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Outcome Evaluation of a Group Education and Support Program for Family Caregivers

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ABSTRACT. One in 16 adults in British Columbia is a caregiver for a close friend or family member with a long term illness or disability. As such, it is not surprising that the government has begun to recognize the valuable role which caregivers play in the health care system. Accordingly, a 10-week group support and education program for family caregivers was developed and implemented in seven diverse communities throughout British Columbia. An outcome evaluation indicated that the program was of value to participants. Results and anecdotal examples from interviews with caregivers, responses on a Caregiver Survey, focus group interviews, and facilitator journals are reported. Many of the program benefits are thought to be sustainable over time. Caution needs to be exercised in expecting already overworked caregivers to form self-sustaining support groups. [*Article copies available from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: getinfo@haworth.com*]

INTRODUCTION

A recent study conducted at the University of Victoria Centre on Aging showed that one in every 16 British Columbians is a family caregiver,

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many of whom provide care to an elderly family member or friend. This represents 8.4% of all households. Caregivers are most apt to be women (72.7%), are likely to be employed (52.2%), and provide an average of four hours of care per day (Caregivers Association of British Columbia, 1995).

The proportion of older person with dementia-people who typically require a disproportionately high share of expensive institutional long-term care-is currently at 8% of those aged 65 and over, and is expected to more than double between 1981 and 2006 (McEwan, Donnelly, Robertson, & Hertzman, 1991). Gurland and Cross (1982) noted that for every individual with a severe dementia in an institution, there are at least two living in the community, usually supported by a family member such as a spouse or daughter.

It is not surprising, therefore, that the "New Directions for a Healthy British Columbia" initiatives, the British Columbia government's efforts to create a renewed health care system, 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)

Much of the impetus for the change from an institutional to home care philosophy is economic. The theory is that, in the long run, it will be less expensive to enable local citizens to promote their own health and well-being than to continue pouring money into an expensive institutional and disease focused health system (Altman & Martin, 1994).

When one examines published evaluations of caregiver programs, an interesting contradiction emerges. Caregivers consistently give favorable reports of support group experiences and indicate what a powerful and positive impact group participation has had on them. However, evaluations of support group participation, which are largely quantitative, are usually forced to conclude that such support 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 satis-

faction 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. 43)

It has been noted 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). Others suggest that caregiver satisfaction is in large part due to caregivers feeling "... grateful that someone pays attention to their needs and shows interest in their problems," or 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). It is apparent that a broader range of evaluation techniques and methodologies is needed in this complicated area of research. The present study of caregivers attempted to incorporate some qualitative methods of inquiry, along with more frequently employed quantitative methods, to assess the outcomes of a group caregiver education and support project carried out in several communities.

Supporting Caregivers in British Columbia

The Supporting Caregivers in British Columbia (SCBC) project was directed toward developing caregiver education and support in areas of British Columbia (BC) which identified themselves as lacking practical support service for "at home" caregivers. Representatives from the Caregivers Association of BC, The Alzheimer Society of BC, and the University of Victoria School of Nursing formed a project steering committee. The Continuing Care Division of the Ministry of Health funded the project.

The goals of the SCBC project were to provide an opportunity for family caregivers to experience being in a support group setting, to have an opportunity to learn more about issues affecting caregiving, and to experience support specifically for their caregiver roles. The program was also intended to enhance caregivers' knowledge about, and access to, other community services. Finally, the program sought to provide opportunities to assess ongoing needs for caregiver support which could lead to the development of support networks and other forms of service in the community.

After an extensive review of the literature, a subgroup of the steering committee developed a 10-week program for small groups of caregivers

(from 6 to 15 individuals). The program was to consist of weekly sessions of roughly two hours each, facilitated by either a lay or professional group leader. Each of the sessions entailed approximately one hour of education and discussion on a pre-determined topic. The second hour of the session entailed mutual group support, where participants would be allowed to share freely whatever they felt important to share (Barusch, 1991; Tosland & Rossiter, 1989). There was an opportunity for two optional topics, to be determined by the group, to be included in the program.

A major component of the program was the development of the "small group" as a support system for the difficult emotions associated with caregiving. An overall attempt was made to ensure that this program was not so much a service offered *to* caregivers by a "professional," but a means by which caregivers could be skillfully brought together in a group to share and develop new resources. As McNight has stated, "Resources empower; service do not (cited in Labonte, 1989, p. 25). Labonte (1993) also claimed 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" (p. 58).

Attempts were also made to include "community organization" as an empowerment strategy. Labonte (1993) describes community organization as ". . . the process of organizing people around problems or issues that are larger than group members' own immediate concerns" (p. 61). Steering committees were formed in every community to get the caregiver groups running and to raise the profile of caregiving issues in each community.

The six communities selected for the SCBC project were purposefully diverse in size, ranging from 5,000 to 5,000,000 in population density. In most of the communities, a large group meeting of interested individuals was held and out of these meetings the local steering committees emerged. The local committees used a variety of methods of client recruitment, including the distribution of brochures and posters, holding meetings with continuing care assessors and home nursing coordinators, and advertising on radio, TV, and in newspapers, using "human interest" stories on caregiving.

Caregiver group facilitators were recruited in each community and were provided with a two-day training workshop. This workshop was an intense, participatory training program conducted by a mental health specialist in a retreat setting. Facilitators were provided with a comprehensive

manual outlining the 10 sessions of the program with choices of learning activities and additional resources.

METHOD

Project Procedures

The SCBC project steering committee decided to use primarily a qualitative methodology-using naturalistic inquiry, qualitative data and content analysis (Patton, 1990). Efforts were made to incorporate as much participation from the caregivers as possible (Barnsley & Ellis, 1992). Procedures included carrying out in-home interviews with all caregivers, both prior to and three months after completion of the 10-week program.

Caregivers also filled out a Caregiver Survey, a questionnaire which was developed for this study. The Survey consisted of self-ratings of health and life satisfaction and health practices pertaining to sleep, diet, activity, smoking, alcohol, and taking breaks. It measured self-rated confidence as a caregiver, types and amount of assistance given, and a "troublesome behavior" scale developed by the steering committee. The Survey was pilot-tested with six family caregiver volunteers and reviewed for content validity by the steering committee.

The Caregiver Survey also included a measure of social support derived from a modified version of the Norbeck Scale of Social Support (Norbeck, 1981). Caregivers were asked to list all of the members in their support network and to assign a "support score" to each member listed. They also noted their satisfaction with their support network. Service use was measured by asking the number of times any of 15 services were used by the caregivers. Self-rated awareness of services was also included. Some of the more frequently used caregiver burden scales were not used as they have proved disappointing in their response to short-term interventions (Green & Monahan, 1987; Hoay, Brown & Levine, 1987; Toseland, Rossiter, & Labrecque, 1989; Zarit, Anthony, & Boutselis, 1987).

Participant caregivers were interviewed in their homes again three months after the end of the 10-week program and asked to fill out the Caregiver Survey again. In addition, follow-up focus group meetings were held with the caregivers from each community program. Focus group interviews were also conducted with each of the seven local program steering committees three months after the program. The program facilitators kept journals to record and evaluate group process, and these were also used as a source of qualitative data.

RESULTS

A total of 56 caregivers registered in the seven community programs. The size of the support groups ranged from 6 to 15 members. Over all groups, three caregivers dropped out due to health reasons, one ceased to be a caregiver, and three chose not to participate in the evaluation. Thus there were 49 caregivers who were interviewed at the end of the program. All but three of the participants were caregivers for a single person. These three were caregivers for 2, 3, and 4 older relatives, respectively. Of the 49 caregivers, 23 (47%) were caring for a spouse, 12 (25%) for a mother, 4 (8%) for a father, 5 (10%) for an in-law and 9 (18%) for a friend, client or other relative. The care recipients were divided about equally between men and women. The mean age of the caregivers was 57.8 years (range of 25 to 80 years) and that of the care recipients was 73.4 years (range of 30 to 94 years). Only 17 caregivers had been giving care for less than three years, while 24 (57%) of them indicated they had been caregivers for three or more years. Thirteen caregivers, nearly one third of the sample, reported that they had been providing care for five or more years.

All but one of the 49 caregivers who completed the program filled out the evaluation surveys and participated in the final interviews. All seven community steering committees and all caregiver groups participated in the follow-up focus group interviews. Through the surveys and in both individual and focus group interviews, participants described a wide range of tangible benefits which they received from the program. Results and examples are presented in the following paragraphs, including direct quotes from participants which can best illustrate the nature of the various benefits participants gained from the group education and training program.

Impressions of the Caregiver Group

In the focus groups as well as in the individual interviews, caregivers were asked about their overall impressions of the caregiver group. Their responses were classified as either positive or negative. Of the 47 open responses to this question, 45 were classified as positive. Perhaps the most positive affirmation of the program was stated as follows:

If you don't continue this program, I don't know what's going to happen. I was in a desperate situation by the time I phoned because I was going to end up in the hospital. That's what I'm saying. You are not only going to have one person in the hospital (the elderly person), you're going to have the caregiver as well. It's a double

whammy! If you take care of the caregiver... you've got two people happy at home. But if you mess up and don't offer something, then you've got two of them (patients).

Other caregivers expressed similar sentiments:

We need someone to help us. We take care of other people, but nobody takes care of us. We felt like we were cared about and cared for at this group. And we cared for each other. We also learned a lot.

If we break down, you wind up with two patients on your hands—the caregiver as well as the person they are caring for. By taking care of us, you get two for the price of one.

Participants described the caregiver group as "wonderful to be with," "a wonderful opportunity," "providing a wealth of information" and "a Godsend." Some caregivers said that they already knew a lot when they joined the group. But even these people claimed to have benefited: "Well you can see the pile of books I got over there—mostly medical books. I knew quite a bit about Alzheimer's as far as the disease itself. But looking after someone—there was a fill-in. They (the group meetings) helped a lot."

Social Support and Connectedness

A series of questions were asked on the Caregiver Survey to determine the type and amount of support that was available to caregivers before the group support program and three months after the end of the program. There were 47 caregivers who completed these items at both times. Each person named in the caregiver's support network was given a support score that ranged from 0 to 20. The support score was arrived at by summing the ratings on each of four types of support: emotional, companionship, advice, and practical help. The ratings for each type of support from the person named were from 0 (none) to 5 (a great deal). Overall, this group averaged between three and four persons whom they considered to be members of their support networks, both before the 10-week program (mean = 3.39) and three months later (mean = 3.95). The average support score for individuals in the support networks increased from 8.07 before the program to 8.71 three months after the program. A total support score for each caregiver was calculated by summing the support scores assigned to each of the members they named in their network, so these scores reflected both quantity and quality of support. The overall mean total support score for participants prior to the group program was 26.86 and

showed a significant increase to 34.50 three months after participants completed the group program ($t(28) = 2.08, p < .05$).

Caregivers were also asked to indicate their satisfaction with the support that they received by responding to the question: "Overall, how satisfied are you with the support that you receive from others?" The response scale was from 1 to 5, with 1 being "very unsatisfied" and 5 being "very satisfied." There was no significant change in the average rating for satisfaction with support before the group program (mean = 3.58) and three months after the program (mean = 3.75).

Many caregivers described the benefits they obtained from gathering with people who were undergoing similar experiences as themselves. One woman, who was caring for her elderly mother, described how she found that her caregiver group members were the only people she could turn to:

I found it increasingly difficult to complain to my husband. It would bring him down. With your mother, there are issues that well up . . . just a lot of emotional experiences which I found difficult. And, you find that there are a lot of people who are in the same boat... there's really no one else who really understands what you are going through.

Improving communication with the outside world was seen by some caregivers as a way to increase their feeling of support. For example, one woman said that as a result of the group's encouragement, she got a computer and was now able to communicate daily with her sister and brother by e-mail, instead of protecting them from the realities she was experiencing in caring for aging parents:

I used to think "Why upset them?" They live far away. But the last while I just sort of know when I can't do much more, that I don't want it anymore. I told my brother that by computer mail at the office where he works and we talk daily and that's a big support for me. I tell him if something happens and he'll answer me.

Health, Life Satisfaction and Self-Care Practices

Caregivers were asked to rate their overall health on a scale of 1 (poor) to 5 (excellent) before and after the program. No significant differences were found. No significant changes in overall satisfaction with life were reported before and after the program, using the same 5-point scale. However, caregivers reported a significant increase in the number of six health-related behaviors. The behaviors were "eating well," "sleeping well,"

"being active," "using respite services," "avoiding smoking," and "avoiding drinking." Before the program, caregivers reported a mean of 2.72 of these behaviors and the number increased to a mean of 4.44 after participation in the group program ($t(24) = 7.49, p < .01$).

Caregiver group members were asked to describe any ways that they have begun to care for themselves differently as a result of the SCBC program. A wide variety of responses were given in the caregiver interviews. "Taking time for myself without feeling guilty" was the number one theme arising. For example, one caregiver noted:

I find that I am taking an hour and going and having coffee with my sister, or something like that... without feeling guilty about it... or without saying, "OK, I won't go." Like I can say to him (her husband), "Listen, I have to go shopping today. Well, I'm sorry, you are OK and I'm going."

This new found assertiveness was apparent among other caregivers as well. One woman claimed that as a result of being in the group, she has begun to realize how much her family expected her to do for them. She had had trouble saying "no" to them. "I mean before all they had to say was 'Mom, can you do this for me?' and Mom was right there. Now its a case of 'Well I'm sorry, Mom can't do it.'"

Another woman explained that since joining the group, she was now able to let someone else care for her husband for awhile to give herself time to "stand on my head in the corner or read a book, or go out, without having someone following me like a puppy dog." One woman started going to a fitness class and found that she really had to keep other events from encroaching on her time. She said, "I'm just going to have to get more selfish, I guess."

Some caregivers said that they had learned to balance things better as a result of the caregiver group program. Here is how one woman described it:

If I work hard one day, I'm starting to take a day off and don't do much the next day and that's more to just preserve my physical well-being. It's the nature of women to erase themselves as they are so busy caring for other people that they have nothing left.

One item on the Caregiver Survey asked participants whether or not they regularly were keeping physically active. A small, but not statistically significant, increase in physical activity was noted between the before and after program responses to this item. However, in the interviews, the caregivers described a whole range of activities that they had taken up or

resumed as a result of their experience in the caregiver program. These activities included swimming, hiking, skiing, going to movies, crocheting, and attending clubs and retiree groups.

Effect on Caregiving Abilities

In the follow-up interviews, caregivers were asked to give examples of ways that they found the caregiver group program impacted on their caregiving abilities. Many of the participants described having more patience, tolerance and understanding as a result of the group program.

I feel I am more patient. I felt that I was rushing my mom trying to do everything for her. Just being to the meetings and listening to the different speakers I heard that we should be more gentle and give some choices, like do you want to wear your blue socks or your brown ones. It's really working ... it struck me that that put mom in control. I wasn't trying to control her before, but when you are busy working and stuff, you tend to bustle in and do things and I didn't realize I was sort of doing that until I saw that on the video.

Dealing with "upsetting" behavior is one aspect of caring for people with mental health problems. In the Caregiver Surveys, caregivers were asked to rate how often certain potentially "upsetting behaviors" occurred in the past month, on a scale from 0 = "never" to 4 = "a few times a day." And when these behaviors did occur, caregivers were asked to rate, on a scale from 1 = "not at all" to 5 = "very upsetting," how bothersome or upsetting these behaviors were to the caregiver. The results for the group of 48 caregivers who completed these ratings are given in Table 1.

The 11 potentially upsetting behaviors shown in Table 1 are ordered in terms of the average frequency of their occurrence over the past month reported before the support group program. Three months following the completion of the program there were four behaviors which increased, on average, including a significant increase in the care recipients refusing help from others, in getting angry with the caregiver, and in embarrassing the caregiver. There were six behaviors which decreased in frequency over that time, including a significant decrease in the frequency of the care recipients' non-talkativeness.

It is most interesting that 8 of the 11 behaviors were rated as less upsetting or bothersome after the group program than they were prior to the program. There were statistically significant decreases in how upsetting four such bothersome behaviors were to caregivers: reliving the past, talking little or not at all, not finishing things, and not recognizing people.

TABLE 1. Caregiver Ratings of the Frequency and Bothersomeness of Potentially Upsetting Care Recipient Behaviors Before and After Group Support Program

Potentially Upsetting Care Recipient Behaviors	Mean Frequency of Behavior		Mean Bothersomeness of Behavior	
	Before Program	After Program	Before Program	After Program
Losing things	2.00	1.97	1.73	1.61
Reliving the past	1.95	1.77	1.33	1.03*
Talking little or not at all	1.84	1.29*	1.83	1.29*
Restlessness	1.76	1.83	1.43	1.55
Not finishing things	1.76	1.70	1.41	1.13*
Frequent waking	1.38	1.33	1.50	1.61
Refuse help from others	1.19	1.78*	1.83	1.77
Illusions or hallucinations	1.18	1.03	.97	.87
Can't recognize people	1.16	1.16	1.53	1.19*
Embarrassing you	1.13	1.67*	1.12	1.42*
Getting angry with you	1.05	1.21*	2.00	1.94

* Difference significant at $p < .05$.

There were overall increases in reports of how bothersome restlessness and frequent waking were to caregivers, and a significant increase in how bothersome it was when the care recipient embarrassed the caregiver. It should be noted that the behaviors which were rated as the most bothersome were not necessarily those that were most frequent. For example, for the group, getting angry with the caregiver was rated as the most troublesome behavior, but rated last in terms of frequency. Refusing help from others was rated as the second most bothersome behavior, but was seventh down the list in terms of frequency.

Caregivers gave many examples of how in the group program they had learned to deal with upsetting behaviors differently, primarily in terms of having greater understanding and patience:

I was really upset-he would go to bed at night with his shirt on. I used to let lots of little things like that bother me. That's what I learned to handle easier. I wished he'd button his shirts quicker. But

it doesn't really matter does it? It was not the serious thing I thought it was. So it took a lot of stress off me, it really did.

Many caregivers described being better able to reach out to others to help in the caregiving. They were better able to call on social workers, siblings, physicians and nursing home staff to assist them when needed. One woman had been caring for her neighbors for two years. Here is how she described the changes she experienced while in the group:

Well, every evening I used to go over and visit with them to make sure they were safe or eating or hadn't fallen. But halfway through the caregiver course I demanded that their children come and assess the situation, and they did. They have brought them several aids at home that I recommended so have picked up some of their responsibility. Its freed my time up lots.

Additional Outcomes

A variety of additional benefits were described by the caregiver group participants. They described the value of having an outlet to express feelings—often ones of anger, sorrow or guilt—in a supportive environment. Likewise, they said they felt understood. They claimed that they were strengthened by realizing that they were not alone. They described the group experience as important for just giving them time out for a few hours a week. Several people said they felt they had learned to be more assertive and felt that they had increased their risk-taking. And lastly, several caregivers noted the benefits of being able to help others through sharing their experiences in the group, and participating in the program evaluation.

It was of interest to know the extent to which participants believed that the benefits of the caregiver program could be sustained beyond the initial 10-week program and the three-month follow-up. Caregivers said they thought the absence of guilt and the better self-care practices would continue on. They had learned to handle financial affairs and make care decisions which they thought would be valuable in the future. One woman said that she could see that the information she received would be invaluable:

In I ever run into another situation in caregiving-one of my in-laws is going to die so it's going to happen-a lot of the stuff we learned was incredible. I've used it already. I have a friend who came over and said I don't know who to phone for help so we pulled out the

manual and found a couple of names for her to call. We did get a gold mine of information about our community.

Negative Reactions

Caregivers were specifically asked to describe any negative ways that they felt they were impacted by the caregiver group program. Several participants said they thought there was too much reading material and, as busy caregivers, they simply did not need to be given a lot more to do. Also, some caregivers found certain aspects of the content did not seem to apply to them. For example, the section on wills and power of attorney didn't apply for two caregivers who said that they had already taken care of such matters. One person found that the program was too short, while another said every week was too often—that every two weeks would have been enough.

One caregiver didn't like the style of the group leader, claiming that the leader seemed too intent on finishing her agenda when the group needed to ask more questions or just talk freely. Another caregiver found the sessions hard to follow because she was hard-of-hearing, indicating that "when only one person spoke at a time I was O.K., but when they all talked back and forth among one another, I couldn't hear a thing that was said."

Several participants did not like filling out paper and pencil questionnaires, such as those given out as group exercises and those associated with the evaluation. One woman explained that the problem for her is that "fixed scales or forced choice questions don't let you give a full description of your unique experience."

Gender was another issue raised by participants. Several caregivers said they would have liked to see more men at the group discussions, while another remarked that they found the one man in their group was not as sensitive to feelings as the women seemed to be. All of these negative reactions noted by the caregivers in this study bring up issues which have important implications for the training of group facilitators.

Health Care Knowledge

One of the goals of the SCBC program was to increase caregivers' knowledge about the use of community services. Data from several sources suggests that knowledge of services increased, although actual self-reported use of services in the three-month period did not show any statistically significant changes. Some caregivers did report making use of

services involving meal, transportation, housework and day care assistance. There were 32 caregivers who indicated the extent to which they felt the program had made them more aware of services. Of these, 15 (46.9%) said they were "a great deal more" aware of services, 10 (31%) were more aware "to some extent," and 7 (21.9%) said they were "not at all" more aware of services. The patterns of service use will be possible to track over time as most of the participants gave their Medicare numbers with consent to have their records examined for service utilization patterns.

Caregivers described the help in learning about services as "a God-send" and one noted that "I have been a full-time caregiver for eight years so I had done most of the research. If I had had this much earlier, it would have saved me a lot of headaches and frustration." Other caregivers said that they knew about the services but "didn't know how to access them." Many caregivers said they felt much better prepared to face the future knowing who to call for what type of help.

DISCUSSION

This study has highlighted the value of using combined approaches to studying self-help programs such as a caregiver support group. The traditional scientific, philosophical stance favors professional and "expert" knowledge over people's own experiential knowledge (Borkman, 1976) and implies that it is only the expert professionals who can be trusted to tell us what is really best for people.

First, experimental procedures such as random assignment, delayed interventions, placebo controls, and the administration of lengthy inventories and scales over-control and objectify group members. They 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).

Second, as caregiver groups are predominantly comprised of women (Aronson, 1991), traditional methodologies which over-emphasize control, manipulation and objectivity are likely to be entirely inappropriate for evaluating caregiving mutual support groups (Barnsley & Ellis, 1992; Harding, 1987; Olesen, 1994). Field Belenky, McVicker-Clinchy, Rule-Goldberger and Mattuck-Tarule (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 that such experiences and feelings are unimportant to the matter at hand.

Third, 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, inventories and interviews, is unresponsive 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 accordingly plan an evaluation which is as respectful and supportive as possible.

Fourth, 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 which 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.

Fifth, many of the benefits resulting from group participation are of an emotional, or 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 them as measureless, and hence inconsequential, because these benefits cannot be given a numeric score. What attempts there have been to numerically quantify such highly subjective and personal experiences such as "spirituality" (Kay & Robinson, 1994) and "loss of self" (Skaff & Pearlin, 1992) among caregivers come across as overly simplistic and reductionistic.

RECOMMENDATIONS

The Supporting Caregivers in British Columbia project steering committee formulated five major recommendations as a result of this study. It became very apparent that caregivers were already very overwhelmed with their caregiving duties. While they can benefit greatly from small group involvement, most of them are not in a position to do the work of starting new groups, maintaining existing groups, leading groups, liaising with local steering committees, and carrying out other roles required in a complete self-sustaining group. Therefore, (1) it is recommended that in partnership with non-profit and private agencies, the government find

ways to contribute to the costs associated with leadership of caregiver groups in each of the provinces.

At the same time, it is not realistic to expect volunteer caregivers to network with other caregiver groups around the province given their already overburdened situation. The groups in this study all found the services of the Project Coordinator invaluable in terms of support, information and as a conduit to other caregiver groups in the province. Therefore, (2) we recommended that the Ministry of Health provide a portion of the costs of infrastructure for organizations which provide education and support for family caregivers in British Columbia. A province-wide agency like the Caregivers Association of British Columbia serves well in this capacity.

A striking feature of the caregiver groups in this project was the absence of First nations and non-English speaking Canadians. Yet it is known that there are many ethnic groups who provide a great deal of caregiving for their elders and who could benefit from the support and education afforded by the SCBC groups. Therefore, (3) it is recommended that future initiatives be undertaken to determine the special needs of cross-cultural groups of family caregivers, to actively recruit these groups and to modify the SCBC program as needed.

A significant feature of caregivers is that they are almost exclusively women. Concern was expressed that the "Closer to Home" initiatives may contribute even more to caregiver burdens borne by British Columbian women. Therefore, the well-being of women caregivers in the community must be attended to before any further care is moved into the community. Supporting caregiver groups would be a visible start to this process. Furthermore, potential male caregivers need to see more opportunities for themselves in these roles. The few men who did come to the SCBC sessions did find them extremely valuable. Therefore, (4) it is recommended that men be targeted as potential caregivers and that their needs for support and education be examined and included in future caregiver group offerings.

Caregivers represent a wide cross-section of people who are employed full-time, employed part-time and retired. Each group has unique needs in terms of timing and formatting of group meetings. Therefore, (5) we recommend that a variety of different groups for different kinds of caregivers be developed. The original program should be seen as a basic model for other kinds of caregiver programs with flexible formats. For example, programs such as evening groups, intense workshops, or educational offerings on television could all be developed.

In the coming decades, more and more people will be cared for by

relatives and friends. It is obviously a rewarding role to be a family caregiver, but one fraught with worry, fatigue and potential isolation. As a society, a tremendous challenge lies ahead in finding ways to provide appropriate education and support for family caregivers.

REFERENCES

- Altman, J. L., & Martin, S. M. (1994). Health promotion in British Columbia. In A. Pederson, M. O'Neill, & I. Rootman, (Eds.), *Health promotion in Canada: Provincial, national and international perspective*. Toronto: W. B. Saunders.
- Aronson, J. (1991). Dutiful daughters and undemanding mothers: Constraining images of giving and receiving care in middle and later life. In C. T. Baines, P. M. Evans, & S. M. Neysmith, (Eds.), *Women's caring: Feminist perspectives on social welfare* (pp. 138-168). Toronto: McClelland & Stewart.
- Barnsley, J., & Ellis, D. (1992). *Research for change: Participator}' action research for community groups*. Vancouver: Women's Resource Center.
- Barusch, A. S. (1991). *Elder care: Family training and support*. Newbury Park: Sage.
- Biegel, D. E., Sales, E., & Schulz, R. (1991). *Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness and stroke*. Newbury Park: Sage.
- Borkman, T. (1976). Experiential knowledge: A new concept for the analysis of self-help groups. *Social Service Review*, 50, 445-456.
- Caregiver Association of British Columbia. (1995). *BC Caregiver News*, 1(1). Penticton: Author.
- Chesler, M. A. (1991). Participatory action research with self-help groups: An alternative paradigm for inquiry and action. *American Journal of Community Psychology*, 19(5), 757-768.
- Collins, C, Given, B., & Berry, D. (1989). Longitudinal studies as intervention. *Nursing Research*, 38(4), 251-253.
- Field-Belenky, M., McVicker-Clinchy, B., Rule-Goldberger, N., & Mattuck-Tarule, J. (1986). *Women's ways of knowing: The development of self, voice and mind*. New York: Basic Books.
- Greene, V. & Monahan, D. (1987). The effect of a professionally guided support and education group on institutionalization of care receivers. *The Gerontologist*, 27(6), 716-721.
- Gurland, B. J., & Cross, P. S. (1982). Epidemiology of psychopathology in old age. *Psychiatric Clinics of North America*, 5(1), 11-25.
- Haley, W., Brown, L., & Levine, E. (1987). Experimental evaluation of the effectiveness of group intervention for dementia caregivers. *The Gerontologist*, 2(3), 376-382.
- Harding, S. (Ed.). (1987). *Feminism and methodology*. Bloomington: Indiana University Press.
- Hills, M. D. (1992). *The invisible caregiver: An evaluation of the family*

caregivers' network society. Unpublished manuscript, University of Victoria, School of Nursing, Victoria, B. C, Canada.

Kaye, J., & Robinson, K. M. (1994). Spirituality among caregivers. *Image: Journal of Nursing Scholarship*, 26 (3), 218-221.

Labonte, R. (1989) Community and professional empowerment, *Canadian Nurse*, 85 (3), 23-28.

Labonte, R. (1993). *Health promotion and empowerment: Practice Frameworks*. Toronto: University of Toronto, Center for Health Promotion.

Lather, P. (1986). Research as praxis. *Harvard Educational Review*, 56 (3), 257-277.

Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist*, 32 (2), 204-208.

McEwan, K. L., Donnelly, M, Robertson, D., & Hertzman, C. (1991). *Mental health problems among Canada's seniors: Demographic and epidemiological considerations*. Ottawa: Health Services and Promotion Branch, Department of National Health and Welfare.

Ministry of Health and Ministry Responsible for Seniors. (1993). *New directions for a healthy British Columbia*. Victoria, BC: Queens Printers.

Norbeck, K. (1981). The development of an instrument to measure social support. *Nursing Research*, 30 (4), 264-269.

Olesen, V. (1994). Feminism and models of qualitative research. In N. K Denizen & Y. S. Lincoln, (Eds.), *Handbook of qualitative research* (pp. 158-174). Thousand Oaks: Sage.

Patton, M. Q. (1990). *Qualitative evaluation and research methods*, (2nd Ed.). Newbury Park: Sage.

Rubin, Z., & Mitchell, C. (1976). Couples research as couples counseling: Some unintended effects of studying close relationships. *American Psychologist*, 31 (1), 17-25.

Skaff, M. M., & Pearlin, L. I. (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist*, 35 (5), 656-664.

Tebes, J. K., & Kraemer, D. T. (1991). Quantitative and qualitative knowing in mutual support research: some lessons from the recent history of scientific psychology. *American Journal of Community Psychology*, 19 (5), 739-756.

Toseland, R. W., & Rossiter, C. M. (1989). Group interventions to support family caregivers: A review and analysis. *The Gerontologist*, 29 (4), 438-448.

Toseland, R. W., Rossiter, C., & Labrecque, M. (1989). The effectiveness of peer-led and professionally-led groups to support family caregivers. *The Gerontologist*, 29(4), 456-471.

Wilner, M. A. (1988). The transition to self-care: A field study of support groups for the elderly and their caregivers. In S. Reinharz & G. D. Rowles, (Eds.), *Qualitative gerontology*. New York: Springer.

Zarit, S., Anthony, C., & Boutselis, M. (1987). Interventions with caregivers of dementia patients: comparison of two approaches. *Psychology and Aging*, 2 (3), 225-232.