel a sense of powerfulness in the group, would logically have a better chance of long-term survival than a group where no such sense of powerfulness exists.

### Beneficial Aspects of Support Group Process

As with Wilner's (1988) qualitative evaluation of a caregiver support group, these caregiver groups mentioned group caring, the opportunity to laugh, the ability to vent emotions and emotional support as all beneficial qualities of group process. Confidentiality and opportunities to process loss were also described by participants as important elements of successful group process.

As with the previous research question, while the self-help literature has documented helpful group processes (Levy, 1976; Wollert, 1986; Kurtz, 1990), little attention has been given in the caregiving literature as to which group processes are particularly helpful and unique to caregiver support groups. The majority of published evaluations of caregiver support groups evaluate the benefits of such groups, without actually documenting the group process that is responsible for such benefits. Much of the caregiver support group evaluation assumes that the same group processes occur in caregiver support groups as occur in other forms of self-help groups, without validating those assumptions through

research.

While more research on the helping processes of caregiver support groups may prove that their processes are unique from self-help groups in general, this dissertation research found the processes within SCBC groups to be very similar to those documented in the self-help group literature. One of the earlier reports of helping processes in self-help groups (Levy, 1976), reflects some of the beneficial group processes mentioned by SCBC participants, although the descriptions are written more in the words of a psychiatrist than those the participants themselves may have chosen. For example, Levy mentions one process as “...direct and vicarious social reinforcement for the development of ego-syntonic behaviors...” (p. 316), the actual description of which sounds very similar to what the SCBC participants described as “feeling cared for and caring for others.”

Wilner’s (1986) descriptions of helping processes within a large sample of self-help groups more closely match the SCBC participants’ own descriptions of helping processes occurring within their groups. For example, the SCBC participants’s themes of “venting of strong emotions” and “confidential interaction” are similar to Wollert’s descriptions of “encouraging catharsis” and “self-disclosure,” respectively. Wollert’s other themes, including “empathizing,” “mutual affirmation,” and “instilling hope,” are akin to what the SCBC participants described at “feeling cared for and caring for others” and “discussing

and processing loss.”

In yet another review of the helping processes occurring in self-help groups, Kurtz (1990) uses comparable words to describe these processes. Thus, it would appear that the helping processes SCBC participants identified as particularly beneficial in their groups are essentially those that have been documented in the self-help literature. That is, caregiver support groups seem to also “...provide their members with a broad range of therapeutic exchanges, but do this by drawing on safe and simple techniques that are grounded in everyday experience” (Wollert, 1986, p. 64). In addition however, as this sample of six caregiver groups would suggest, the processes of “providing opportunities to laugh at themselves” and “discussing and processing loss” may be unique to caregiver support groups. For example, Wilner (1988) found in her qualitative evaluation of caregiver support groups that there seemed to be a special need for comic relief, so that caregivers could use the group as “...a place to laugh and experience comic relief from the intensity and tragedy of their lives” (p. 155). Further research into the actual helping mechanisms of caregiver support groups may help to clarify their similarities and differences with other types of self-help groups.

Caregivers in this evaluation were careful to emphasize the importance of skilled facilitation and leadership in ensuring effective group process. These

groups were fortunate to have skilled and trained facilitators, many of them current or retired health care professionals, but less skilled facilitators might result in less positive impacts on caregiver participants. Again, more research on caregiver support group process, including the effects of various styles of leadership and facilitation, would be helpful to direct both current and future caregiver support groups.

#### Summary of Findings at the Level of the Small Group

At three months post-program, five out of the six original caregiver support groups were still meeting regularly, and caregivers could articulate their needs and the factors they felt that influenced the long-term sustainability of their groups. In particular, caregivers stated the need to plan for future members, seek ongoing facilitation/leadership, and engage in meaningful political action / advocacy. Furthermore, group participants could identify helpful aspects of their group process. That is, caregivers knew that they needed to continue to laugh, care for each other, share powerful emotions, offer a safe place to confide in each other, and help each other with their losses, if they were going to continue to reap the benefits of group membership. Overall, it appears that many of the principles of beneficial group process that apply to self-help groups in general also apply to

caregiver support groups, including those that are facilitator-led. More research would be beneficial to help elucidate any beneficial group processes that may be unique to caregiver support groups, and factors that might ensure their long-term success and viability as self-led groups.

### Level Three: Level of the Community

Hume (1993) has documented the lack of discussion in the community development literature about either the experience of community development for participants, or ways to sustain community development initiatives over time. Therefore, evaluating the SCBC program -- which was conceived as a community development project -- at the level of the community was very important. In particular, it was important to give voice to the community members who participated in the SCBC community development process, and to let them talk about their experiences and lessons learned as community developers.

From the focus group interviews with the community steering committee members, profiles emerged for community characteristics that influenced the SCBC project's outcome as a community development process. In addition, these interviews revealed elements of the community development process that were particularly important to the outcomes of the SCBC project. These findings will

now be discussed in turn.

### Community Characteristics Which Influenced the Outcomes of the SCBC Project

Focus group participants identified several unique characteristics of their communities that they felt helped the SCBC project, including: a local community senior's center; a centralized, accessible and coordinated health unit; and a safe place to meet with good transportation. Unique aspects of their communities that were perceived to hinder the SCBC project included: overwhelmed community members; turf wars; cultural and language barriers; community size; and weather/season.

Few published evaluations of caregiver support groups and/or community development initiatives could be found to compare these findings with. One report of a training program for family caregivers of older adults (Feeney-Mahoney & Shippee-Rice, 1994) did mention that long-term care facilities were chosen for the program, as they met the criteria of being "... (a) easily accessible by public transportation and roadways, (b) free parking, and (c) centrally located" (p. 75). These criteria are similar to the helpful characteristics of communities mentioned by the SCBC steering committee members.

The same report by Feeney-Mahoney and Shippee-Rice (1994) mentions

weather and season as factors that negatively affected the caregiver training program. Their experience, like that of many of the community members involved in the SCBC program, was that no caregivers were interested in a summer program, and winter sessions were not popular due to the dangerous winter driving conditions. In terms of other community characteristics hindering the community development process, Hume (1993) mentions the difficulty of “overwhelmed community members.” That is, particularly in smaller communities, both this research and the research of Hume’s, noted that the same pool of people tend to be drawn upon for community work. When community members become overwhelmed with yet another “good cause” requesting their time and energy, it can make it difficult for projects such as the SCBC program to get off the ground.

The other community characteristics hindering community development work found in this research -- turf wars, cultural / language barriers, and community size -- are important for future community developers working with these kinds of initiatives to bear in mind. As Chalmers and Bramadat (1996) have noted, these community characteristics speak to the *divisions and resistance* that exists in communities; divisions and resistance that need to be overcome as part of any community development or coalition building process.

Additional research on the community context affecting community

development initiatives would be very useful. As Hume notes, “understanding the context of each community may give us a greater understanding of why some communities access and are successful with community development activities and others not so successful (1993, p. 52). Without a better understanding of these community characteristics and contexts, community development projects, particularly those involving numerous different communities, may only result in a loss of precious time and money.

#### Elements of the Community Development Process Influencing the SCBC

##### Project's Outcome

A number of important lessons on community development processes emerge from the insights and experiences shared by the steering committee participants. To begin with, a number of guidelines for successful community development projects emerge, many of which are similar to the 15 “lessons” that Hume (1993) has offered, in her review of community development projects in British Columbia.

For example, the focus group participants talked about the importance of having a wide variety of people, particularly “fire lighters,” involved in a community development project. Similarly, Hume (1993) notes that community

action best begins with “a committed individual or group.” In both cases, it seems imperative that community development projects target key committed and enthusiastic individuals to spearhead these projects. Unfortunately, as will be addressed further in the policy section of this discussion, it seems that this kind of community development work falls heavily on the shoulders of women.

Both the SCBC focus group participants and Hume (1993) also mention the importance of support from the local media for ensuring successful community development work. When discussing the importance of working with the local media, focus group participants also mentioned the importance of working jointly with local businesses. Hume’s review also mentioned working with local politicians. In reality, working with all three groups -- local media, businesses, and politicians, would likely help community members to maximize the chances of success in community development work.

In addition, the SCBC focus group participants mentioned further elements of community development process they found important. Some elements like “working well together and being committed,” “facilitating word of mouth” and “having courage” may seem intuitively obvious, but were stressed as being extremely important, and can easily be overlooked by community development initiatives, that often over-emphasize outcomes at the expense of process.

Taken together, while these findings do not suggest a “cookbook”

approach to community development, they do offer initial documentation of some of the process considerations that affected a wide-scale community development initiative involving family caregivers of the elderly. Hopefully, this documentation will offer guidance to similar future projects. It might also be seen as a step in the right direction in changing the manner in which such projects have traditionally been evaluated and written up -- in ways such that "...the focus of reporting is on outcomes and not the participatory process that produced those outcomes" (Hume, 1993, p. 51).

#### Summary of Findings at the Level of the Community

Out of these findings emerged a portrait of community characteristics that both helped and hindered the SCBC project community development process. In addition, community members offered perceptions of their involvement in the community development process, and identified aspects of that process that were particularly beneficial to the outcomes of the SCBC project. This information, not normally supplied with traditional evaluations of caregiver support initiatives, gave the SCBC evaluation greater strength by including data on both project outcomes *and* process. Therefore, this information is of great potential benefit to future such community-based caregiver support initiatives, who can anticipate the

kinds of outcomes most realistic to expect, and the processes most likely to produce those outcomes.

#### Level Four: Level of Health Care Services

The findings at this level pertain to the impact the SCBC program may have had on caregiver participants' knowledge and use of community health services, and to how the program may have influenced caregiver's decision making process around institutionalization of their care-receiver. This information was deemed to be important, particularly for the funders of the project (Ministry of Health, Continuing Care Division), who had expressed concerns over a perceived under-utilization of community services by family caregivers of the elderly. Naturally, given the predicted shortage of long-term care facility beds in the coming years, the Ministry of Health also has great interest in any initiative that might be seen to reduce or delay the need for long-term care beds.

#### Caregivers' Knowledge and Use of Community Health Care Services

As a whole, caregivers were generally well aware of the various community health services available, and how they may have helped them as

caregivers. These results are similar to ones found by Gonyea & Silverstein (1991), who also found that Alzheimer's disease caregivers were reasonably aware of available services. However, the large percentage of caregivers who felt the SCBC program had affected their awareness of services "a great deal" (48%) reveals that many caregivers still had much to learn about services. It also reveals that almost half of the caregivers found the program very helpful in teaching them about those services. Previous research has also found this kind of group format to have a very positive impact on participants's knowledge of services (Toseland, Rossiter & Labrecque, 1989).

However, caregiver knowledge of services is but one of the many possible variables affecting the actual usage of community services by care-receivers. Even though the SCBC program was successful in raising the awareness level of caregivers regarding community services, there were no significant (statistically, or otherwise) changes in average reported usage in any of the 15 services assessed between time one and time two. This lack of relationship between caregiver support / education group participation and differences in participant utilization of community services has been noted in other evaluations of such groups (Caserta, Lund, Wright & Redburn, 1987; Toseland, Rossiter & Labrecque, 1989). Gonyea and Silverstein (1991), however, found higher rates of formal service usage among members of an Alzheimer's disease caregiver support

group. The authors suggest that either support groups socialize members into accepting and utilizing community services, or that caregivers who join support group members may already be high users of services to begin with, and simply view support groups as yet another service to use. Obviously more research would be useful to clarify the relationship between caregiver group participation and community service utilization.

Regardless of how caregiver groups may impact participants's use of community services, the data from this dissertation reflect the concern that caregivers traditionally *under-utilize* community services. Even the most commonly used community service in this study, in-home personal care, was only used on the average a maximum of 13.83 times in a three month period; less than five times a month on average. All of the other community services surveyed averaged much lower reported usage. In fact, a large majority of caregiver respondents had not made use of any of these formal community services, a finding mirrored in a survey by Gonyea and Silverstein (1991).

This under-utilization of services by caregivers, many of whom are under tremendous strain caring for family members with significant cognitive and/or physical impairments, is of great concern to community service providers and health care policy planners. Their concern stems from the belief that caregivers who fail to avail themselves of available community support services (e.g., respite

services) until a crisis point, are ultimately putting both themselves and their care-receiver at increased risk of health problems and institutionalization (Bass, Noelker & Rechlin, 1996; Caserta et al., 1987; Montgomery & Borgatta, 1989; Gonyea & Silverstein, 1991). Yet despite considerable encouragement to use community services, many caregivers continue to refuse such services.

There are several reasons for this reluctance to use formal community services. For one, caregivers may be inoculated over great periods of time to the stresses of caregiving, to the point where they may view very stressful situations as “normal.” Caserta et al. (1987), for example, found in a survey of caregivers that the most prevalent reason (94%) given by caregivers for not using available services was a perceived lack of need, despite very stressful caregiving situations. Thus, caregivers may be well aware of services, but fail to identify themselves as “appropriate” consumers of those services (Gonyea & Silverstein, 1991).

Alternatively, caregivers may simply be so stressed by the demands of caregiving that trying to access and use a community service, however helpful, becomes another stressor in itself. As Montgomery and Borgatta (1989) stated: “...the experiences of strain on time, physical resources, and emotional resources, the same circumstances that create the need for support services, also tend to prevent caregivers from using these services effectively” (p. 463).

A third explanation may be the relatively short time -- three months -- that

this evaluation followed caregivers after the SCBC program. Perhaps in one or two years, as caregiving tasks and stresses multiplied, caregivers participating in the SCBC program may be more likely to avail themselves of community services that they learned about in the program.

### The SCBC Project and Caregiver's Propensity to Institutionalize Their Care-Recipient

Given that the SCBC program was a B.C. government sponsored initiative through the Ministry of Health (MOH) , it is not surprising that the MOH stakeholders in the program wanted an evaluation of the program's potential impact on caregiver's propensity to institutionalize their care-receivers. Despite the considerable gender and/or morale issues (which will be addressed later in this chapter) that arise when caregiver support initiatives are evaluated on the basis of whether they keep caregivers "in the trenches" longer, MOH personnel did feel that the SCBC program would be seen as successful and cost effective if it postponed or prevented placement of the care-receiver in a long-term care facility.

In fact, throughout the evaluation, the results showed that most caregivers were a long way from placing their loved ones in a long-term care facility. A full

75.4 percent of caregivers at time one, and 70 percent at time two, were not considering placement at all or only “giving it some thought.” Thus, it appears that the SCBC program showed considerable success in recruiting and retaining caregivers who were reasonably early in their caregiving career or had not yet reached a “crisis” stage.

Since most caregivers in the SCBC program were a long way from believing they needed to place their care-receiver, the program appeared to have negligible impact on caregiver’s thinking around institutional placement. The percentages of caregivers at the various stages of institutional placement decision-making remained essentially unchanged between time one and two, and the small differences in percentages that did exist did not achieve statistical significance. It must be remembered, however, that this research included only a three month post-program follow-up, and lacked a formal control group. Both of these factors may have limited the ability to detect a real program impact on patterns of institutionalization. Certainly, the qualitative data reported under question one in this chapter would suggest caregivers felt strongly that their involvement in the SCBC program was going to enable them to continue caring for their loved ones at home longer.

There are several published studies that have shown that caregiver support/education groups, like the SCBC program, can postpone or prevent the

placement of care-receivers by their caregivers. Greene and Monahan (1987), for example, found that caregiver participation in a group program very similar to the SCBC program resulted in a 56% lower institutionalization rate in the treatment group compared to the control group (at the end of a 12 month period). Similarly, Mittleman et al. (1993) found that caregivers who joined support groups ended up placing their care-receivers in nursing homes at rates that were half of those found in the control group. Finally, Mohide et al (1990) found that a caregiver support intervention, which included a caregiver support group, produced a slightly longer mean time to long-term institutional placement (compared to a control group).

Montgomery and Borgatta (1989) have suggested that the effect of caregiver involvement in support groups on nursing home placement may depend on the caregiver's relationship to the care-receiver. That is, they reported that participation in support services, such as caregiver support groups, tends to delay nursing home placement for children (usually daughters) of care-receivers, whereas support services tend to encourage spouses to place their elderly care-receivers in nursing homes. As they noted, "...given the strong resistance to nursing home placement that is found among spouses and the taxing nature of their caregiving tasks, this outcome could also be viewed as encouraging, because it might reflect more appropriate use of available services" (p. 463).

Haley (1989) has also noted that support group participation may facilitate

some caregivers' pursuit of nursing home placement, and that such an event should be seen as a "...favorable clinical outcome for some caregivers..." (p. 480). This outcome would be particularly favorable if it prevents long-term placement of the caregiver *in addition to* the care-receiver, due to excessive caregiver stress and burden. Thus, it could be well said that caregiver support initiatives such as the SCBC program are very beneficial to caregivers *and* are cost-effective, regardless of whether caregivers are encouraged to keep their elderly family members at home longer, or if they encouraged to seek institutional placement sooner than they might have normally considered.

#### Summary of Findings Related to the Level of Health Care Services

It was found that a large number of caregivers felt the SCBC program substantially increased their knowledge of community health services, although the program appeared to have no impact on caregivers' actual usage of those same community health care services. Furthermore, it appeared that the SCBC program had no significant impact on caregiver's plans for institutional placement of their care receiver.

While these findings would suggest that the SCBC program had minimal impact at the level of community health services, it must be remembered that this

evaluation occurred only three months after the official end of the program. This time period may have simply been too short to observe any changes in caregiver / care-receiver use of community health services, including long-term care facilities. Again, the qualitative data presented in the discussion of research question #1 would suggest that caregivers felt the program enabled them to care for their care receivers at home for longer periods of time, and a longer-term follow up evaluation and use of a control group may have concurred with these qualitative findings.

### Strengths and Limitations of the Study

This section will address the methodological strengths and limitations of the SCBC evaluation presented in this dissertation. The perceived strengths will be addressed first, followed by a discussion of the limitations inherent in the methodologies chosen.

#### Strengths of the Study

The identified strengths of the methodologies chosen for the evaluation of the SCBC program include: use of participatory qualitative methodologies;

triangulation of methods and data; the multi-level scope of the evaluation; and the inclusion of data on both program outcomes and the processes that influenced those outcomes.

### Use of Participatory Qualitative Methodologies

As discussed in chapter two, the traditional over-dependence on quantitative methodologies to evaluate caregiver support initiatives (and other similar mutual aid programs) is increasingly seen as inappropriate (Borkman, 1976; Chesler, 1991; Tebes & Kraemer, 1991; Rappaport, 1993). Therefore, while quantitative methods were not totally eschewed in the SCBC evaluation (they provided valuable data on such things as caregiver use of community health services), five out of the nine research questions used qualitative methodology, and efforts were made to make the research process as participatory as possible. Wherever feasible, caregiver input into the process of planning and conducting the evaluation research was sought throughout the project. Overall, the use of participatory and qualitative methods allowed important evaluation information to be collected in ways that were keeping with the ethos of mutual aid and community development. Having caregivers included in forming the questions and methods helped to ensure the relevance of the eventual findings.

### Triangulation of Methods and Data

Some authors have expressed misgivings about combining qualitative and quantitative methods and data within the same study (Guba & Lincoln, cited in Patton, 1990; Morse, 1991). Overall, however, there appears to be widespread support for the integration and triangulation of various methodologies and sources of data within studies (Duffy, 1987; Myers & Haase, 1989; Patton, 1990) particularly in evaluation studies, where the need to “...gather the most relevant possible information for evaluation users outweighs concerns about methodological purity based on epistemological and philosophical arguments” (Patton, 1990, p. 193).

The use of both qualitative and quantitative methodologies in the SCBC evaluation allowed a wide variety of research questions to be asked. Furthermore, it allowed the evaluation to prevent many of the difficulties associated with *over-reliance* on traditional quantitative methodologies (discussed in chapter two), while still allowing some valuable quantitative data to be collected. In turn, the quantitative data could be triangulated with the rich qualitative data that was obtained. For example, the quantitative data on powerlessness and powerfulness was strengthened by the qualitative data emerging from focus group interviews

with caregivers. In addition, conducting focus group interviews with several different sources (i.e., six different communities) allowed further triangulation of data.

#### Broad Scope of Evaluation: Multi-Levels

One of the strengths of this research was the numerous levels at which the SCBC program was evaluated, ranging from the level of the individual caregiver, right up through to the level of community and community health care services. Many traditional evaluations of caregiver support programs evaluate at only one level -- usually at the individual caregiver level -- by measuring such things as caregiver burden, depression and/or anxiety (Greene Jackson & Lewis Cleary, 1995). By evaluating at many broad levels, similar to the different levels of empowering strategies (RNABC, 1992) discussed in chapter two, this evaluation of the SCBC program was able to give a much broader perspective on the possible outcomes (and processes) of the program.

#### Data on Both Outcome and Process of Project

As Hume (1993) noted in her review of government sponsored community

development initiatives in B.C., the majority of evaluations on such initiatives usually contain ample data on outcomes, but very little discussion of process. This evaluation was able to encompass data on both the outcomes of caregivers' participation in the SCBC program, and data on the process occurring in the caregiver groups and within the various communities. This kind of data on community development process is extremely important for the planning and implementation of future community development programs. Furthermore, when a particular program is embracing concepts such as community development and empowerment (as the SCBC program did), outcomes may in fact be of secondary importance to the process of fostering problem solving skills, self-reliance, feelings of powerfulness, and the formation of small groups and coalitions (RNABC, 1992; Chalmers & Bramadat, 1996).

#### Limitations of the Study

Some of the limitations inherent in this dissertation include the lack of control, the low number of participants, and the lack of long-term follow-up.

### Lack of Control

The quantitative methodology used in this dissertation was a one group pretest - post-test design, with no comparison or control group. While this is a frequently used research design, particularly for program evaluation, it has numerous weaknesses and threats to internal validity (Burns & Grove, 1993). In particular, the lack of a control or comparison group (such as untreated caregivers) makes it difficult for the design to make causal inferences. Thus, although this dissertation research found several significant differences in outcome measures between time one and time two (pre and post program), it cannot be concluded that those differences were in fact caused by participation in the SCBC program.

However, the inclusion of qualitative focus group interview helps to triangulate the quantitative data, and overcome some of the deficiencies of the quantitative methodology. Moreover, as was discussed in detail in chapter two, the inclusion of more experimental control is actually *undesirable* when evaluating mutual aid / community development initiatives such as the SCBC program. The introduction of rigid experimental control procedures, such as assignment of participants to experimental and control groups, can do violence to the spirit of mutual aid and community development programs, and as such are often considered to be inappropriate for evaluating such programs (Borkman,

1976; Chesler, 1991; Tebes & Kraemer, 1991).

### Low Number of Participants/Subjects

This dissertation research had an adequate sample size for the qualitative component of the research. However, the relatively small number of completed caregiver surveys from phase I (N = 49) and phase II (N = 28) resulted in low statistical power to detect significant differences between pre and post program quantitative data (Burns & Grove, 1993). While 87.5 percent of Phase I caregivers (49 out of 56) completed both pre-and post surveys, only 42.4 percent of Phase II caregivers (28 out of 66) completed both surveys. The low survey completion rate in Phase II reflects a change in the way surveys were collected between Phase I and II: the evaluation budget in Phase I allowed surveys to be collected in person, whereas budgetary restrictions in Phase II necessitated they be mailed in, resulting in a lower completion rate of both pre and post surveys.

Related to the issue of small sample size is the issue of sample representativeness. The caregivers participating in the SCBC evaluation were selected with convenience sampling, as outlined in the recruitment strategies listed in chapter three. A common concern reflected in the caregiving literature is that caregivers who respond favorably to recruitment efforts by joining caregiver

support groups (such as the SCBC participants), may not be representative of most caregivers. In fact, it is known that only a small percentage of caregivers ever participate in caregiver support groups (Schultz, 1990). Therefore, while the SCBC program may have been very helpful for the caregivers who participated in this evaluation, it is largely conjecture as to whether the program would have been helpful to the vast numbers of caregivers the SCBC program failed to attract.

#### Lack of Long-Term Follow Up.

By allowing only a three month follow up after the SCBC program's completion, this dissertation research did not provide for a longer-term evaluation of the program's impacts. Due to budgetary restrictions and time constraints, a longer term evaluation could not be conducted. Regrettably, this is the case with most evaluations of community development initiatives, and Hume (1993), in her review of government-sponsored community initiatives in B.C., notes that she could not find any "...material that addressed sustaining or maintaining community development initiatives over long periods of time" (p. 21).

Consequently, although efforts were made to determine which caregiver groups were still meeting regularly ten months after the program had ended (Schell, 1996), the lack of other long-term follow up made it difficult to track

other aspects of the SCBC program. For example, it would have been useful to know caregivers's perceptions of factors affecting the long-term sustainability of their caregiver groups, a year or more after this evaluation had been completed.

### Implications of the Study

The main implications arising from this dissertation research relate to nursing practice, and public policy regarding family caregiving.

### Implications for Nursing

The results of this dissertation research have a number of implications for nursing practice, particularly for community health and home care nurses working with the community dwelling elderly. These implications include: working with caregiver support groups; community development work; caregiver advocacy and nursing education.

### Nurses's Work With Caregiver Support Groups

Given the anticipated increase in the number of frail elderly being cared for in the community, nurses can expect to be working with more caregivers in the future (Davis, 1996). With their combination of communication skills, group skills, and knowledge of many of the medical conditions with which elderly persons and their caregivers are coping, such as dementia, nurses are in many ways the ideal individuals to work with caregivers in education and support groups such as the SCBC program groups. Just as nurses have traditionally helped families by offering expecting parents education and support for their new parenting roles and responsibilities, so too are nurses well positioned to help families by offering caregivers group education and support for their new caregiving roles (Feeney-Mahoney & Shippee-Rice, 1994).

#### Nurses as recruiters.

One important role that nurses can play with caregiver education and support groups is simply that of recruiter. Despite their large numbers, family caregivers are notoriously hard to reach and to connect with services.

Montgomery and Borgatta (1989) note that "...these families are fiercely

independent, have little contact with formal service providers, are reluctant to accept help, and are difficult to find or serve until they reach a crisis point” (p. 463). Community and home care nurses, being as well connected as they are with the community-dwelling elderly, are in ideal positions to reach out to family caregivers and actively recruit them into caregiver groups. In particular, male caregivers need special encouragement and special recruitment methods (Davies, Priddy & Tinklenberg, 1986). The results of this dissertation also suggest that nurses need to be aware of logistical barriers that may prevent caregivers from attending groups, such as transportation difficulties and the inability to leave the care-recipient, and must be creative in finding solutions to these obstacles (Gage & Kinney, 1995).

Finally, this research would suggest numerous benefits that result from participation in a support and education group like the SCBC program, benefits that nurses should actively promote when recruiting caregivers into such groups. For example, nurses could mention the increases in understanding and knowledge about confusing community health services, as well as the decreased feelings of powerlessness that caregivers experience as a result of support/education group attendance.

Nurses as facilitators.

Nurses can also take on more direct roles in caregiver groups, such as that of facilitator. Approximately half of the SCBC group facilitators were either current or retired nurses, and caregivers reported that the opportunity to discuss issues with a nurse was a very positive part of the group. Other reports of nurse-facilitated caregiver groups have had similar positive feedback from caregivers (Feeney-Mahoney & Shippee-Rice, 1994). Within the self-help literature, however, certain authors maintain that when professionals (such as nurses) assume an ongoing facilitator role in a mutual aid group, it reduces the members' ability to help themselves or press for social change (Kurtz, 1990; Stewart, 1990). Obviously, the style of the facilitator is very important, and the SCBC facilitators were carefully trained to facilitate in a manner that was empowering and encouraging of eventual self-leadership within the groups.

The results of this dissertation research also demonstrated that nurse facilitators of caregiver groups can enable facilitator-led groups to eventually become self-sustaining and self-led mutual aid groups. Finally, the dissertation results suggest that nurses who do act as facilitators of caregiver support groups need to be aware that the group processes that caregivers find most beneficial are very similar to the regular group processes described in the self-help group

literature.

### Nursing and Community Development

As nurses find themselves working more with government sponsored caregiver support initiatives, they are likely to find that such initiatives, like the SCBC program, are framed within a community development perspective. It is important, therefore, that nurses have community development skills, including well developed collaborative abilities and the ability to form working partnerships in the community (Chalmers & Bramadat, 1996). The results of this dissertation research would also suggest that nurses need to complete a preliminary community assessment, so they are aware of unique community characteristics that might help or hinder the community development process.

Furthermore, as suggested both by this evaluation and the work of Hume (1993), nurses should be aware of important factors within the community development process itself, such as the use of key individuals or “fire lighters” in the community, and effective use of the local media. Finally, nurses need to be savvy about the rhetoric of empowerment and community development. While policy makers may espouse the virtues of these terms, nurses may not actually be given the time or resources they actually need to use an empowerment model of

community nursing practice. Or, more importantly, they may not be given the administrative support to actually share power with the community members with whom they work (Chalmers & Bramadat, 1996; Skelton, 1994). Anticipating some of these potential problems is the first step to help nurses prevent such problems in the first place, or dealing with them when they do invariably come up.

### Nursing and Caregiver Advocacy

Another implication for nursing to be discussed is nursing's role in caregiver advocacy. Nurses are merely perpetuating the exploitation of women if they merely help caregivers 'adjust' to their burdens. What is needed from nurses is lobbying of policy makers for legislation that changes the caregiving status quo (Hortenstine Brackely, 1994). Nurses are the largest group of health care professionals in Canada, and nursing associations have tremendous potential to form lobbying coalitions with such organizations as the Alzheimer Society of Canada, and the Caregivers Association of B.C.. Such coalition building is a powerful tool of both empowerment and political change (RNABC, 1992), and may ultimately help form the basis for a larger social movement of caregivers (Hume, 1993).

Nurses, being predominantly women themselves, need to also lobby for

changes in caregiving policy from a feminist perspective. After all, nurses themselves suffer from the same low status that is accorded caregiving and women's work (Bunting, 1992). Furthermore, being predominantly female, nurses are likely to do 'double shifts' of caregiving in their lives: doing one shift of caregiving at work for strangers, and then coming home and putting in another 'shift' of caregiving at home for family members. So for their own sake, and not just the sake of other family caregivers, nurses need to realize the caregiving is a women's issue, and lobby for changes in public policy. What is required, however, is not that women stop caregiving altogether. Rather, nurses need to work towards a more equitable distribution of caregiving, and a re-examination of the assumptions and expectations that surround women and caregiving (Hooyman, 1990; Bunting, 1992).

Finally, it should be noted that the caregivers themselves in this SCBC evaluation mentioned the important role that becoming *politically active* played in the long-term health of their groups. This finding, combined with the fact that this research showed significant increases in caregivers' feelings of *powerfulness* as a result of SCBC program participation, suggests that nurses need to form ongoing *partnerships* with caregivers for the purposes of advocating for change. When advocating for change in the world of caregiving, nurses must not neglect caregivers themselves as powerful allies and partners in the fight for such change.

### Nursing Education

This research would also suggest some implications for nursing education. Primarily, the SCBC project itself is a wonderful example for nursing students how nurses can put ideas such as community development, empowerment and mutual-aid into practice. Again, much of the nursing literature on these ideas -- particularly community development -- is highly theoretical, and projects such as the SCBC program could be used to help demonstrate to nursing students how these ideas translate into the real world of nursing. The SCBC evaluation is also a useful case study for nursing students learning the principles of nursing research, as it demonstrates not only how to address methodological issues, but also the political realities of collaborative research.

### Summary of Implications for Nursing

In summary, the results of this dissertation research highlight the importance of nurses becoming more involved with caregivers and ways of supporting caregivers. There are many roles that nurses can play with caregiver groups and community development initiatives aimed at developing caregiver

resources. Most importantly, however, nurses need to be advocates for change in public policy that affects caregivers, and change in societal expectations of women and who cares for our elderly. Finally, projects such as the SCBC program can provide valuable lessons for nursing students learning about such concepts as empowerment, community development and mutual aid.

### Implications for Public Policy

In chapter two, I discussed some of the more important factors influencing Canadian policy on elder care, factors that certainly came into play with the development, implementation and evaluation of the SCBC program. The experience of the SCBC program suggests a number of changes are needed to make public policy more responsive to the needs of Canadians caregivers. These changes include: clarifying responsibility for elder care policy; creating stable funding for caregiver support initiatives; addressing the economic consequences of caregiving; and attending to the gendered nature of caregiving and community work.

### Clarifying Responsibility for Elder Care Policy

Unfortunately, progressive reform of Canadian public policy on elder care and caregiving is hampered in a political climate where federal and provincial governments are wrangling over shifting funding and responsibility arrangements. In addition, despite a great deal of rhetoric from all levels of government about the importance of “community care,” the vast majority of health care funding continues to go to an acute care system predominated by hospitals and doctors; a system which by its very nature is ill-suited to effectively help elderly persons and their caregivers.

What would help this situation greatly is for the federal government to increase and stabilize its transfer payments of health care funding to the provinces, and to legislate that a percentage of that funding be committed by provincial governments to community support of the elderly and their caregivers. Such legislation would help to avoid the wide discrepancies between provinces in how they address elder care and caregiver support. It would also help to stop community elder care and caregiver support from being disjointed and sporadic afterthoughts of provincial health care planners (McDaniel & Gee, 1993). This change, however, would be extremely difficult to implement, as the Canadian Constitution clearly gives provincial governments responsibility for health care

matters. Furthermore, the current political climate is one where provincial governments are demanding more -- not less -- jurisdiction over a wide range of matters, health care policy included.

### Creating Stable Funding for Caregiver Support Initiatives

This evaluation of the SCBC program, like many other evaluations of caregiver support initiatives, found that caregivers derived great benefit from a program of education and support. Yet the SCBC program, like so many other caregiver support initiatives, suffered from a lack of stable funding. Thus, like other so-called “demonstration projects,” once the one-time funding was over, the program dissolved, and no other caregivers benefited. What is needed is government policy that makes stable funding a high priority -- as high as funding for hospitals and physicians -- for a wide variety of caregiver support programs. These programs could include not only caregiver education and support programs, but other forms of support, such as computer/telephone support networks, respite services, and caregiver advocacy organizations.

One possible danger with additional government funding for caregiver support programs (e.g., more SCBC type programs) is that merely helping the caregiver ‘adjust’ to their role can in fact lead to widespread exploitation of

women caregivers (Hortensine-Brackely, 1994). That is, if the primary motivation for caregiver support programming is to keep caregivers 'in the trenches' longer to reduce institutional placements, the caregiver's well-being can quickly get lost in the interest of 'cost-effectiveness.' Hooyman (1990) echoes this concern:

...education and support programs are a recent policy development oriented to reducing caregiver burden. Yet their cost-effectiveness is often evaluated in terms of whether they prolong the caring relationship, not the caregivers's well-being....most caregivers will persevere to the breaking point, bound by love or duty to those for whom they care. Under such conditions, cost containment approaches make the public purse the beneficiary of policies, while victimizing caregivers as unpaid servants (p. 234)

While caregiver support programs can be very helpful, and may therefore help caregivers who sincerely want to care for their elderly family members at home as long as possible, they must not be evaluated solely on their ability to reduce institutional placements. Such caregiver support programs are also insufficient by themselves, in that they generally fail to address the economic and gender issues of caregiving.

Addressing the Economic Consequences of Caregiving.

When discussing policy that would address the economic consequences that women (and occasionally men) incur as a result of devoting themselves to the care of an older family member, a common sentiment is that monetary compensation for caregiving is an important first step (Hooyman, 1990). For example, the province of Nova Scotia, and a number of American states have already instituted programs where relatives who meet certain program requirements can be paid as providers of in-home care (Hooyman, 1990; Keefe, 1993).

As Hooyman notes, the debate over remunerating caregivers with wages and benefits for the care they give centers around the value we as a society give to such care. The debate also reflects how our society values women and the work they do. The response by policy makers that “there’s no money” for remuneration of caregiving work is belied by the reality that there *is* money to pay people to build wider highways, operate the armed forces, or buy MRI machines for hospitals: it is all a matter of what our society will pay money for, and what we think we can get women to do for free.

As Keefe (1993) notes however, even when programs are in place to pay

family caregivers (with the exception of Sweden's program), such programs are not universally available, do not compensate adequately, and are not accompanied by other formal services. In addition, surveys have shown that caregivers would rather have the provision of formal services (e.g., homemaker services, respite care) than financial compensation (Keefe, 1993). It thus appears that financial compensation packages as they exist now, serve current policy makers -- trying to reduce the cost of formal services -- much better than they do actual family caregivers. All of this speaks to the need for real policy change on a large scale. Perhaps, as with the feminist movement and the environmental movement, real political and economic change for caregivers may only come with a "caregiver movement," buoyed by the activism of the growing numbers of family caregivers who will no longer accept the status quo (RNABC, 1992).

Finally, the other arena in which caregiving has economic consequences in need of policy change is the workplace. There exists a need for workplace policies that allow for such things as flex time, job sharing, and 'parent-care sabbaticals,' that would prevent the penalization of workers' involvement in caregiving (Hogan, 1990; Medjuck & Keefe, 1994). Hooyman (1990) also raises the option of an insurance system for paid caregiver leave, perhaps as part of the present unemployment insurance scheme. While some corporations are independently realizing that such policies are actually *increasing* their competitiveness by

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preventing burnout or resignations by their caregiving employees, government legislation to enforce such workplace policies would help less broad-minded corporations to come on board.

Changing the Gendered Nature of Caregiving and Community Work.

A common thread running through all of the above policy implications is that women are doing all the work of caregiving. Ironically, even when policies and programs are implemented to assist caregivers -- such as community development initiatives like the SCBC program -- women are doing all of that work as well! This gender imbalance inherent to caregiving and community work is a systemic problem in our society, with no easy solutions, but one that must ultimately be addressed. As Hooyman (1990) notes:

...in the long run, fundamental solutions are needed to reintegrate women's and men's personal and work lives so that caregiving of the elderly is a shared public and private, male and female, responsibility, rather than divided along gender and economic lines as a low-cost alternative to public responsibility (p. 222).

In the meantime, policies are needed that support the growing numbers of caregivers, while keeping the traditional perpetuation of gender inequities to a minimum. For example, programs like the SCBC program should continue, but special efforts could be made to recruit male caregivers. Education for female caregivers could focus on assertive techniques to say “no” to caregiving and/or challenge gender inequities in caregiving responsibilities within their own families. Similarly, government agencies funding community development initiatives could require that such projects include plans for equitable gender distribution of workload and committee representation (Hume, 1993).

#### Implications for Government Sponsored Community Development

Participants’s comments from the evaluation of the SCBC program indicate a consensus that the community development process was a success. That is, community members generally felt they were able to identify their own issues, decide how they wanted to address them, and that they were given ample opportunities for participation and involvement throughout the process (Hume, 1993).

Some critics might argue on theoretical grounds however, that the degree

to which the government controlled the funding, and hence the power, for the SCBC project made it more like *community based programming* than actual *community development*. As Hume (1993) notes though, "...community based programming can turn into a community development process in the hands of committed individuals or groups" (p. 9), which was certainly the case in the SCBC program. Furthermore, while the sharing of more power and responsibility with caregivers may be fine in an ideal sense, SCBC participants repeatedly stated that they did not have the time, energy or inclination to become more involved. This will always remain the challenge for government sponsored community development programs; that is, how to find the right balance of giving people power and responsibility without overwhelming members of the community (Hume, 1993).

The main policy implication arising out of this dissertation research for government sponsored community development projects is, not surprisingly, the need for stable funding. While community development projects such as the SCBC program have great potential for helping communities to better their resources around issues like caregiving, all too often the funding and projects are concluded, just as the community is starting to build up some steam and momentum.

### Summary of Policy Implications

Current public policy regarding elder care is failing Canada's elderly and their caregivers, and a number of factors -- such as 'the new Conservatism' and myths about elder care -- have contributed to the mediocre state of such policy. Some of the changes needed in caregiver public policy include clarifying provincial/federal responsibilities, establishing stable funding for caregiver programs (including fair and adequate financial compensation for caregivers), and addressing the gendered nature of caregiving. Finally, if community development projects are going to be sponsored by the government at all, stable funding needs to be created for them, so that such projects can be given a reasonable chance of long-term success.

### Recommendations for Further Research

A number of recommendations for further research can be made after reviewing the results of this dissertation research:

- 1) To begin with, this dissertation research is an all-too rare example of how qualitative and participatory forms of research can be integrated with the traditional quantitative methods of evaluating caregiver support initiatives.
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Therefore, the first overall recommendation is for additional evaluation research on caregiver support initiatives that make more use of qualitative and participatory kinds of methodologies, that are more in keeping with the aims and principles of support / mutual-aid group initiatives.

- 2) A unique contribution of this dissertation is the observation that caregiver participation education and support initiatives like the SCBC program is associated with increases in feelings of powerfulness, and decreases in feelings of powerlessness. Therefore, it would be valuable to try and replicate the results of this research with other similar caregiver support initiatives. Furthermore, additional qualitative research would help to determine how these increases in feelings of powerfulness might translate in the day-to-day work of caregivers.
- 3) Less research is now needed on the potential benefits of these kinds of caregiver support initiatives, and more is needed on how best to keep these initiatives sustainable over extended periods of time. While this research provided valuable documentation of the process of developing and implementing a program like the SCBC initiative, information is now needed on the kinds of supports (financial, and otherwise) to continue these kinds of programs for more than just a few months.
- 4) This research, like other evaluations of caregiver support initiatives, found it difficult to recruit caregivers into the program, which may reflect an overall lack

of service use by caregivers. Therefore, research is needed about innovative methods of locating and encouraging family caregivers to make use of available services, including education and support groups. In particular, further research would help to determine the ways in which hospital, community, and home care nurses might recruit caregivers for support initiatives such as the SCBC program.

5) Perhaps most importantly, research is needed on how to best address the gender imbalances inherent in the work of caregiving. As an obvious start, research is needed on the kinds of things that would support men in their decisions to provide care -- such as support/education groups specifically targeted for men. Alternatively, more needs to be known on how to best help women to “just say no” to the automatic acceptance of the caregiver role.

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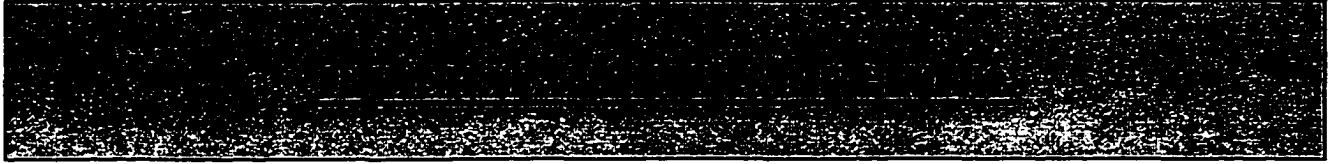
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## Appendix 1

***S.C.B.C. evaluation: Focus group questions for support group meeting***

Thank participants for agreeing to participate. Introduce self and group as appropriate. Review questions, purpose and time frame for discussion. Put questions on flip chart in front of room. Establish group norms: freedom to disagree, freedom to not answer any of the questions, anonymity, and confidentiality.

1. What do you believe were the main benefits of this group, if any?
2. What plans does your group have for meeting in the future? What kind of group would you like to be? (e.g., all caregivers vs. a disease specific group? Only support or education or both? Open vs. closed membership? Monthly vs. weekly meetings?)
3. What kinds of things are helping -- or would help -- your group's ongoing existence? What do you need to survive over the long term?
4. What aspects of the group were particularly beneficial for you? For example, what kinds of things were said or done in the group that were particularly helpful?
5. Is there anything else you would like to say about your experience?



## INTRODUCTION

Thank you for volunteering to participate in this survey. The information you give will be used to evaluate and improve programs for caregivers. Plan to spend about 30-45 minutes to fill out this form. Help will be available to you if you need it. **DO NOT PUT YOUR NAME ON THE SURVEY**; this will ensure that the information you give remains confidential. If you find that a question does not apply to you, write N/A. Furthermore, if you need to explain your response, or if you need more room to write, please feel free to write on the form or use the back of the page.

### CAREGIVING SITUATION

The first part of this survey asks you about the type of relationship you have with the person you care for and the challenges you have in this role.

1. Who is the person you are caring for? Is it your .....(circle one)

- |            |                   |                           |
|------------|-------------------|---------------------------|
| (a) Spouse | (d) Mother in law | (g) Friend                |
| (b) Mother | (e) Father in law | (h) Neighbour             |
| (c) Father | (f) Grandparent   | (I) Other (specify) _____ |

2. Approximately how long have you been fulfilling your role as a caregiver?

**Time in years:** \_\_\_\_\_ --or if less than one year-- **Time in months:** \_\_\_\_\_

3. Where does the person you are caring for live? (circle)

- |                            |                                   |
|----------------------------|-----------------------------------|
| (a) With you in your home  | (d) With others in their own home |
| (b) With you in their home | (e) In a facility                 |
| (c) Alone                  |                                   |

4. Have you ever been in an education or support group designed for family caregivers?

YES ( )                      NO ( )

*If yes*, which one(s) \_\_\_\_\_

**SOCIAL SUPPORT**

5. The next section of this survey asks about some of the important people in your life. Many people find that caregiving is easier when there are other people around to help, or give support.

These are some ways that your friends, family members, neighbours or other people might be supportive of you:

- **Emotional support:** Someone who offers love, affection, comfort, or sympathy.
- **Advice:** Someone who provides information and advice.
- **Companionship:** Someone who you do activities with (e.g. bridge), they help take your thoughts off of your problems.
- **Practical help:** Someone who lends money, or helps with driving, chores, or caregiving.

0= NOT AT ALL  
 1= RARELY  
 2= ON SOME OCCASIONS  
 3= OFTEN  
 4=VERY FREQUENTLY

Now list the **first names** (optional) of people who help and support you. Beside their name, write their relationship to you. Then write the number which describes *how much* they support you *in the different ways* described above. (Use the back page if necessary)

<u>NAME</u>	<u>emotional</u>	<u>advice</u>	<u>companionship</u>	<u>practical help</u>
ie- Sally...(sister)	( 2 )	( 1 )	( 3 )	( 4 )
_____	(   )	(   )	(   )	(   )
_____	(   )	(   )	(   )	(   )
_____	(   )	(   )	(   )	(   )
_____	(   )	(   )	(   )	(   )
_____	(   )	(   )	(   )	(   )

6. On a scale from one to five, try to rate, in general, how satisfied you are with the support you receive from others. (circle the number)

<p>1-----2-----3-----4-----5</p>	<p>1= very unsatisfied                  2= somewhat unsatisfied                  3= neutral                  4= somewhat satisfied                  5= very satisfied</p>
----------------------------------	---

7. This section asks about some of the things you do as a caregiver. The question has two parts. First you are asked how often you help with each activity, and secondly you are asked how you feel about helping with each activity.

**How often?**  
*(in the past month)*

D= a few times /day  
 W= a few times/wk  
 M= a few times/mo  
 Y= a few times/yr  
 N= never

**Your reaction:** *How much does it bother or upset you when you have to help with this?*

0= not applicable  
 1= not at all  
 2= a little  
 3= moderately  
 4= very much  
 5= extremely

**YOU HELP WITH                      HOW OFTEN?                      YOUR REACTION**

- a) Bathing.....(      ).....(      )
- b) Dressing.....(      ).....(      )
- c) Feeding.....(      ).....(      )
- d) Grooming.....(      ).....(      )
- e) Urinating.....(      ).....(      )
- f) Moving bowels.....(      ).....(      )
- g) Walking/transferring.....(      ).....(      )
- h) Driving (e.g., to doctor).....(      ).....(      )
- i) Banking\finances.....(      ).....(      )
- j) Shopping.....(      ).....(      )
- k) Household management  
 (e.g., cleaning, maintenance).....(      ).....(      )
- l) Problem solving/ advice.....(      ).....(      )
- m) Emotional support.....(      ).....(      )

- n) Cooking.....( ).....( )
- o) Giving medications.....( ).....( )
- p) Other: \_\_\_\_\_( ).....( )

**8. Using the same format as above, indicate how often the following problems have occurred in the past month, and how much the problem bothers you when it happens. Fill in the blanks with the appropriate letter and number.**

<p><b><u>How often?</u></b> <i>(in the past month)</i></p> <p>D= a few times /day  W= a few times/wk  M= a few times/mo  Y= a few times/yr  N= never</p>	<p><b><u>Your reaction:</u></b> <i>How much does it bother or upset you when this behaviour occurs?</i></p> <p>0= not applicable  1= not at all  2= a little  3= moderately  4= very much  5= extremely</p>
--	---

**BEHAVIOURS**

**HOW OFTEN?**

**YOUR REACTION**

- a) Wandering or getting lost.....( ).....( )
- b) Asking the same question.....( ).....( )  
over and over again
- c) Hiding things (money).....( ).....( )
- d) Being suspicious/accusative.....( ).....( )
- e) Losing or misplacing things.....( ).....( )
- f) Not recognizing familiar people.....( ).....( )
- g) Forgetting what day it is.....( ).....( )
- h) Starting, but not finishing things.....( ).....( )

<p><b><u>How often?</u></b> <i>(in the past month)</i></p>	<p><b><u>Your reaction:</u></b> <i>How much does it bother or upset you when this behaviour</i></p>
--	---

D= a few times /day	<i>occurs?</i>
W= a few times/wk	0= not applicable
M= a few times/mo	1= not at all
Y= a few times/yr	2= a little
N= never	3= moderately
	4= very much
	5= extremely

<b><u>BEHAVIOURS</u></b>	<b><u>HOW OFTEN?</u></b>	<b><u>YOUR REACTION</u></b>
--------------------------	--------------------------	-----------------------------

- i). Destroying property.....(        ).....(        )
- j) Doing things that embarrass you.....(        ).....(        )
- k) Waking you up at night.....(        ).....(        )
- l) Being constantly restless.....(        ).....(        )
- m) Being constantly talkative.....(        ).....(        )
- n) Talking little or not at all.....(        ).....(        )
- o) Engaging in behaviour that is potentially dangerous.....(        ).....(        )
- p) Reliving situation from the past.....(        ).....(        )
- q) Seeing or hearing things that are not there (e.g., hallucinations or illusions).....(        ).....(        )
- h) Expressing extreme fear of being left alone.....(        ).....(        )
- l) Refusing services or help.....(        ).....(        )
- j) Being extremely angry towards you.....(        ).....(        )

<b>HEALTH STATUS</b>
----------------------

These are questions about your health and the health of the person you are caring for. How healthy you are, and the person you are caring for is, will impact on what it is like to be a caregiver.

9. How would you describe your state of health? Would you say, in general, your health is... (circle one)

- |               |          |
|---------------|----------|
| (1) Excellent | (3) Fair |
| (2) Good      | (4) Poor |

10. How would you describe your state of health compared to other people your age? Would you say, in general, your health is...(circle one)

- |   |                                    |
|---|------------------------------------|
| (1) Excellent compared to others my age | (3) Fair compared to others my age |
| (2) Good compared to others my age      | (4) Poor compared to others my age |

11. Which of the following would you say you are able to do on a regular basis? (please circle all that apply)

- |                               |   |
|-------------------------------|---|
| (1) Eat a balanced diet       | (4) Avoid smoking                         |
| (2) Get enough rest and sleep | (5) Avoid alcohol, or drink in moderation |
| (3) Keep physically active    | (6) Taking breaks from caregiving         |

12. During the past year, how often have you or the person you are caring for had any of the following short term health problems? Write **the number of times** this problem occurred in the space provided. If 0, leave the space blank.

	<b>YOURSELF</b>	<b>THE PERSON YOU CARE FOR</b>
(1) Flu	(   )	(   )
(2) Colds	(   )	(   )
(3) Infections	(   )	(   )
(4) Injuries due to accidents	(   )	(   )
(5) Other short-term illnesses	Specify: _____	Specify: _____

13. During the past year, have you or the person you are caring for had any of the following long-term health problems? (**check all that apply**)

**HEALTH CONDITION**

**THE PERSON YOU  
CARE FOR**

a) Heart problems, angina	( )	( )
b) High blood pressure	( )	( )
c) Stroke	( )	( )
d) Cancer	( )	( )
e) Respiratory ailments (ie-asthma)	( )	( )
f) Digestive problems	( )	( )
g) Arthritis or rheumatism	( )	( )
h) Diabetes	( )	( )
i) Osteoporosis/Orthopaedic problems	( )	( )
j) Eye problems not relieved by glasses (cataracts, glaucoma, retinal degeneration)	( )	( )
k) Hearing impairment	( )	( )
l) Dental Problems	( )	( )
m) Skin problems	( )	( )
n) Alzheimer's disease	( )	( )
o) Other serious memory problems	( )	( )
p) Mental or emotional distress	( )	( )
q) Alcohol or drug addictions	( )	( )
r) Multiple sclerosis	( )	( )
s) Parkinson's disease	( )	( )
t) Epilepsy	( )	( )
u) Headaches or Migraines	( )	( )
v) Other (specify)	_____	_____

14. What do you believe is the main reason why the person you care for requires caregiving?

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15. What significant events (if any) have occurred in your life which have made caregiving

more difficult? (Use the back of the page if you need more room)

16. What significant events (if any) have occurred in your life which have made caregiving easier?

17. On a scale from one to five, try to rate, in general, how satisfied you are with your life. (circle the number)

1-----2-----3-----4-----5

1= very unsatisfied

2= somewhat unsatisfied

3= neutral

4= somewhat satisfied

5= very satisfied

18. To accurately evaluate the kinds of health care services used by caregivers and care-receivers (such as hospital use), it is very helpful to have your B.C. care card number(s). This information will be used to find out what kinds of services -- such as caregiver groups -- can best meet the needs of family caregivers. **Again, like all questions on this survey, your name will NOT appear with any of the information you give; all information will be coded (without names), and will be destroyed once this caregiver evaluation is complete.**

*(If appropriate, please feel free to discuss this request with the person you care for. Remember, they too have the right to withhold this information, if they so choose.)*

Your B.C. Care Card number: \_\_\_\_\_

The B.C. Care Card number of the person you care for: \_\_\_\_\_

19. Please indicate how well you are able to financially meet some of the basic necessities in your life--such as food, clothing, medications and small luxuries. Circle the statement that best describes *your* financial situation. *Presently.....*

- a) I am able to afford all that I need and most of what I want.
- b) I am able to afford what I need but I cannot afford small luxuries.
- c) I can barely afford what I need
- d) I cannot afford what I need

<b>SERVICES USED</b>
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20. It would be helpful to know what kinds of services you are aware of and use. First, please indicate if you are aware of *how the following services might help your caregiving situation*, and secondly, indicate the number of times you or the person you care for have used the service in the past 3 months:

<u>Service:</u>	<u>Aware of how</u> <u>it could help:</u>		<u>#of times used</u> <u>in the past 3 months</u>
	<u>YES</u>	<u>NO</u>	
• Meals on wheels	—	—	_____
• Adult day care	—	—	_____
• Home Nursing program	—	—	_____
• Geriatric Outreach Services	—	—	_____
• Homemakers:			
home cleaning	—	—	_____
personal care	—	—	_____
meal preparation	—	—	_____
in-home respite	—	—	_____
• Rehab services:			
occupational therapy	—	—	_____
Physio / rehab therapy	—	—	_____
• Facility respite care (respite beds)	—	—	_____
• Mental health services	—	—	_____
• Disease specific groups (e.g., arthritis, Alzheimer's, Parkinson's) Specify _____	—	—	_____
• Handi-Dart Bus/subsidized Taxi coupons	—	—	_____
• Senior's Center			

**BACKGROUND INFORMATION**

**The last part of this survey asks more about you, and the person you are caring for, this will help show how different people think and feel about caregiving.**

21. What is your gender?

- (a) Female                      (b) Male

22. What is the gender of the person you are caring for?

- (a) Female                      (b) Male

23. When were you born? \_\_\_\_\_ day/month/year

24. When was the person you are caring for born? \_\_\_\_\_ day/month/year

25. Are you single, married, widowed, divorced or separated? (circle)

- (a) Single                      (c) Widowed                      (e) Separated  
(b) Married                      (d) Divorced

26. Is the person you are caring for single, married, widowed, divorced or separated? (circle)

- (a) Single                      (c) Widowed                      (e) Separated  
(b) Married                      (d) Divorced

27. Canadians come from many ethnic or cultural backgrounds (such as French, German, Italian). From which ethnic or cultural background did you descend?

\_\_\_\_\_

27. Employment (yourself only) Circle:

- (a) Full-Time                      (d) Not working outside the home  
(b) Part-Time                      (e) Retired  
(c) Unemployed and seeking work

**This is the end of the survey. Once again, thank you very much for your time and assistance in filling this form out. Please be sure to bring this form to your next caregiver group meeting.**

**INTRODUCTION**

This is a follow-up survey to the first one that many of you were kind enough to fill out about six months ago. The purpose of this survey is to help us get a better understanding of how your caregiver support group may have affected your role as a caregiver. This information will be used to help improve future caregiver groups which will be offered in B.C. in the near future. This information will also be used to try and find out in what ways caregiver groups actually help caregivers. This survey should take about 20 to 30 minutes to complete, and your participation in this survey is **GREATLY APPRECIATED**. If questions do not apply to you, please write N/A and leave blank.

**HEALTH**

1. How would you describe your present state of health? Would you say, in general, your health is... (circle one)
 

(1) Excellent	(3) Fair
(2) Good	(4) Poor
  
2. Which of the following would you say you are able to do on a regular basis? (circle all that apply)
 

(1) Eat a balanced diet	(4) Avoid smoking
(2) Get enough rest and sleep	(5) Avoid alcohol, or drink in moderation
(3) Keep physically active	(6) Take breaks from caregiving
  
3. On a scale from one to five, try to rate, in general, how satisfied you are with your life at the present time. (circle the number)
 

1-----2-----3-----4-----5	1= very unsatisfied
	2= somewhat unsatisfied
	3= neutral
	4= somewhat satisfied
	5= very satisfied

**4. SOCIAL SUPPORT: This part of the survey asks you about the kinds of support you are receiving from friends, family members, neighbours...**

**TYPES OF SUPPORT:**

- **Emotional support:** Someone who offers love, affection, comfort, or sympathy.
- **Advice:** Someone gives information & advice.
- **Companionship:** Someone who you do activities with (e.g. bridge), they help take your thoughts off of your problems.
- **Practical help:** Someone who lends money, or helps with driving, chores, or caregiving.

**AMOUNT OF SUPPORT:**

- 0= NOT AT ALL
- 1= RARELY
- 2= ON SOME OCCASIONS
- 3= OFTEN
- 4=VERY FREQUENTLY

Please list the **first names** (optional) of people who help and support you. Beside their name, write their relationship to you (eg., son, friend, support group member). Then write the number which describes *how much* they support you *in the different ways* described above.

<u>NAME</u>	<u>emotional</u>	<u>advice</u>	<u>companionship</u>	<u>practical</u>
eg. Nancy (sister)	( 4 )	( 1 )	( 2 )	( 3 )
_____	( )	( )	( )	( )
_____	( )	( )	( )	( )
_____	( )	( )	( )	( )
_____	( )	( )	( )	( )
_____	( )	( )	( )	( )

5. On a scale from one to five, try to rate, in general, how satisfied you are with the support you receive from others. (circle the number)

1-----2-----3-----4-----5

- 1= very unsatisfied
- 2= somewhat unsatisfied
- 3= neutral
- 4= somewhat satisfied
- 5= very satisfied

6. Overall, how well do you feel you are *presently* able to manage your role as a caregiver (please circle)

1-----2-----3-----4-----5

1= very manageable  
2= somewhat manageable  
3= neutral  
4= somewhat manageable  
5= very manageable

7. How has the caregiver program affected you role as a caregiver?

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8. What *significant events* (if any) have recently occurred in your life which have made caregiving easier or more difficult?

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9. This section asks about some of the *things you are now doing* as a caregiver. The question has two parts. First you are asked **how often you help** with each activity, and secondly you are asked **how you feel about helping** with each activity.

**How often?**  
(in the past month)

N= never  
Y= a few times/year  
M= a few times/month  
W= a few times/week  
D= a few times/day

**Your reaction:** *How much does it bother you when you have to help with this?*

0= not applicable  
1= does not bother me at all  
2= bothers me a little  
3= bothers me moderately  
4= bothers me very much  
5= bothers me extremely

<b><u>YOU HELP WITH</u></b>	<b><u>HOW OFTEN?</u></b>	<b><u>YOUR REACTION</u></b>
a) Bathing	( )	( )
b) Dressing	( )	( )
c) Feeding	( )	( )
d) Grooming	( )	( )
e) Urinating	( )	( )
f) Moving bowels	( )	( )
g) Walking/transferring	( )	( )
h) Driving (e.g., to doctor)	( )	( )
i) Banking\finances	( )	( )
j) Shopping	( )	( )
k) Household tasks (e.g. cleaning)	( )	( )
l) Problem solving/ advice	( )	( )
m) Emotional support	( )	( )
n) Cooking	( )	( )
o) Giving medications	( )	( )
p) Other: _____	( )	( )

**10. Using the same format as above, indicate how often the following problems have occurred *in the past month*, and how much the problem bothers you when it happens. Fill in the blanks with the appropriate letter and number.**

**How often?**  
(in the past month)

N= never  
Y= a few times/year  
M= a few times/month  
W= a few times/week  
D= a few times/day

**Your reaction:** *How much does it bother you when you have to help with this?*

0= not applicable  
1= does not bother me at all  
2= bothers me a little  
3= bothers me moderately  
4= bothers me very much  
5= bothers me extremely

<b><u>BEHAVIOURS</u></b>	<b><u>HOW OFTEN?</u></b>	<b><u>YOUR REACTION</u></b>
a) Wandering or getting lost	(   )	(   )
b) Asking the same question over and over again	(   )	(   )
c) Hiding things (money, Jewellery, etc.	(   )	(   )
d) Being suspicious or accusative	(   )	(   )
e) Losing or misplacing things	(   )	(   )
f) Not recognizing familiar people	(   )	(   )
g) Forgetting what day it is	(   )	(   )
h) Starting, but not finishing things	(   )	(   )
i). Destroying property continued from last page....	(   )	(   )

**How often?**  
(in the past month)

N= never  
Y= a few times/year  
M= a few times/month  
W= a few times/week  
D= a few times/day

**Your reaction:** *How much does it bother  
or upset you when you have to help with this?*

0= not applicable  
1= does not bother me at all  
2= bothers me a little  
3= bothers me moderately  
4= bothers me very much  
5= bothers me extremely

<b><u>BEHAVIOURS</u></b>	<b><u>HOW OFTEN?</u></b>	<b><u>YOUR REACTION</u></b>
j) Doing things that embarrass you	( )	( )
k) Waking you up at night	( )	( )
l) Being constantly restless	( )	( )
m) Being constantly talkative	( )	( )
n) Talking little or not at all	( )	( )
o) Engaging in dangerous behaviour	( )	( )
p) Reliving the past	( )	( )
q) Seeing or hearing things that aren't there	( )	( )
h) Expressing extreme fear of being left alone	( )	( )
I) Refusing services or help	( )	( )
j) Being extremely angry at you	( )	( )

**11. SERVICES USED**

Please indicate the number of times you or the person you care for have used the service in the past 3 months:

Number of times used  
in the past 3 months

Service:

- Meals on wheels \_\_\_\_\_
- Adult day care \_\_\_\_\_
- Home Nursing program \_\_\_\_\_
- Geriatric Outreach Services \_\_\_\_\_
- Homemakers:
  - home cleaning \_\_\_\_\_
  - personal care \_\_\_\_\_
  - meal preparation \_\_\_\_\_
  - in-home respite \_\_\_\_\_
- Rehab services:
  - occupational therapy \_\_\_\_\_
  - Physio / rehab therapy \_\_\_\_\_
- Facility respite care (respite beds) \_\_\_\_\_
- Mental health services \_\_\_\_\_
- Disease specific groups (e.g.,  
Alzheimer's, Parkinson's)  
Specify \_\_\_\_\_
- Handi-Dart Bus/Taxi coupons \_\_\_\_\_
- Senior's Center \_\_\_\_\_

12. How much did the caregiver program *affect your awareness* of services in your community? (circle)

- (1) Not at all
- (2) Somewhat
- (3) A great deal

Please comment: \_\_\_\_\_  
\_\_\_\_\_

13. Since joining your caregiver group, have you, or the person you care for, used -- or been put on the waiting list for -- any new services in your community?

- (1) No
- (2) Yes

If yes, which ones? \_\_\_\_\_

14. When were you born? \_\_\_\_\_ (day / month / year)

15. Finally, if you haven't already volunteered this information, providing us with the number of your B.C. Health Care Card would be very helpful to better understand what health care services caregivers are using, and how the use of those services changes over time. If you wish to volunteer this information, **your identity or name will not be revealed in any way. In other words, information is kept confidential and anonymous. There will be no effect on your ability to use these services.**

Your B.C. Care Card number: \_\_\_\_\_

The B.C. Care Card number of the person you care for: \_\_\_\_\_

**This is the end of the survey. Once again, thank you very much for your time and assistance in filling out this survey. Please be sure to bring this form to your get-together with your caregiver group in March. If you are unable to make the get-together, someone will arrange to have your survey picked up at your convenience.**

**UNDERSTANDING CAREGIVING**

Dear Caregiver:

Thank you for volunteering to participate in this evaluation, a component of the program that was necessary in order for the caregiving groups to get funding. The information you give will be used to improve future programs for caregivers. Do not put your name on the survey as your responses are intended to be private. While your input will be extremely valuable, you are free to refuse to complete this and free to not answer any individual question. You will be contacted again, three months after the end of the program. If you have any concerns or questions while filling this survey out, please call collect after 6:00 PM to:

Dr. Elaine Gallagher

## YOUR CAREGIVING SITUATION

Whenever the term caregiver is used in these questions, it refers to a person who is providing unpaid help to a family member or friend with a long-term illness or disability. Unless specified otherwise, if you are a caregiver to more than one adult, answer the questions on behalf of the one person who you provide the most care to.

- 1.a. How many adults are you the main unpaid caregiver for? \_\_\_\_\_
- b. In addition, how many other adults do you assist? These are people who either have someone else as their main caregiver or they only need occasional help. \_\_\_\_\_
2. What relation are you to the person who you provide the most care for? (Circle)
 

(1) Spouse	(4) Friend	(7) Daughter- in- law
(2) Daughter	(5) Neighbour	(8) Son - in - law
(3) Son	(6) Grandchild	(9) Other (specify) _____
3. Approximately how long have you been fulfilling your role as a caregiver to that person? Time in years: \_\_\_\_\_ (If less than one year) Time in months: \_\_\_\_\_
3. Where does the person you provide the most care for live? (circle)
 

(1) With you in your home	(2) With you in their home	(3) Alone
(4) With others in their own home	(5) In a facility	
4. What is your gender? (1) Female (2) Male
5. What is the gender of the person you are caring for? (1) Female (2) Male
6. When were you born? \_\_\_\_\_ day/month/year
7. When was the person you are caring for born? \_\_\_\_\_ day/month/year
8. Are you (1) Single (2) Widowed (3) Separated (4) Married (5) Divorced
9. Is the person you are caring for (1) Single (2) Widowed (3) Separated  
(4) Married (5) Divorced

10. Canadians come from many ethnic or cultural backgrounds (such as French, German, Italian). From which ethnic or cultural background did you descend?

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11. a. What is your employment status? ( Circle):

- (1) Full-Time                      (2) Part-Time              (3) Not working outside the home  
 (4) Retired                              (5) Unemployed and seeking work

b. Did you quit work, change jobs or reduce your hours of work in order to become a caregiver? (1) No \_\_\_\_\_

(2) Yes \_\_\_\_\_ If yes, please explain.

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12. How would you describe your state of health? Would you say, in general, your health is...

- (1) Excellent (2) Good (3) Average (4) Fair (5) Poor

13. In general, how satisfied you are with your life. (circle the number)

- (1) very unsatisfied    (3) neutral  
 (2) somewhat unsatisfied                                      (4) somewhat satisfied  
 (5) very satisfied

14. How close are you to deciding to place your loved one in an institution such as a nursing home?

- (1) Not at all (2) giving it some thought (3) giving it serious thought

- (4) have requested placement (5) have completed placement

15. Caregivers sometimes experience a variety of situations in which they feel powerless. Some of these are listed below. To what extent do these fit with your experience?

1 = I never feel this way	3 = I feel this way about half of the time
2 = I occasionally feel this way	4 = I feel this way fairly often
5 = I feel this way most of the time	

- \_\_\_\_\_ (1) Feeling that you are not respected by doctors, nurses or other professionals
- \_\_\_\_\_ (2) Feeling like others don't believe you or trust your judgement
- \_\_\_\_\_ (3) Feeling like the person you care for's illness is in control instead of you.
- \_\_\_\_\_ (4) Feeling uncertain about the future
- \_\_\_\_\_ (5) Feeling that you lack the skills or confidence to do a good job of caregiving
- \_\_\_\_\_ (6) Feeling unable to protect your family member from harm, indignity or pain.
- \_\_\_\_\_ (7) Feeling that there are not enough opportunities for respite
- \_\_\_\_\_ (8) Feeling as though you are not free to express your true emotions openly
- \_\_\_\_\_ (9) Feeling alone, stranded and without support

16. Caregivers have also talked about situations in which they felt powerful. To what extent do the following match with your experiences?


1 = I never feel this way	3 = I feel this way about half of the time
2 = I occasionally feel this way	4 = I feel this way quite often
5 = I feel this way most of the time	

- \_\_\_\_ (1) I feel I have made a positive change in my loved ones' life
- \_\_\_\_ (2) I feel I have coped with a very difficult situation
- \_\_\_\_ (3) I feel confident in my own capabilities as a caregiver
- \_\_\_\_ (4) I feel like I possess knowledge about caregiving which can benefit others
- \_\_\_\_ (5) I feel as though I am respected for my caregiving abilities by professionals
- \_\_\_\_ (6) I feel I recognize and attend to my own needs
- \_\_\_\_ (7) I feel assertive in expressing my ideas to others
- \_\_\_\_ (8) I feel fulfilled in my caregiving work
- \_\_\_\_ (9) I feel as if I am adequately rewarded for my efforts as a caregiver.

17. To access accurate information on the amount of services used (such as hospital use), it is necessary to have B.C. care card numbers. **Your name will not be attached to this information so as to protect your privacy.** Please ask permission of the person you care for if possible as they too have the right to withhold this information.

Your B.C. Care Card number: \_\_\_\_\_

The B.C. Care Card number of the person you care for: \_\_\_\_\_

- 
- 1) What roles and activities did you fulfill in the process of establishing the Caregiver education/support group in your community?
  - 2) What do you think were some of your particular successes in terms of your efforts to get this “Supporting Caregivers in B.C.” (SCBC) project off the ground in your community? (e.g., promotion, marketing, community involvement, linkages with other components of formal care system such as referrals from home support, continuing care, Drs., etc.)
  - 3) What unique characteristics do you feel exist in your community which supported your efforts to get the “SCBC.” project going in this community, and in maintaining it?
  - 4) What unique characteristics do you feel exist in your community which hindered your efforts to get the SCBC project going in this community, and in maintaining it?
  - 5) What are the future goals for this project in your community and what do you see your role as, if any, in keeping the caregiver group in your community self-sustaining?
  - 6) What did you see as Joyce Crawford’s role in this whole process? (i.e., before, during and after the implementation of the program.) Did you have enough information at the beginning? What should her future role be in relation to the various groups around the province?
  - 7) This program is most likely going to be offered in 10 other communities in the near future. While every community is unique and different, what kind of advice would you give to other steering committees like yourself in future communities? For example: What part of the whole process would you change? What part of the whole process would you keep the same? (i.e., the setting up of their group, marketing, dividing up the labor, getting facilitators, getting caregivers.)

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UNIVERSITY OF VICTORIA

**REQUEST FOR APPROVAL OF PROPOSED RESEARCH  
INVOLVING HUMAN SUBJECTS**

*Please type this and all accompanying information. Please submit original plus 3 copies of application form and accompanying documents.*

TO: Committee on Research and Other Activities Involving Human Subjects  
Office of Research Administration, Room B115, Sedgewick Building

FROM: Elaine M. Gallacher July 29, 1994

(Name)

School of Nursing

Faculty

(Department)

(Position)

(Phone Number or Local)

NOTE: Position = ie. Student, Grad Student, Research Assistant, Faculty)

1. Short title of proposed research: Supporting Caregivers in British Columbia

*Please attach an outline of the proposed research, with emphasis on the procedures involving human subjects. That is, what are the subjects going to be doing? Include copies of questionnaires, tests, interview schedule, Letter of Informed Consent, etc.*

2. Who are the subjects?

The subjects are family caregivers (and their recipients of care) who volunteer to take part in the 10-week program and those who volunteer for the control group.

3. How will the subjects be obtained?

Subjects will be recruited through pamphlets, newspaper advertisements and word-of-mouth.

4. To what extent is the participation of the subjects voluntary? How is this assured, procedurally?

Participation is completely voluntary. Informed consent will be obtained at the outset. If people refuse to be in the evaluation, no services will be withheld.

How is the subject's right to withdraw at any time assured?

Subjects will be informed at the outset of their right to withdraw from the evaluation at any time.

5. To what extent are appropriate guarantees of anonymity or confidentiality given to the subjects? How is this implemented (e.g., will data records contain names or other means of identifying individuals)?

All data will be coded using a unique client identifier and at no time will names be used. Subjects will be told this in the informed consent.

6. Is there any possibility of physical, psychological, or other risk in the research? If so, explain in detail, on a separate page; include the necessity for this risk or hazard and the potential value of the research justifying it.

There is no potential for risk in this research.

What safeguards for the subjects, the researcher, and the University are part of the research plan?

n/a

7. When, and to what extent, is the nature and purpose of the research or study explained to the subjects?

Subjects will be told of the evaluation at the time they register in the 10-week program.

Considering this question and question 4, when and how is informed consent obtained?

Informed consent will be obtained in writing at the first of the 10-week sessions.

8. Please list any institutions or organizations involved in the research (e.g., by providing subjects, facilities, or access to data). Also indicate whether their written permission is attached or is to be forwarded to the Committee.

Caregivers Association of British Columbia.  
Alzheimers Association of British Columbia.

9. Person designating him/herself as in charge of the research:

Elaine Gallagher

(Name)

(Signature)

Supervisor (if any):

(Name)

(Signature)

Chair/Director of Department or School:

x Anita Molzahn, Director, School of

(Name)

Nursing

(Signature)

(Date)

10. Additional information, required before final approval can be issued:

Approximate starting and termination dates:

September 1, 1994 - February 1, 1996

Name(s) and position of all person(s) who will be conducting the research:

NOTE: Position = ie. Student, Grad Student, Research Assistant, Faculty

1. Elaine Gallagher, Faculty
2. Brad Hagen, Grad student.
- 3.
- 4.
- 5.
- 6.

APPROVED BY COMMITTEE ON RESEARCH AND OTHER ACTIVITIES INVOLVING HUMAN SUBJECTS:

(Chair's Signature)

(Date)

DATES: From To

## Consent Form for Participation in the Study: Supporting Caregivers in B.C.

I understand that this research project is examining the experiences of persons who are primary caregivers of a frail older friend or family member. I understand that I will be asked questions about my experience as a family caregiver. I will fill out questionnaires and/or be interviewed on 4 occasions at approximately 6 month intervals.

I understand that my participation is completely voluntary and that I can withdraw from the study at any time, without explanation.

I understand that any data collected in the study will remain confidential; interview results will be coded and kept in a locked filing cabinet. No names will be used on any published reports of the evaluation thereby ensuring my anonymity.

I understand that a face-to-face interview may be done and if so, it will be audiotaped. The tape will be erased after the conversation is transcribed into written format. Again, no information will be reported on my identity.

I understand that I am not obligated to participate in this evaluation and if I refuse, I will still be eligible to be in the support/education program. I \_\_\_\_\_, do agree to participate in this evaluation.

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

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

Interviewer: \_\_\_\_\_