A QUALITATIVE STUDY TO DETERMINE THE IMPACT OF CAREGIVER EDUCATION AND SUPPORT GROUPS

by Brad Hagen and Elaine M. Gallagher

Introduction

Health professionals and government policy-makers have realized the important contribution that family members make in caring for the frail elderly in the community. How can we best support them in this important role? One method of offering assistance to family caregivers is through groups to provide education and mutual support. Interestingly, evaluations of the benefits of these groups, using primarily quantitative scales and instruments, have not produced the expected improvements. Consequently, efforts to secure and maintain funding have been disappointing. However, participants themselves usually claim that the group experience is invaluable. This article describes an alternative approach to evaluating a program involving support groups for family caregivers, using focus group interviews conducted three months following a 10-week program. This was one component of a larger evaluation of the Supporting Caregivers in British Columbia (SCBC) program, funded by the B.C. Ministry of Health.

Literature Review

A number of authors have reviewed the published evaluations of group interventions for caregivers of persons who are physically frail or suffer from dementia (Biegel, Sales, & Schulz, 1991; Gallagher, 1985; Knight, Lutzky, & Macofsky-Urban, 1993; Kuhlman, Skodol-Wilson, Hutchinson, & Wallhagen, 1991; Lavoie, 1995; Toseland & Rossiter, 1989; Zarit, 1990). Comparisons between caregiver groups are difficult to make because of their heterogeneity. Caregiver group participants appear "subjectively" very pleased with their experience and report a number of benefits as a result of their experience. However, the use of "objective" standardized instruments to measure

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a variety of outcome measures (e.g., depression, anxiety, burden) indicate that the benefits of group interventions may be marginal and highly equivocal.

Addressing the disappointing "objective" results from the published evaluations of caregiver groups, researchers called for greater scientific rigour and/or the use of different outcome variables (Callahan, 1989; Greene & Monahan, 1989; Lavoie, 1995; Mittleman *et. al,* 1993; Mohide *et. al,* 1990). Other authors, however, questioned the appropriateness of using traditional quantitative methodologies to evaluate the outcomes of caregiver group interventions. Chesler (1991) and Tebes and Kraemer (1991) noted that experimental procedures, such as random assignment, delayed interventions, placebo controls, and the administration of lengthy inventories/scales that objectify group members, are antithetical to the values and goals of mutual aid groups. Such goals often include member participation in the design and operation of activities, local grassroots orientation, consciousness-raising, and empowerment.

Furthermore, traditional evaluation methodologies that emphasize objectivity have also been criticized from a feminist point of view. These methodologies are thought to devalue the importance that many women place on subjectivity, inner experience, morality, internal knowledge, and emotionality (Barnsley & Ellis, 1992; Field-Belenky, McVicker-Clinchy, Rule-Goldenberg, & Mattuck-Tarule, 1987; Harding, 1987; Olesen, 1994). Since many of the benefits that caregivers report from support group participation are in an emotional realm, and although these benefits may make real and tangible differences in caregivers' ability to give care, they may not lend themselves to quantification and measurement. This evaluation, therefore, aimed to understand the participants' perspectives of being in a caregiver group. Thus, it seemed appropriate to use qualitative focus group interviews as the preferred methodology.

Description of the Program

The SCBC program was a provincial government initiative to support family caregivers, and is described

in more detail elsewhere (Hagen & Gallagher, 1996; Gallagher & Hagen, in press). The initiative involved offering and evaluating a caregiver education and support group program in six communities in British Columbia. The program consisted of 10 weekly caregiver support group meetings run by a local community facilitator. Facilitators were provided with training at a weekend training workshop. Each of the 10 weekly group meetings involved opportunities for both support and education. It was up to each of the six groups to decide whether (and how) they were going to continue to meet after the funded program (with paid facilitation) had ended.

A steering committee oversaw the program and its evaluation. It comprised representatives from the provincial Caregivers Association, the Alzheimer's Association of B.C., and the University of Victoria School of Nursing. The evaluation methods included an in-home interview and a short questionnaire with all caregivers before and three months after the program, and focus group interviews with all six caregiver groups three months after the end of the 10-week program. The results of the in-home interviews are reported elsewhere (Gallagher & Hagen, in press).

Evaluation Methods

This article describes the results of the caregiver focus group interviews, conducted to learn how each group viewed: their group process, outcomes of the group experience, and what each group needed to ensure its future viability. The two authors and two trained RN research assistants carried out the focus groups. The tape-recorded interviews were semi-structured. Time was allotted to let the members of each group discuss whatever was of particular importance to them and to answer and discuss the following questions:

- Briefly describe the things that stand out in your mind about the 10-week support group you attended.
- What plans does your group have for meeting in the future? What kind of group would you like it to be?
- What would your group need to continue meeting?
- What else, if anything, would you like to say about your experience of being in this group?

Data Analysis

The audiotapes from the six focus group interviews were transcribed in their entirety. After reviewing the

transcripts numerous times to get a sense of the whole (Sandelowski, 1995), the data were analyzed by the authors using NUDIST qualitative analysis computer software (Richards & Richards, 1990). Emergent themes and concepts in relation to outcomes of the group experience, group process, the future needs of each group, and societal issues 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 were developing from the data (Tesch, 1987; Tesch, 1990).

Focus Group Participants. The focus groups ranged in size from four to 11 participants. The original facilitators also participated in two of the groups. A total of 56 people had registered in the program and of these, three dropped out due to health reasons, one ceased to be a caregiver, and three chose not to participate in the evaluation; thus, 49 caregivers participated in the focus groups. Most of the original participants were caregivers for one person (n = 46), although some cared for two (n = 1), three (n = 1), and four (n = 1) older relatives. Of the 49 caregivers, 23 (47%) were caring for a spouse, 16 (33%) for a parent [mother, 12 (25%), father, four (8%)], five (10%) for an in-law, and nine (18%) for a friend, client, or other relative. Ninety-five percent of the caregivers were female; the care recipients were divided about equally between men and women. The mean age of the caregivers was 57.8 years and that of the care recipients 73.4 years. Only 17 people had been giving care for less than three years, while 24 (57%) of the valid responses indicated three or more years. In fact, nearly a third (13) said they had been providing care for five or more years.

Results

Four categories of themes emerged from the data. These included outcomes of the group experience, findings related to group process, future plans for the group, and societal issues.

Outcomes of the Group Experience

This category concerned the impact that the group experiences had had on caregivers themselves and their ability to carry out caregiving. The major themes emerging included: learning that they were not alone; learning about resources and the system; learning not

to feel guilty; and feeling able to care for loved ones longer.

   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. One participant stated:

   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 group's 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 was important for some participants to know that others were having to deal with their own personal reactions to the stresses of caregiving. For example, one woman, who was looking after her husband, shared, "I found out that I wasn't the only person who got really mad and yelled at him!"

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

   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 co-ordination 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 co-ordination 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. 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. Caregivers stated that despite the tremendous time and energy they devote to caregiving, they still were often plagued with feelings of guilt — feelings that "only added to the difficulty of caregiving." In particular, they felt tremendous guilt when they did take time to care for themselves. Involvement in the support group helped to deal with 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 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.

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

   Yeah, this (the group) is the way you keep your 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. **An** important outcome arising from this support group experience was that most participants felt they could care for their family members longer, as a result of learning how to better take care of themselves. As well, some caregivers recognized that unless they considered imminent institutional placement of their frail family member, they themselves were at risk for serious health problems. 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.

Findings Related to Group Process

Participants were very eager to discuss what occurred in their caregiver support group. This category includes caregivers' descriptions of group processes they felt helped to produce positive outcomes. 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 express humour and laughter. Participants stressed the important role that laughter played in their caregiver support groups. The 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 that when she became particularly angry at her mother for whom she was caring, 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 sometimes "gallows" humour. The ability to laugh was an important stress release, which allowed caregivers to go back into their difficult environments somewhat renewed and recharged.

Feeling cared for and caring for others. Many caregivers found the experience of being *cared for* particularly rewarding and valuable. Participants quickly realized that it was important for 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. One woman stated to the other women in her group:

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.

Caregivers felt that their caregiving situations at home always demanded *one-way* caring. The *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. Participants said that most of their non-caregiving friends and family found it too uncomfortable to listen to them vent their emotions. Yet in a group of fellow caregivers, participants felt they had the permission and understanding to finally talk about their feelings that were "eating away at them." The venting of sadness was a prominent theme, with most participants needing to express grief about the loss of their freedom, their former relationships, and the former personhood of their now dependent relative. The opportunity to vent anger was also very 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 ... 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 and what are you going to do ?!

Having permission from fellow caregivers to be as "mad as hell" seemed to give caregivers the opportunity to own and express their anger. Consequently, there may have been a reduced potential for it to become destructive or potentially leading to abuse of their family member. As one woman put it, "It's all right to be angry as long as you don't let that eat you up."

Confidential interaction. The *confidential* nature of the interaction in the groups was also important to caregivers. Group facilitators stressed the importance of confidentiality throughout the sessions, and participants stated this norm helped to create a "safe place" where they could really "bare their souls." The participants stated it was important to remind themselves each week that confidentiality was vital to producing positive outcomes. Two participants related:

... 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.

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

Processing *loss.* Processing loss was the final theme emerging out of the interview data. All the participants were experiencing loss, some more profound than others, and needed a "safe place" to grieve and work through their losses. One woman, caring for her husband with Alzheimer's disease, described:

... 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 appeared to make caregiving a little more tolerable. Perhaps this was due to a greater realization that *this* was the way that things had turned out, and trying to finally live life to the fullest with acceptance of that fact.

Future Plans for the Groups

The third and final category arising from the data was the future and sustainability of their caregiver support groups, after the official 10-week period had ended. The themes that emerged in this category included: planning for new members; meeting future needs; and taking political action.

Planning for new members. Participants stated they realized they should consider recruiting new members in order to sustain the future of their groups. They felt a dilemma: they were very comfortable and "cozy" with each other and were wary of "outsiders," but realized that they would need new members as established group members left. Individual groups had different "marketing" ideas. They indicated that they felt the groups should continue to be "generic" ones, that is, open to all caregivers, not just caregivers of people

with a specific condition (e.g., dementia). Additionally, participants expressed a desire to actively recruit more male caregivers to join their groups.

Meeting future needs. All of the groups expressed that the primary need for the future was funding for facilitators. One of the aims of the SCBC program was to prepare the group for self-leadership (i.e., self-led, with no facilitator) at the end of the 10-week period. However, only two of the six groups were truly self-led after three months. The others were led by their facilitators on a temporary volunteer basis while the group members and others from the communities explored alternative funding for a trained facilitator.

Taking political action. Most participants experienced an awakening of consciousness about caregiver issues as a result of their involvement with their caregiver group. Consciousness-raising often led to the desire to engage in lobbying and political action. A caregiver group devoted one meeting to a letter-writing blitz to politicians regarding the need for support services for caregivers. For many of the participants, the search for funding for facilitators was the beginning of a bigger political process. One participant stated:

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.

Another group got the local community TV and radio stations to do stories about the plight of caregivers with the hope that other people would begin to lobby politicians about the issue. One caregiver 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 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!

Societal Issues

The caregivers, all women except two, were starting to realize that caregiving was a women's issue. One woman described the difficulty she had getting the system to be flexible regarding her need for respite:

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

Participants were eager to become political and to educate local politicians about what it was like to care for chronically ill relatives. However, many of these participants were extremely burdened and stressed, and had little time or energy to become politically active.

Conclusions

Traditional evaluations of caregiver support groups have attempted to determine whether involvement in these groups quantitatively changes participant's scores on scales measuring stress, feelings of burden, and life-satisfaction. However, the results have been marginal or equivocal. This has been attributed to insensitive measures, insufficient duration of the group, or small sample sizes. The authors suggest that another approach is to ask the participants directly to describe their experiences. Their narratives provide a rich data base upon which to draw conclusions about the meaning of the experience to the participants.

Participants in this evaluation project reported how involvement in a caregiver support group was of benefit to them. The results may fit for members in other caregiver groups or serve as useful goals to strive toward. The results may be useful in securing funding for such endeavours in other jurisdictions. The project identified the highly gender-biased nature of family caregiving and outlined ways that caregivers may want to become more politically active.

Critics of this approach will argue that unless we can put numbers to these descriptions, they contain little real information about the value of the program. We would argue that putting numbers to information is not always necessary and in some cases may be contrary to the goals of the program.

The authors conclude that caregiver groups offer an important opportunity for caregivers to learn that they are not alone, there are resources in the community to assist them, and the work they do is valued. They can also learn specific strategies for coping with stress, anger, and grief. For many caregivers, particularly those with longer durations of caregiving, these groups may represent the first opportunity for a "safe place" where tears, humour, and a hug are easily accessible. As such, nurses have a major opportunity to support and facilitate the ongoing availability of support groups for family caregivers.

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