DEVELOPMENT AND EXAMINATION OF A CAREGIVER EDUCATION PROGRAM

by

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Abstract

This project proposed to develop and evaluate a ten-week education series for a mixed group of caregivers of frail older adults. A systematic literature review was conducted of selected studies to determine the effectiveness of educational group interventions for caregivers. It was determined that the average efficacy of programs ranged from medium to large. The sample size of many of the studies was not large enough to detect small effects. Key components of reviewed education interventions were identified and incorporated into the current education intervention. Self-efficacy theory was used to guide the facilitation and development of the education curriculum. A steering committee composed of key professionals and family caregivers invited from the community assisted with the selection of topics for the curriculum.

The primary goal of the education intervention was to enhance caregiver confidence. Confidence in being a caregiver was conceptualized as caregiver self-efficacy. Caregivers who signed up for the education series completed two surveys: the first after the first session, the second, after the ninth session. The outcome variable selected for the study was caregiver self-efficacy; the co-variates to be explored were depression and burden.

The method was modified due to difficulties in the development of the project, high attrition of participants, and low participation rate in the surveys. As it turned out, over the course of the series, rather than following the curriculum, the structure of the program focused on caregiver support. As a result, the curriculum was not evaluated for its educational merit or for its impact on the outcome measures, caregiver self-efficacy, depression, and burden. Instead, the small number of participants who remained in the study completed a satisfaction survey. As well three interviews were conducted with two caregivers and the facilitator. The satisfaction survey and interviews yielded a generally positive outcome of meeting these caregivers' needs. A set of recommendations based on participants' comments as well as difficulties encountered in conducting the study is presented to assist future implementation of the educational program.

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Introduction

Currently, a number of educational programs for caregivers are offered in the Greater Vancouver Regional District (GVRD). The Alzheimers Society of BC offers a six-session program targeted to caregivers of people with dementia. The 10 session program developed by the Caregiver's Association of British Columbia (CABC) is run by various volunteers and programs throughout the province. The Vancouver Coastal Health Authority (VCHA) has adapted CABC's manual and offers the education program four to six times per year. The Gero-psychiatric Education Program (GPEP) through VCHA conducts *Caring and Learning Together,* an eight session education program with a mental health focus for formal and informal caregivers of the Vancouver/Richmond area: it is offered about eight times per year.

Although other educational programs were operating in the GVRD, the Victorian Order of Nurses - British Columbia Branch (VON British Columbia) saw a need to develop and implement an education series for caregivers. Historically, VON British Columbia has utilized family caregivers' input in planning and decision making related to its programming. Caregivers, who were involved in setting up the VON's respite program, requested more in-depth content than was currently being offered by their monthly support group. With funding from VON Canada, VON British Columbia hired a project co-ordinator (the author) to develop, deliver, and evaluate an education program for caregivers. In order to keep the development of the project local and grass roots and to partly address issues of objectivity in the evaluation, a steering committee consisting of local informal and formal caregivers was invited to guide the development of the series. As it turned out, due to the way the project progressed, I was not involved in the implementation of the project but solely involved in its development and evaluation, with little feedback from the original steering committee.

Although the proposed education series was intended to complement the previously existing programs in the GVRD, not to compete with them, it did compete as reflected in difficulties in recruiting participants. Therefore, the education program was moved to an adjacent community. Even though the VON has experience with working with care–recipients with dementia in its respite program, it was thought to open the sessions to all caregivers, since the Alzheimers Society already provides an excellent education program specifically for caregivers of people with dementia. The target population of the VON's Caregiver Education Series was therefore determined to be informal caregivers, especially those providing in-home care for an older person. It was expected that the project would attract a diverse set of caregivers (i.e. persons who may or may not be caring for someone with dementia).

Although some of the curriculum content was derived from other caregiver programs, this project was novel because it had been developed around the concept of self-efficacy, which also served as the primary outcome measure for evaluating the impact of the program on caregivers. According to Zarit and Leitsch (2001) many caregiver programs focus on outcome measures such as depression or well-being, which may not be a realistic consequence of receiving the intervention. This evaluation was designed to measure caregiver self-efficacy as an outcome of receiving the intervention, which is a realistic consequence of receiving the program since it had been developed around the concept of self-efficacy. Many evaluations of caregiver education programs have focused on the effect of the program on caregiver depression and perceived burden; whereas, this evaluation would explore the relationship between self-efficacy, depression, and burden. Identifying the mediating variable or variable that can be influenced by an education program could assist professionals in the future development of interventions by focusing on the identified impressible quality, in this case, caregiver self-efficacy.

Review of the Literature

Education: an important need for caregivers

Caregiving for a person with a disability can be potentially burdensome because of the change in roles, strain from demanding roles, and social isolation imposed by caregiving (Greene & Mohanan, 1987). Family caregiving for someone with Alzheimer's disease or dementia has been widely acknowledged in much of the literature for the prevalence of very high levels of stress for the caregiver (Haley, Levine, Brown & Bartolucci, 1987). The person suffering from dementia may experience a severe decline in cognitive functioning, self-care, or changes in personality and behaviours. The range, frequency, and types of problem behaviours exhibited by the demented older adult can be both physically and emotionally demanding for the caregiver (Mace & Robins, 1981; George & Gwynther, 1986; Haley, Levine, Brown, Berry & Hughes, 1987). The stress related to the physical and emotional demands can lead to negative outcomes for the caregiver in terms of burden, isolation, depression, and health problems.

An education program could be particularly beneficial to a caregiver looking after an older adult with dementia. The education program could assist the caregiver to understand and learn different methods of distraction, or ways to prevent behaviours such as wandering and sexual inappropriateness. The education program could serve as a connection to other social supports, which would be particularly important for someone who has little social support since he or she may be dealing with the caregiving role in isolation (Bourgeois, Beach, Schultz and Burgio, 1996). Thus, an education program, which teaches techniques in behaviour management with an emphasis on social support, would be most healthful, particularly for a caregiver providing care to someone with complex needs and behaviours.

Indeed, caregivers have identified both information and education as significant needs in supporting their ability to provide care. Whereas information refers to the knowledge obtained, education refers to the actual action or process by which information is processed or received by the student. Information could be translated through a handout, pamphlet, website, or resource directory; education is translated through a process between the student and instructor that follows a more structured course. In a Canadian study (Cranswick, 1997) key information on how to be an effective caregiver was identified as an important support to coping with the demands of providing care by 14% of female caregivers and 10% of male caregivers[1]. General knowledge was cited by 14% women and 12% men. Specifically, information on the nature of the disease or disability was identified by 14% of women and 12% of men.

Fortinsky and Hathaway (1990) indicate that at the time of diagnosis of Alzheimer's Disease (AD), the most significant needs cited by the caregiver were education and information on Alzheimer's Disease and emotional support. Specifically, the most frequent response, written materials about AD, was indicated as instrumental by 72% of active caregivers. Education workshops, although the fourth frequently mentioned choice, was identified by 57% of caregivers. Support groups and counseling were also acknowledged as most beneficial by 67.3% and 64% of caregivers respectively,

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[1] Caregivers were asked "what would make it easier to cope with the demands of providing care?" Additional responses included "respite" (15% of men & women); "financial compensation" (15% women & 16% men); "counselling" (5% men & women). About 50% of caregivers responded "nothing". It appears that about 15% of respondents offered more than one response.

the second and third most frequently cited services. Former caregivers, who were also surveyed, indicated a need for these elements in the same sequence, but with higher percentages of caregivers reporting each of these needs.

Although education and information has been reported as a significant support for caregivers, (Cranswick, 1997; Fortinsky & Hathaway, 1990) little information is available concerning specific educational topics as identified by caregivers. Fortinsky and Hathaway (1990) asked caregivers of someone with AD, what their educational needs would be in order to provide effective care. At the time of diagnosis of AD, 70% of caregivers indicated wanting knowledge on the stages of the disease, behaviour management techniques, medications, and financial issues.

Hamlet and Read (1990) conducted a small survey of caregivers whose care-recipient was currently in hospital. These researchers report that the most common themes asked for were dealing with interpersonal relationships, coping with anger, stress, guilt, and loss; planning for the future discharge; and community resources. Lorensen (1992) suggests that caregivers need reliable information on the ageing process, the illness the care-recipient suffers from, the interventions for that illness, the technology available to assist, how to manage 24 hours per day, and how to cope with caring for long periods of time.

Schmall (1994) identifies the education needs of family caregivers as the following: 1) Understanding the medical condition in terms of signs, symptoms, progression, and functioning; 2) Skills for coping, managing stress, managing behaviour, problem-solving and providing physical care; 3) Family issues including the issues around conflict with other family members, their expectations, and the care-recipient's dependency on the caregiver; 4) Communicating with someone who is cognitively impaired; 5) Identifying and accessing community resources: the benefits of the resources and accepting assistance; 6) Dealing with the emotional aspects of caring; and 7) Residential care, legal and financial arrangements for someone who is incapable.

Curriculum Content

In order to develop the curriculum for the current project a detailed analysis of existing curricula and reports of caregiver interventions was undertaken. Table 1 presents the topics that have been included in education programs targeted to mixed groups (i.e. caregivers looking after care-recipients with various disabilities) compared to homogenous caregiver groups (i.e. caregivers looking after someone with a specific disease such as dementia).

Table 1: Curriculum Content of Educational Programs Targeted to Mixed and Homogeneous Caregiver Groups

Topics	Mixed Caregiver Groups (n=13)	Homogeneous Caregiver Groups (n=11)
Behaviour Management	Gallagher & Hagen (1995) Mehrotra et al. (1984) **(n=2)**	Alzheimer's Society; Brodaty, et al. (1994);Chiverton & Caine (1989); Coen et al. (1999); Coogle et al. (1994); Ghatak (1994); Glosser & Wexler (1985); GPEP (2000); Haley et al. (1987); Hebert et al. (1993) Hepburn et al. (2001); Kahan, et al (1985); Morano & Bravo (2002) Robinson & Yates (1994); Zanetti, et al. (1998) **(n=15)**
Caregiver Role and Changes	Couper (1988); Leutz et al. (2002)[2]; Montgomery (1984); Montgomery & Borgatta (1985);Torres-Stanovik (1990); Wood (1986) **(n=6)**	Chiverton & Caine (1989); Coogle et al. (1994); Hepburn et al. (2001) Van Den Heuvel et al. (2000) **(n=4)**

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[2] Leutz et al (2002) evaluated Haigler, D., Mims, K., & Nottingham, J. (1998). *Caring for you caring for me: education and support for caregivers.* Georgia: University of Georgia Press.

	Mixed Caregiver Groups (n=13)	**Homogeneous Caregiver Groups (n=11)**
Communication	Bane & Halpret (1986); Barusch & Spaid (1991); Gallagher & Hagen; (1995); Kaasalainen, Craig, & Wells (2000); Mehrotra et al (1984); Montgomery (1984); Montgomery & Borgatta (1985); Wood (1986) **(n=8)**	Alzheimer's Society; Chiverton & Caine (1989); Coen et al. (1999); Coogle et al. (1994); GPEP (2000); Haley et al. (1987); Morano & Bravo (2002); Ostwald, et al. (1999). Ripich et al. (1998) **(n=9)**
Community Resources/ Getting Support	Bane & Halpret (1986); Barusch & Spaid (1991); Gallagher & Hagen (1995); Greene & Mohanan (1989); Leutz, et al. (2002); Kaasalainen et al. (2000); Mehrotra et al. (1984); Montgomery (1984); Montgomery & Borgatta (1985); Schwiebert & Myers (1994); Torres-Stanovik (1990); Toseland et al. (2001); Wood (1986) **(n=13)**	Alzheimer Society; Brodaty, et al. (1994); Coogle et al. (1994); Haley et al. (1987); Kahan, et al (1985) ; McFarland & Sanders (2000); Morano & Bravo (2002); Van Den Heuvel et al. (2000) **(n=8)**
Coping Strategies	Bane & Halpret (1986); Barusch & Spaid (1991); Gallagher & Hagen (1995); Greene & Mohanan (1989); Montgomery (1984); Torres-Stanovik (1990); Toseland et al. (2001). **(n=7)**	Alzheimer's Society; Brodaty & Gresham, (1989). Chiverton & Cain (1989); Coen et al. (1999); Coogle et al. (1994); Gallagher, Thompson & Devries (1994); Gendron et al. (1996); Ghatak (1994); Haley et al. (1987); Hebert, et al. (2003). Marriott et al. (2000); Steffen (2000);Van Den Heuvel et al. (2000). Zanetti, et al. (1998) **(n=14)**
Disease Specific Information	Greene & Mohanan (1989) **(n=1)**	Alzheimer's Society; Brodaty, et al. (1994); Chiverton & Caine (1989); Coen et al. (1999); Coogle et al. (1994); GPEP (2000); Ghatak (1994); Glosser, G., & Wexler, D. (1985) Haley et al. (1987); Hepburn et al. (2001); Hebert et al. (1993); Kahan et al (1985); Marriott et al. (2000); McFarland & Sanders (2000); Morano & Bravo (2002); Ostwald et al., (1999); Van Den Heuvel et al. (2000); Zanetti et al. (1998) **(n=18)**

Topics	Mixed Caregiver Groups (n=13)	Homogeneous Caregiver Groups (n=11)
Grief and Loss	Barusch & Spaid (1991) **(n=1)**	Alzheimer's Society; Coen et al. (1999); Coogle et al. (1994); Ghatak (1994); McFarland & Sanders (2000); Morano & Bravo (2002) **(n=6)**
Health and Ageing	Barusch & Spaid (1991); Greene & Mohanan (1989); Kaasalainen et al. (2000); Mehrotra et al. (1984); Montgomery (1984); Montgomery & Borgatta (1985); Schwiebert & Myers (1994) **(n=7)**	GPEP (2000) **(n=1)**
Legal Issues	Barusch & Spaid (1991); Couper (1988); Gallagher & Hagen (1995); Mehrotra et al. (1984); Montgomery & Borgatta (1985); Torres-Stanovik (1990) **(n=6)**	Alzheimer's Society; Coen et al. (1999); Coogle et al. (1994); Glosser, G., & Wexler, D. (1985); Morano & Bravo (2002); Kahan, et al (1985) **(n=6)**
Practical Techniques to Care i.e. nutrition, medication management ADL techniques	Bane & Halpret (1986); Barusch & Spaid (1991); Greene & Mohanan (1989); Montgomery (1984); Torres-Stanovik (1990); Wood (1986) **(n=6)**	Chiverton & Caine (1989); Coogle et al. (1994); Haley et al. (1987); Hepburn et al. (2001); Kahan, et al (1985); McFarland & Sanders. (2000); Ostwald, et al., (1999); Van Den Heuvel et al. (2000) **(n=8)**
Residential Care	Kaasalainen et al (2000); Leutz, et al. (2002); Torres-Stanovik (1990) **(n=3)**	Alzheimer's Society; Coogle et al. (1994); Van Den Heuvel et al. (2000) **(n=3)**
Self-Care	Barusch & Spaid (1991); Gallagher & Hagen (1995); Leutz, et al. (2002); Montgomery (1984); Montgomery & Borgatta (1985); Torres-Stanovik (1990); Toseland et al. (2001) **(n=7)**	Coogle et al. (1994); GPEP (2000); (n=2)

Topics	**Mixed Caregiver Groups (n=13)**	**Homogeneous Caregiver Groups (n=11)**
Skill Building: Focus upon a particular skill	Increase Life Satisfaction & Problem-solving (Lovett & Gallagher, 1988; Steffen et al 1998) **(n=2)**	• Anger Management (Gallagher-Thompson & Devries, 1994; Gallagher-Thompson et al. 2001; Steffen 2000) • Behavioural Management (Robinson & Yates, 1994) • Communication training (Ripich et al, 1998) • Confidence building (Ostwald, et al., 1999) • Counselling & support (Mittelmen et al., 1995) • Pleasant events training (Teri et al., 1997). • Problem solving (Gendron et al., 1996; Teri et al., 1997; Van Den Heuvel et al. 2000). • Social-Skills Training (Robinson, 1988) • Stress-management & coping skills (Marriott et al. 2000) **(n=13)**
Stress Management	Gallagher & Hagen (1995); Greene & Mohanan (1989); Montgomery (1984); Kaasalainen et al. (2000); Schwiebert & Myers (1994); Torres-Stanovik (1990) **(n=6)**	Alzheimer's Society; Brodaty et al. (1994); Coen et al. (1999); Haley et al (1987); Hebert et al. (1993, 2003); Kahan et al (1985); Marriott et al. (2000); Van Den Heuvel et al. (2000) **(n=9)**

As can be seen, few programs targeted to mixed groups have included information about behaviour management (n=2), skill-building techniques (n=2), and disease-specific information (n=1). On the other hand, these appear to be common elements of education series for homogeneous groups of caregivers. These include: 18 programs entailed content on disease-specific information, 15 programs provided information about behaviour management, and 13 programs included content on skill-building. Common topics to both homogeneous and mixed caregiver groups were caregiver role and changes, communication techniques, community resources, coping strategies, providing hands-on care, and stress management.

After reviewing the literature, caregiver manuals, evaluated programs, and discussions about caregiver programs, key characteristics of previously evaluated educational programs that have contributed to improvements in emotional distress and well-being for caregivers were identified. The findings are reported in the next section.

Systematic Review

When developing an intervention the researcher should first conduct a thorough examination of the literature in order to estimate a realistic effect size for this type of intervention, which would in turn determine the sample size needed to evaluate the program (Windsor et al. 1994). There are two methods to use: meta-evaluation and meta-analysis. The selection of method is dependant on the development of the literature for that intervention. For caregiver educational programs, a meta-evaluation or systematic review was chosen because there were few evaluations based on vigorous research methods. A meta-analysis would have been conducted had the literature been comprised of a large number of strong evaluations.

A systematic review or meta-evaluation was conducted to evaluate the educational interventions designed to alleviate distress for both caregivers of adults with dementia (homogeneous groups) and of adults with various disabilities (mixed/heterogeneous groups). The intent of the review was the following; 1) To assess the methodological rigour of published interventions based on set standard criteria; 2) To uncover key elements of successful interventions in order to integrate the findings into the present education intervention; and 3) To establish an average effect size.

Methods

Literature Search

Using the search terms "caregiver, caregiving, caregive, carer" and "curriculum, training, education, handbook, guide, program, session, series, intervention, psychoeducation, burden, evaluation, outcome" a search of electronic databases was undertaken to find studies testing education interventions for caregivers. The reviewed databases included Ageline (1978-2003), PsychINFO (1987-2003), SocioFile (1963-2003), and the Humanities and Social Science Index (1983-2003).

Inclusion Criteria

The studies that have been included in this review were assessed using four criteria appraising internal validity[3]: design, characteristic, measure, and intervention (Windsor, Baranowski, Clark, & Cutter, 1994). The first criterion, design, specifies that the study must be a random controlled trial (i.e. assignment to control and treatment groups through random methods) or quasi-experimental design (i.e. assignment to control and treatment group by other methods: non-random). The addition of a control or comparison group decreases threats to internal validity because the pre-test and post-test scores of the treatment group can be compared to that of the control or comparison group who did not receive the treatment or intervention[4]. Therefore, the review excluded one group pre-test post-test evaluations since they did not include a control or comparison group.

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[3] Internal validity is the extent to which the observed effect or dependent variable can be attributed to the intervention or independent variable and not due to some other variable (Windsor et al. 1994; Babbie, 1991)

[4] For more information on factors related to internal validity see Windsor et al. (1994, p. 149-150).

The second criterion stipulates that the study must evaluate an education intervention or psycho-educational intervention held in a group setting as opposed to an intervention held in a home, or otherwise individual setting. Interventions that were implemented online, by teleconference, or video in an individual setting were excluded. The third criterion requires that the study measure an emotional response of the caregiver such as caregiver distress, burden, or ability to cope. It excluded studies measuring delayed nursing home placement or mortality rates.

The fourth criterion, intervention, stipulates that the review only include interventions that were education focused, that is, the program consisted of a structured set curriculum, lecture or presentation, and was not purely a discussion or support group on a particular topic. The intervention may have a discussion or support component but this may not be the main focus of the program. Thus, psycho-educational programs were included if the support aspect was secondary to the educational component (Sorensen, Pinquart, Habil, & Duberstein, 2002). The intervention could also include education programs that were strictly skills based, such as providing training in physical care, communication, or relaxation through exercise.

Results

Sample Description

The systematic review yielded 65 articles that met the word search criteria. Of these, 37 articles were excluded as they did not meet the inclusion criteria: nine articles did not include a control or comparison group, eight did not evaluate the program, six did not conduct the program in a group format but in the home, eight were not education interventions, and six did not measure the emotional distress of the caregiver. After exclusions, 28 articles were reviewed: eight based on mixed caregiver groups and 20 based on homogeneous groups.

Overall the sample sizes[5] used in the studies ranged from nine to 103 with an average of 30 and median of 22. For evaluations based on heterogeneous groups, the sample sizes ranged from 19-81, with an average of about 41, and a median of 23.5; for homogeneous groups the samples ranged from nine to 103, with a mean of approximately 26 and a median of 18. The number of sessions or length of the program ranged from four to 18 sessions for mixed caregiver interventions (average of 8.75 sessions) and from three to 17 sessions for homogenous groups (average of 8.3 sessions).

In terms of design, 50% (n=4) of mixed caregiver programs were randomly controlled trials and 50% were quasi-experimental designs. Whereas, 65% (n=13) of homogenous caregiver interventions consisted of random controlled trials, the remaining 35% (n=6) were quasi-experimental designs. Overall, combining both types of groups, 61% were randomly controlled designs and 39% were quasi-experimental. Appendices B and C present the sample characteristics, duration of intervention, components, and findings.

With an average sample size of 30 and median 22, the studies conducted on education interventions were based on small sample sizes and relatively short duration, with an average length of eight sessions. Although more than half employed randomly controlled trials, the review suggests that evaluations of education interventions were not well developed.

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[5] For studies in which the control and treatment group did not contain the same number, the lowest number was utilized in calculating the average sample size.

Statistical Power, Sample Size, and Effect Size

According to Cohen (1988) there are four important parameters of inferential statistics: statistical power, significance criterion, sample size, and effect size. These four parameters are related to each other and any one parameter is a function of the other three. Statistical power refers to the "probability of rejecting the null hypothesis when it is false", in other words, making the correct decision to reject the null hypothesis and thus conclude there is an effect (Loether & McTavish, 1993, p. 493). Statistical power is the complement to type II error. Whereas statistical power is the probability of rejecting the null hypothesis when it is false, type II error is failing to reject the null hypothesis when it is false.

Type I error refers to the rejection of the null hypothesis when it is in fact true, thus, concluding there is an effect to the intervention when there is not. The significance criterion is in fact the probability of committing type I error. Neither the probability of committing type II error nor the power of a test can be computed for a particular test of a null hypothesis, but various values for the parameters can be assumed to guard against type I and type II error. Cohen (1992) suggests setting the statistical power of a test to at least 80% with an alpha set at .05 to guard against type I and type II error.

Sample size is directly related to and a function of the standard error of the statistic. Further explained by Cohen (1988), the larger the sample size, other parameters equal, the smaller the standard error and the greater the reliability of the results. Since this review has set the statistical power to 80% and the alpha set at .05 as suggested by Cohen (1988), the focus is the relationship between sample size and effect size. The effect size, or magnitude of the effect of the intervention, is calculated by comparing the difference in means between the control and treatment groups. The larger the effect size present, with other parameters equal, the greater the power of the test. Because the four parameters are a function of each other, it follows that the larger the effect size, the smaller the sample size necessary to detect statistically significant results and to reach statistical power (Cohen, 1988, p. 11). Previously, it was discussed that the sample size in the reviewed studies were relatively small. By the same logic, programs with a small sample size may have reached statistical power had their sample size been larger. As can be seen in Appendices B and C, there are several studies that do not report statistically significant findings. Because the sample sizes used were small, these studies are at risk for rejecting a true finding or type II error. It is suggested that further evaluations guard against type II error by employing larger sample size in their evaluations.

Methodological Rigor

After identifying articles for the systematic review, the studies were rated on design, selection of participants to groups, the length of the program, and on the reliability of measures. The methodological criteria are shown in Table 2. The scoring system was adapted by the system used by Brodaty, Green, & Koschera (2003) in their meta-analysis of psychosocial interventions for caregivers. This method for scoring was utilized to identify the methodologically strong studies as the findings and characteristics of stronger programs would be given more merit than studies based on weak research design.

Table 2:
Criteria for Rating Methodological Quality of Evaluation

Criterion	Score
1. Design	
Randomized Controlled Trial[6]	1
Quasi-experimental[7]	0
2. Selection into Groups	
Randomized	2
Matched control group	1
Non-random	0
3. Characteristics of Program/ Number of sessions	
More than 10 sessions	4
9-10 sessions	3
6-8 sessions	2
3-5sessions	1
1-2 sessions	0
4. Outcome Measures	
Well-validated / reliable	1
Questionable or unreliable	0

The applied scoring system conforms to the criteria for the systematic review. In terms of design, higher ratings were given to random controlled trials rather than quasi-experimental trials. Consequently, studies that used random methods to assign participants into control and treatment groups received a higher score than those that used other methods of selection.

The third criterion rated the studies on intensity and duration. According to Glass et al. (1981) there are substantive characteristics and methodological characteristics of a study to be considered in a meta-analysis. A substantive characteristic is a feature of the study that is specific to the problem studied. For instance, a substantive feature to a caregiver education program could be the number of sessions or class size. On the other

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[6] Random Controlled Trial assumes random assignment into control and treatment groups

[7] Quasi-experimental design assumes non-random assignment into control and treatment groups

hand, a methodological characteristic is based on research methods e.g. sample size, randomization, or reliability. Although the duration and intensity of the study are substantive qualities, they are considered methodological characteristics for this review as both duration and intensity affect the validity of the study. A program that encompasses low intensity or a small number of sessions is more likely to have threats to internal validity as opposed to a longer and more intense program. To illustrate, it would not be reasonable to assume that a participant's well-being (outcome variable) improved from attending two classes (intervention) over 6 months: in this scenario it is easier to attribute the results to some other extraneous variable. Thus, the third methodological criterion assigned higher scores to the studies with greater intensity and duration. The fourth criterion relates to the instrument used to measure the outcome variables. Studies that used well-validated or reliable instruments; as opposed to instruments that have not been well-tested, received a higher score.

Table 3 presents the results of the methodological ratings for mixed caregiver groups, and Table 4 presents the results for homogeneous caregiver groups. As shown in these tables, the scores ranged from two to eight, out of a possible eight. Only four of the studies met all criteria for methodological rigor: the studies were randomly controlled designs, the sessions were of long duration (more than 10 weeks) and the instruments used were well validated and reliable. One of the programs was mixed (Toseland et al. 2001), the remaining three were for homogeneous caregiver groups (Hebert et al, 1992; Mittelmen et al. 1995; Marriott et al. 2000). The four studies were relatively recent, which suggests the development over time of stronger designs for caregiver education interventions.

Table 3:
Methodological Ratings of Mixed Caregiver Intervention

Investigators (year)	Design (0-1)	Selection into Groups (0-2)	Program Characteristics (0-4)	Measurement (0-1)	Rating Score (0-8)
1. Barusch & Spaid (1991).	1	2	2	1	6
2. Greene & Mohanan (1989)	0	0	2	1	3
3. Montgomery & Borgatta (1985)	1	2	2	1	6
4.Kaasalainen et al. (2000).	0	1	2	1	4
5. Lovett & Gallagher (1988)	1	2	3	1	7
6. Schwiebert & Myers (1994).	0	0	1	1	2
7. Steffen et al (1998)	0	0	3	1	4
8. Toseland et al. (2001).	1	2	4	1	8

Table 4:
Methodological Ratings of Homogeneous Caregiver Intervention

Investigators (year)	Design (0-1)	Selection into Groups (0-2)	Program Characteristics (0-4)	Measurement (0-1)	Rating Score (0-8)
1. Brodaty & Gresham (1989).	0	0	4	1	5
2. Brodaty et al. (1994).	0	0	2	1	3
3. Chiverton & Caine(1989).	0	0	1	1	2
4. Gallagher-Thompson et al. (2001)	0	0	2	0	2
5. Gendron et al., (1996)	1	2	2	1	6
6. Haley, Brown & Levine (1987); Haley (1989)	1	2	3	1	7
7. Hebert et al. (1993)	1	2	3	1	7
8. Hebert et al. (2003).	1	2	4	1	8
9. Hepburn et al. (2001)	1	2	2	1	6
10.Kahan et al (1985)	0	0	2	1	3
11.Marriott et al. (2000)	1	2	4	1	8
12.Mittelman et al., (1995)	1	2	4	1	8
13.Ostwald et al., (1999)	1	2	2	1	6
14.Ripich et al. (1998)	0	0	1	1	2
15. Robinson (1988)	1	2	1	1	5
16. Robinson & Yates [8] (1994).	1	2	2	1	6
17. Steffen (2000)	1	2	2	0	5
18. Teri et al., (1997).	1	2	3	1	7
19. Van Den Heuvel et al. (2000).	1	2	3	0	6
20. Zanetti et al. (1998).	0	1	2	1	4

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[8] Based on first run of the program, after completion of the 6 sessions, participants volunteered for alternative treatment group (n=6)

In terms of developing the current education program, it was crucial to determine if the effects of the program differ depending on certain characteristics of the studies. However, the first step in the process, was to determine which studies were based on solid research methods before putting an emphasis on the program components. The scoring system identified four studies that conformed to relatively strong research methods. As is discussed in the following section, these four studies also reported statistically significant results (Toseland et al. 2001; Hebert et al, 1992; Mittelmen et al. 1995; Marriott et al. 2000); however, only two of the studies reached 80% statistical power (Toseland et al. 2001; Marriott et al. 2000).

Statistically Significant Findings

Overall, 19 of the 28 reviewed studies reported statistically significant results. As portrayed in Table 5, five of the eight mixed caregiver groups (62.5%) reported positive benefits, specifically improvements to depression (n=3), coping (n=1), burden (n=1), morale (n=1), and anxiety (n=1). Of the homogeneous groups, 14 of the 20 studies (70%) reported a positive outcome: depression (n=7), burden (n=5), reaction to care-recipient's behaviour (n=2), self-efficacy (n=2), anger (n=1), coping (n=1), and stress (n=1).

Table 5: Summary of Statistically Significant Findings

Dependent Variable	Mixed Caregiver Groups	Homogeneous Caregiver Groups
Anger/Hostility		Anger management skill training (Steffen, 2000)
Anxiety	Support and education project (Greene & Mohanan, 1989)	
Burden	Caregiver Support Project (Barusch & Spaid, 1991)	Stress & Coping (Hepburn et al. 2001) Kahan, et al (1985) Confidence-building (Ostwald, et al., 1999). Behavioural Management & Social Skills Training (Robinson & Yates 1994). Zanetti, et al. (1998).
Coping	Psychoeducation for adult children Schwiebert & Myers (1994).	Education based on Lazarus and Folkman Coping Model (Chiverton & Caine, 1989)
Depression	Support and Education Project (Greene & Mohanan, 1989) Problem solving skills & Pleasant events skills (Lovett & Gallagher, 1988) Health Education (Toseland et al. 2001).	Gallagher-Thompson, Arean, Rivera & Thompson (2001) Hepburn et al. (2001) Kahan, et al (1985) Stress Management/coping skills (Marriott et al. 2000) Mittelman et al., (1995). Anger Management skill training (Steffen, 2000) Pleasant events /Problem solving training (Teri et al. 1997).
Morale	Problem solving skills and Increasing Pleasant events skills (Lovett & Gallagher, 1988)	
Reaction to Care-recipient's Behaviour		Stress & Coping (Herbert, et al. 2003; Hepburn et al. 2001)
Self-efficacy		Managing Disruptive Behaviour (Steffen, 2000) Van Den Heuvel et al. (2000)
Stress		Training in coping (Brodaty & Gresham, (1989).

Effect Size

For each study that produced statistically significant results[9], the effect size was calculated based on the difference in means between the treatment and control groups or between treatment groups if no control group was utilized. Once the difference between means was calculated, a power table showing equivalent effect size was consulted (Cohen, 1988). The calculated effect size was categorized into small, medium or large. An effect size was considered large (0.8) if the difference between group means was around 37%, medium (.5) if about 24% and small (0.2) if about 10% difference (Cohen, 1992). For studies that reported statistically significant results for multiple variables, the effect size was calculated for each variable.

Because the results were skewed toward higher scores, the median and mode were chosen to describe central tendency. As shown on Table 6, there were 11 outcome variables that were calculated to have large effects, one to have medium to large effect size, five medium, and eight having small effect size. The median for homogeneous groups was .7; the median for mixed caregiver groups was .55. The overall median for both groups was .55, the mode was for large effects.

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[9] The study by Hepburn at al. (2001) was excluded as the pre-test and post-test were not reported.

Table 6: Effect Size Emotional Distress for Caregivers

Study	Group Type	Outcome Variable	Mean Difference[10]	Actual Effect size	Effect Size
Schwiebert & Myers (1994).	Mixed	Coping	2.5%	0.1	Minimal
Barusch & Spaid, (1991).	Mixed	Objective Burden	7%	0.15	Small
Steffen (2000)	Mixed	Self-efficacy	7.54%	0.15	Small
Chiverton & Caine (1989).	Homogeneous	Emotional Competence	8.3%	0.17	Small
Ostwald, et al., (1999).	Homogeneous	Burden	9.4%	0.19	Small
Hebert, et al. (2003).	Homogeneous	Reaction to Behaviour Problems	11%	0.21	Small
Chiverton & Caine (1989).	Homogeneous	Therapeutic Competence	13%	0.25	Small
Kahan, et al (1985)	Homogeneous	Burden Depression	19% 21%	0.4 0.4	Small Small
Mittelman et al., (1995).	Homogeneous	Depression	r=.23	0.23	Small-Medium
*Lovett & Gallagher, (1988)	Mixed	Morale T2 vs. C T1 vs. C	 24.6% 26.6%	 0.5 0.55	 Medium Medium
Barusch & Spaid, (1991).	Mixed	Coping	26 %	0.55	Medium
Steffen (2000)	Homogeneous	Anger	29.9%	0.6	Medium
Van Den Heuvel et al. (2000).	Homogeneous	Self-efficacy in patient care	r=.29	0.29	Medium
*Greene & Mohanan. (1989)	Mixed	Depression	r=.4	0.4	Medium -Large
*Greene & Mohanan. (1989)	Mixed	Anxiety	r=.6	0.6	Large
Robinson & Yates (1994).	Homogeneous	Objective Burden	33%	0.7	Large

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[10] For three of the studies, the effect size was calculated based on Pearson's Product Moment (Cohen, p. 14, 1988)

Study	Group Type	Outcome Variable	Mean Difference[10]	Actual Effect size	Effect Size
*Gallagher-Thompson, et al. (2001)	Homogeneous	Depression	35%	0.72	Large
Zanetti, et al. (1998).	Homogeneous	Burden	38%	0.85	Large
*Lovett & Gallagher, (1988)	Mixed	Depression			
		T1 vs. C	39.5%	0.88	Large
		T2 vs. C	41.5%	0.9	Large
* Marriott et al. (2000)	Homogeneous	Depression			
		T vsC1	40%	0.9	Large
		T vs. C2	57%	1.4	Large
*Teri et al., (1997).	Homogeneous	Depression			Large
		T1	61%	1.55	
		T2	121%	>2	
*Brodaty & Gresham, (1989).	Homogeneous	Stress	125%	>2	Large
*Toseland et al. (2001).	Mixed	Depression	294%	>2	Large
Median Mixed (n=9)	---	---	---	0.55	Medium
Median Homogeneous (n=15)	---	---	---	0.7	Medium/ Large
Overall Median (n= 24)	---	---	---	0.55	Medium

* Met 80% statistical power with alpha set 0.5.

Statistical Power

Even though the results of the above studies have reported statistically significant findings, a systematic review must also determine statistical power to examine threats to internal validity of the studies, specifically type I and type II error. As previously discussed, type I error refers to the probability of rejecting a null hypothesis when it is true (Cohen, 1992). It relates to the risk of accepting that there is an effect from the intervention, when in fact, there is not i.e. concluding the program has affected caregiver depression when it actually occurred due to sampling error. Type II error, on the other hand, relates to accepting a null hypothesis when it is not true. Thus, type II error occurs when an effective education program is concluded as ineffective. To guard against type II error, the review compared the calculated effect size to the sample size for each program based on Lipsey's Power Chart (Lipsey, 1990) to determine if the program reached 80% statistical power.

According to Cohen (1992), in order to reach 80% statistical power, a sample size of at least 393 would be required in both treatment and control groups to detect a small effect size with an alpha set at .05. Furthermore, a sample of at least 64 is needed to detect a medium effect size, and a sample of at least 26 to detect large effect size or differences between the control and treatment groups.

Of the 28 reviewed studies, seven met statistical power of 80% with an alpha set at .05. Three of the studies that met 80% statistical power were of mixed caregiver groups (Greene & Mohanan, 1987; Lovett & Gallagher, 1988; Toseland et al. 2001). The remaining four were of homogeneous groups (Brodaty & Gresham, 1989; Gallagher-Thompson et al., 2001; Marriott et al. 2000; Teri et al. 1992).

The remaining 11[11] studies that reported statistically significant results but did not meet 80% statistical power are at risk of type I error. Thus, these 11 programs have reported that the program is effective when in fact the results could be due to sampling error and not as a result of the program. It is concluded that few of the studies reached statistical power of 80% based on Cohen's (1992) criteria. As well, there were only four programs identified as having all components of methodological rigor.

Discussion of Studies Meeting Statistical Power Criteria

Mixed Caregiver Groups

Of the educational programs targeted to mixed groups of caregivers, only three studies (Greene & Mohanan, 1989; Lovett & Gallagher, 1988; Toseland et al. 2001) have statistically significant results that reached 80% statistical power with an alpha set at 0.5. Greene and Mohanan (1989) report significant decreases in anxiety and burden immediately post intervention. The effects did not carry over to 6 months post-intervention. The authors attribute the short-term effects to a possible regression to the mean as the treatment group's scores were generally high at baseline. Greene and Mohanan's (1987) educational intervention for caregivers had three components to each workshop:

1) Constructively dealing with negative feelings. The sessions were professionally guided to deal with the negative feelings from caregiving, emotional isolation, and also provided an opportunity for caregivers to ventilate feelings and experience social connections.
2) Education on disease, resources, communication, and ageing.
3) Relaxation training through visualization and muscular relaxation.

The relevant components of the study were it encompassed a strong support element, education, and skills training in stress management. Due to the threats to internal validity, the results of the program should be taken cautiously. A study possesses internal validity if the results reflect the influence of the independent variable rather than some extraneous or uncontrolled variable (Babbie, 1991). Unfortunately, this study has

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[11] The study by Hepburn at al. (2001) was excluded as the pre-test and post-test were not reported.

major threats to internal validity due to the selection of participants into control and treatment groups which resulted in regression to the mean. Since caregivers self-selected into control and treatment groups, it is possible that the more stressed caregivers chose the treatment groups because they were in more urgent need for assistance; whereas, the participants who were managing well may have chosen the control group. As it turned out, the statistically significant findings were reliant on the participants with initially high scores. Thus the results suffer from validity threats due to selection and regression to the mean, as the statistically significant findings were reliant on the participants with initially high scores.

On the other hand, Toseland et al (2001) employed a randomly controlled trial: participants were randomly distributed to treatment and control groups. The researchers report statistically significant improvements in depression for the Health Education intervention group. This study also met all the ratings of methodological rigor, which makes the components of this program particularly relevant to the development of the current intervention. The intervention was more than 10 sessions, and similar to Greene and Mohanan (1987) embodied a strong social support focus. The characteristics of the education program included content on the emotional aspects of being a caregiver, resources, relaxation techniques, cognitive restructuring, self-care, and time for individualized problem-solving with the group. Common to Greene and Mohanan (1987) was the support component to each session, which provided peer models to demonstrate effective ways of coping. Specific to this program were the individualized problem-solving and cognitive restructuring techniques i.e. finding ways to solve a problem constructively and ways to think positively.

The random controlled trial conducted by Lovett and Gallagher (1988) scored seven out of a possible eight in methodological criteria. There were two treatment groups: one group received training in increasing life satisfaction; whereas, the second treatment group received training in problem solving skills. Both treatment groups resulted in statistically significant improvements to morale and depression; however, only the results to depression reached 80% statistical power. This study is further discussed for its measure of self-efficacy in the chapter, *Theoretical Rationale*.

Homogeneous Caregiver Groups

Of the 20 education programs targeted to homogeneous caregiver participants, four of the studies met 80% statistical power and reported improvements to caregiver distress (Brodaty & Gresham, 1989; Gallagher-Thompson, Arean, Rivera & Thompson 2001; Marriott et al. 2000; Teri et al., 1997). Brodaty and Gresham (1989) conducted their sessions in a small group format (four participants), and focused on self-help, social connections within the group, skills training in assertiveness and managing problem behaviours. The program also included a family therapy session and focus on role change. In addition to the education program, the care-recipients received activity programming and a reassessment of psychiatric and physical health.

Additionally, after the 10 sessions, telephone conference calls were conducted throughout the following year that encouraged group members to be self-supportive. Only at 12 months follow-up, the intervention showed statistically significant lower levels of stress for the education group (25% decrease) compared to the respite only treatment group (105% increase). The waitlist control group experienced no change even after taking the intervention. In the respite only treatment group, the care-recipients received memory training. The authors suggest that the care-recipients were already approaching such cognitive disability, that retraining had no effect. They further contend that the caregivers who received respite were frustrated at the lack of improvement in the care-recipient, which led to increases in stress scores. Again, the results should be interpreted with caution as the respite only treatment group had a huge increase in stress and the results could be due to sampling error or to the characteristics of the group.

The researchers, Gallagher-Thompson, Arean, Rivera & Thompson (2001) targeted the education program, *Coping with Frustration,* an 8 session program, to the Hispanic/Latino population. The program consisted of cognitive behavioural strategies to manage anger and frustration from caregiving, relaxation training, challenging dysfunctional thoughts through the use of positive statements, and assertiveness training. The program established a large effect size on depression for its participants. The treatment group experienced a 29% decrease in depression and the control group experienced an average increase of 6.67%. Common components to the other programs were relaxation training and cognitive restructuring training. However, the authors were rated two out of eight on methodological criteria because the participants were not randomly selected to groups and the instruments used were not well validated.

On the other hand, Marriott, Donaldson, Tarrier and Burns (2000) were one of the two programs that met all methodological criteria and reached the established statistical power. They reported on the impact of a 14 session intervention on depression as measured by the Beck Depression Inventory (Beck et al, 1961). The results indicated statistically significant improvements in caregiver depression at post-test and follow up (three month post-test). The intervention consisted of three main components: 1) Three sessions on caregiver education and knowledge of dementia; 2) Six sessions on stress management including relaxation training and caregiver appraisal of stress-response; and 3) Five sessions on coping skills training. Stress management, coping skills training, and the longer duration of the intervention were similar components to previously reviewed programs. These program characteristics are meaningful to this review as this study met both methodological and statistical power criteria.

Teri, Logsdon, Uomoto, and McCurry (1997) report a statistically significant improvement in depression (HRDS) at post-test in a randomly controlled trial of a nine session program. This program scored seven out of eight on methodological criteria. There were two treatment groups to the program. Treatment 1 focused on skills training in Pleasant Events: it included skills in monitoring stress, education on the depressive cycle, the connection between pleasant events and depression, and how to identify, plan and increase pleasant events. The second treatment group focused on problem solving skills. This intervention group centred on specific problems encountered by the caregiver: each caregiver had a turn in-class to share and problem-solve with the assistance of the facilitator and their peers. Both treatment groups were calculated to have a large effect size on caregiver depression in comparison to the control group. See Table 7 for a list of the studies and the significant components.

Table 7: Studies Meeting Statistical Power, Calculated Effect Size and Intervention Components

Study[12]	**Effect Size**	**Outcome Variable**	**Components of program**
Greene & Mohanan. (1989)	Medium	Anxiety	Professionally guided to deal with emotional aspects of care caregiving/ social support
	Large	Depression	Education on disease, resources, communication, ageing Relaxation Training: visualization, muscular relaxation 8 sessions
* Lovett & Gallagher (1988)	Large	Depression	Increasing life satisfaction Problem solving skills training 10 sessions
*Toseland et al. (2001).	Large	Depression	Coping strategies, using resources, emotional reaction to caregiving, problem solving Support component throughout sessions focused on reinforcing and practicing skills previous learned. 18 sessions
Brodaty & Gresham, (1989).	Large	Stress	Small group format (n=4) Social support Skills training in assertiveness, behaviour management Use of activities to manage behaviour Family therapy session Role change. Additional to education was care-recipients received activity programming and assessment 10 sessions plus regular telephone follow up for 1 year
Gallagher-Thompson, et al. (2001)	Large	Depression	Cognitive behavioural strategies to manage anger and frustration Relaxation Training Challenging dysfunctional thoughts Assertiveness training 8 sessions

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[12] These studies met statistical power of 80 % with alpha set 0.5.

Study[12]	**Effect Size**	**Outcome Variable**	**Components of program**
*Marriott et al. (2000)	Large	Depression	Caregiver education (3 sessions) Stress management (6 sessions) Coping skills training (5 session) 14 sessions
*Teri et al., (1997).	Large	Depression	*Treatment 1:* Behaviour-Therapy Pleasant events: monitoring stress, depressive cycle, connection between pleasant events and depression, identifying, planning and increasing pleasant events *Treatment 2* : Behaviour Therapy-Problem Solving: specific to caregiver needs 9 sessions

A common element to all the programs that met sufficient statistical power, were that they all had sessions relating to the emotional aspects of caring and coping. Common to some of the programs were the use of relaxation training (Gallagher-Thompson, et al. 2001; Greene & Mohanan, 1989; Marriott et al. 2000) and a strong support aspect (Green & Mohanan, 1989; Toseland et al., 2001; Brodaty & Gresham, 1989). Unique aspects were the use of activities to manage behaviour (Brodaty & Gresham, 1989), increasing pleasant events (Teri et al 1997), the addition of non-educational components to the intervention such as regular telephone follow-up (Brodaty & Gresham, 1989), and follow-up sessions that reinforced and practiced previously learned skills (Toseland et al. 2001).

The current education intervention included a strong support aspect and relaxation training as these were common elements to the studies that met 80% statistical power. Although the length of the program was identified as a strong element to the studies meeting statistical power, the length of the current education intervention was stipulated by the funding organization to consist of only 10 sessions, not more.

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* These studies scored high (7-8) on methodological criteria

Type I and Type II Error

Studies that reported statistically significant results but did not meet 80% statistical power are at risk to type I error, that is accepting a program that may have produced the results due to sampling error rather than as a result of receiving the intervention. On the other hand, programs that produced non-statistically significant results and did not have sufficient sample size to reach 80% statistical power, are at risk of type II error.

One of the reasons that may have contributed to a lack of difference in means between the intervention and control groups is that some of the studies had too small of sample size to achieve sufficient statistical power. In fact, none of the programs reviewed employed large enough samples sizes to detect a small effect size, with 80% power (Cohen, 1992). Programs that produced non-statistically significant results and did not have sufficient sample size to reach 80% statistical power, are at risk of type II error. A practitioner does not want to disregard an effective treatment. In applied research, it is better to have an increased risk of a type I than a type II error. Three of the mixed caregiver groups reported non-statistically significant findings and did not employ sufficient sample size to detect small effects, only a few could detect medium effects. These studies are at risk of rejecting a program that may in fact have a positive effect on its recipients.

Summary

In conclusion, the systematic review indicated that the associations attained for caregiver education interventions were medium to large effects (Cohen, 1992). The median was medium effect size; the mode was large effect size. The median effect size for education programs for caregivers of family members with dementia was .7. The median effect size for both groups combined and for mixed groups was .55. However, all of the programs lacked sufficient sample size to detect small effects as they employed sample sizes less than 393. The results of the systematic review suggest that the proposed intervention would need to incorporate components of the most successful programs and that it is reasonable to propose a medium to large effect size for the current intervention. It is suggested that interventions should be of greater intensity and duration than 10 weeks to provide ongoing support and to test the efficacy of interventions.

If the statistical power is less than 80%, the effects of the intervention risk type II error. Many of the educational intervention studies are based on small sample sizes and therefore, the results can not be applied to other groups of caregivers. It is also suggested that educational interventions utilize larger sample sizes in order to reach 80% statistical power and reduce threats to internal validity.

According to the systematic review, there are certain elements that are more common amongst a mixed or heterogeneous group of caregivers compared to providing an education series geared toward a homogeneous group such as caregivers of people with dementia. A mixed or heterogeneous group of caregivers will have a diverse range of information needs in regards to the disease or debilitating conditions from which their care-recipients are suffering from, practical techniques to care, and those pertaining to behaviour management. In order to address the needs of a mixed group of caregivers, the curriculum must be less disease specific and more focused on providing resources and community supports for the caregivers to utilize independently and in complement to the education series. If the caregivers were all caring for someone with Parkinson's Disease, for example, the curriculum and content could focus specifically on the behaviours related to the disease process of Parkinson's Disease.

Critical to the development of this program, was to include aspects of the reviewed programs that met statistical significance and 80% statistical power. The curriculum for the current educational program focused upon increasing pleasant events (Teri et al. 1997), developing social support (Green & Mohanan, 1989; Toseland et al., 2001; Brodaty & Gresham, 1989; Mittelman et al. 1995), providing relaxation training throughout the sessions (Gallagher-Thompson, et al. 2001;Greene & Mohanan, 1989; Marriott et al. 2000) using activities to manage problem behaviour (Brodaty & Gresham, 1989), and reinforcing and practicing previously learned skills (Toseland et al. 2001). As will be discussed further in the next section self-efficacy training was a key component to the curriculum. It was chosen to guide the development of the curriculum and the teaching method as it is relevant to behaviour change. Besides developing the curriculum through self-efficacy training, as will be discussed in the next section, this education intervention also carried the relevant aspects of other programs that have reported successful outcomes on emotional distress

Additionally, in an attempt to offer an education series that serves a wide range of needs, it was decided by the steering committee to include a session on behaviour management techniques and optional topics specific to caring for someone with dementia. The caregivers' needs and goals were to be reviewed in the first session and therefore dementia specific topics could be included later in the series if needed.

Theoretical Rationale for Caregiver Education Program

Self-efficacy Concept

Some researchers propose that it is the subjective interpretation of the situation that is the “primary factor responsible for mediating the degree of stress experienced” by caregivers (Deimling & Bass, 1986 cited in Mowat & Laschinger, 1993, p. 1106). Furthermore, George and Gwynther (1986) have proposed that the well-being of the caregiver may be attributed to the particular characteristics of the caregiver and caregiving situation rather than to the condition of the care-recipient. It has also been suggested that caregivers who cope well may possess a high level of self-efficacy (Mowat & Laschinger, 1993).

The concept of self-efficacy was originally developed by Bandura (1977) through Social Learning Theory. According to Bandura (1977), self-efficacy is the individual’s perception of confidence in his/her ability to complete a specific task or behaviour successfully. According to the theory, behaviour is determined through constant interactions between cognitive, behavioural, and environmental factors. The feedback provided to individuals from situational factors influences their cognitive assessment of the consequence of their behaviour and their decision regarding whether to perform that behaviour again in the future. Regardless of the amount of knowledge people have, motivation and ultimately behaviour, are determined by the way they judge their capabilities (Bandura, 1982).

According to the concept of self-efficacy, there are two types of expectations: outcome expectations and efficacy expectations (Bandura, 1977). Outcome expectation is the belief that a given behaviour will lead to a certain given outcome. Efficacy expectation is the belief that one can successfully perform that behaviour to achieve the expected outcome. Moore (1990) further explains that self-efficacy theory proposes that a person will act if he or she sees a connection between the behaviour and the result, and the person is confident in his or her ability to perform that behaviour. Furthermore, the person will not perform a behaviour if he or she lacks this confidence (Mowat and Laschinger, 1993; Schmall, 1995). Thus, the key to behaviour change is achieving confidence and building upon the confidence in performing the behaviour. In order to build upon self-efficacy, the intervention should focus upon both expectations.

The facilitation and instruction for the first expectation, outcome expectation, must not focus solely on skill building, but also on empowering the caregiver with knowledge in order to believe that a certain behaviour will lead to a certain outcome. Thus, for example, a session on changing negative thinking, should include education on the theory behind reorienting negative thoughts as well as the tools to achieve this skill.

Bandura (1982) identified four sources and thus four ways to increase self-efficacy expectation. The first source of self-efficacy is performance accomplishments. These are based upon the person's own experience. Performance accomplishments or "skills mastery" is developed by actually learning and practicing the appropriate behaviour. It is perceived as the greatest influence on a person's perception of self-efficacy. Repeated failures can reinforce feelings of powerlessness (Schmall, 1994, cited in Schmall, 1995) and have a great effect on lowering perceptions of self-efficacy, particularly if they do not reflect a lack of effort (Redman, 1985). Thus, the goals set should be realistic and achievable. In self-efficacy training, people should be encouraged to try more difficult tasks, after successfully performing simple tasks (Moore, 1990).

Bandura (1982) further asserts that the goals should be practiced in a "non-threatening and psychologically safe environment". Often when joining a support group a set of rules regarding respect for others is openly discussed and facilitated. A similar set of rules was utilized for this education series and thus promoted a "safe" environment.

According to Schmall (1995), skill-building will be enhanced when a caregiver has the opportunity to practice a skill in an educational setting, receive feedback, apply the skill in the real world, and then return to the group to discuss how well the technique worked. Some of the education interventions found in the literature review practiced skill building in this way (Gallagher & Hagen, 1996;Gallagher-Thompson & Devries, 1994; Gallagher-Thompson et al. , 2001; Hepburn, 2001; Lovett & Gallagher, Robinson, 1988; Robinson & Yates, 1994; Steffen 2000, Teri et al., 1997). This skill building method was developed into the teaching of the curriculum for this project. The skills for relaxation training, visualization, stress tracking, pleasant events training were taught then reviewed in following sessions. Participants were asked to practice the skill at home, return to class with a tracking sheet (if applicable) and asked to share their experience and problem solve with the other participants. The format provided the opportunity for participants to practice the skill in class, practice the skills at home, and to return to class and receive feedback.

The second source of self-efficacy expectation is verbal persuasion. Verbal persuasion refers to how the individual's belief in his or her capabilities to cope or act in certain situations can be influenced by the verbal persuasion of others: individuals are persuaded an action will work and that they can perform that action. The group participants as well as the facilitator can be a source of verbal persuasion. Verbal persuasion is most successful if the person modelling the behaviour resembles the characteristics of the observers (Bandura, 1982; Merritt, 1989). Thus, it is important to have a facilitator who has experience as a family caregiver and to incorporate his or her personal experience in the education sessions. Verbal persuasion can also be encouraged in an education program amongst participants who are supportive of each other. Verbal persuasion in accepting respite, or home support services, could enhance the self-efficacy of program participants in accessing and accepting services.

The third source, vicarious experience, (i.e. observing other people successfully mastering the behaviour) may be facilitated naturally through belonging to a group and trading techniques between participants. The current program practiced skills as a group, providing the opportunity for participants to see models and co-participants master the skills in practical techniques to care, such as transfers, approaching someone with dementia to brush their teeth, or practice a relaxation exercise such as visualization or progressive muscular relaxation. Time was allotted amongst participants to share their experience in managing behaviours, in identifying stress and ways to cope which would also encourage this third source of self-efficacy.

The fourth source is emotional arousal. People tend to perform more poorly when in a highly anxious state (Mowat & Laschinger, 1993). Thus, it can be proposed that some caregivers may not be performing very well due to their emotional state. The authors suggest the use of reassurance and social support to help decrease anxiety and physiological arousal: individuals would be more relaxed and thus have more confidence in their abilities. The program emphasized relaxation training, and visualization as this was a component identified in other successful programs, but also this would assist to decrease anxiety gained from the week, and thus enable participants to respond, reflect, and concentrate on the sessions. These techniques were encouraged to be used on their own, and may have more long-term benefits to their emotional state. The four sources of self-efficacy expectations were included in the curriculum as well as in the training for the facilitator.

Efficacy perceptions vary in three dimensions: magnitude, strength and generality (Bandura, 1982). Magnitude refers to the complexity of the tasks that the person believes that he or she can accomplish. A person with a low magnitude can perform only the simplest tasks. In order to enhance magnitude, the educator must be able to assist the "student" by arranging tasks in order of increasing difficulty as tasks/goals must be built upon. If the tasks are too difficult, the person will be more likely to give up the task (Moore, 1990).

Strength, the second dimension of efficacy perception, determines the person's level of confidence. Moore (1990) perceives strength as a determinant to the extent of the coping effort, and thus, a strong efficacy expectation will encourage people to cope and have endurance in that behaviour. The third dimension is generality. This refers to whether the efficacy expectations will extend from one situation to the next. For example, will the efficacy expectation learned in the workshop be transferred to the home situation?

The goal for developing the education program is to enhance caregiver confidence or caregiver self-efficacy. Thus, to evaluate the program's goal, the evaluation must measure that goal. Confidence has been conceptualized as caregiver self-efficacy. Furthermore the concept of self-efficacy acts as the framework in the design and development of the curriculum: the curriculum's content was formatted to include the above methods in encouraging the four sources of self-efficacy.

Caregiver Self-efficacy, Depression, and Burden

Burden and depression are two measures of emotional distress that relate to the health and ability of the caregiver to continue to provide care, and are thus important outcome variables to an intervention that is designed to support the caregiver in continuing to provide care in the community. When caregivers become too depressed or burdened, they may be unable to continue to provide quality care to the care-recipient. As can be seen on appendices B and C, of the 28 studies, nine studies measure burden, five measure depression, and 11 measure both depression and burden. Thus depression and burden are common outcome variables used to determine the effectiveness of education interventions.

Research has identified relationships between self-efficacy and other psychological variables such as anger, depression and burden. Haley, Levine, Brown and Bartolucci (1987) were among the first to study the relationship between caregiver self-efficacy and other psychological variables. These researchers developed three self-efficacy scales; 1) self-efficacy of the caregiver's ability to manage specific activities of daily living; 2) self-efficacy of the caregiver's ability to manage Instrumental Activities of Daily Living (IADL); and 3) self-efficacy to manage behavioural problems. Haley et al's (1987) research revealed a negative relationship between self-efficacy and depression as measured by the Beck Depression Inventory. Specifically, a lack of confidence (i.e. self-efficacy) in managing behavioural problems, managing Instrumental Activities of

Daily Living (IADL's) and managing Activities of Daily Living (ADL's) of the care-recipient were significant predictors of depression in the caregiver.

Lovett and Gallagher (1988) examined the effectiveness of a psycho-educational program on depression and morale. Their research indicated a negative relationship between problem solving and pleasant events self-efficacy and depression.
Gastman (1994) performed a correlation analysis that indicated that self-efficacy, trait anger, and anger suppression were significantly correlated with subjective burden. Caregivers who reported higher trait anger and lower measures of self-efficacy experienced higher subjective burden. Trait anger and self-efficacy to control negative thoughts (r=-. 40, p<. 0001), self-efficacy to accomplish self-care activities (r=-. 37, p<. 0001), and self-efficacy to manage caregiver situations (r=-. 37, p<. 0001), contributed to predicting subjective burden as measured by the Screen for Caregiver Burden Scale. Caregiver self-efficacy for controlling distressing thoughts was the strongest contributor in the regression equation. Gastman (1994) used an earlier version of Steffen et al.'s (2002) scale of caregiver self-efficacy, which was utilized for the present project.
Chou (1997) reports a link between caregiver self-efficacy and depression as measured by the Beck Depression Inventory (BDI) (Beck et al. 1961). Research also reveals that filial obligation, self-efficacy, involvement in care, and coping predicts burden in Taiwanese caregivers. Zeiss, Gallagher-Thompson, Rose, and McKibbin (1999) measured the relationship between self-efficacy, depression, and burden in 217 caregivers, where 53% of the care-recipients had dementia. The researchers specifically examined self-efficacy for self-care: the behaviours that caregivers could participate in to reduce stress and enhance their well-being. They also examined self-efficacy for problem-solving. The regression coefficients indicated that higher self-efficacy for both self-care and problem

solving were related to lower scores of depression as measured by the Beck Depression Inventory and subjective burden, as measured by the Memory and Behaviours Problem Checklist. Steffen (2000) also provides evidence that caregiver self-efficacy is predictive of depression.

The literature provides evidence that caregiver self-efficacy is a predictor variable to both depression (Chou, 1997; Haley, Levine, Brown & Bartolucci, 1987; Lovett & Gallagher, 1988; Steffen, 2000; Zeiss et al., 1999) and burden (Chou, 1997;Gastman, 1994; Zeiss et al., 1999). Although the goal of the project was to enhance caregiver self-efficacy, a secondary goal was to treat depression and burden as outcome measures as they have been found to have a negative relationship to self-efficacy.

Self-efficacy and Educational Programs Targeted to Mixed Caregiver Groups

Of the eight evaluated programs for mixed caregiver groups, only one (Lovett & Gallagher, 1988) employed self-efficacy as an outcome measure. The intervention consisted of 10, two-hour sessions providing education sessions on the nature of Alzheimer's Disease and other diseases, common problems, community resources, and provided opportunities to discuss and resolve problems with other participants. The intervention also included the use of relaxation techniques and the use of cognitive techniques to manage stress.

Participants were randomly assigned to two treatment groups and one waitlist control group. Participants of group one were taught self-change skills to increase life satisfaction (i.e. pleasant events self-efficacy); whereas, group two participants were taught skills to problem solve (i.e. problem solve self-efficacy). Participants of group three were deemed the wait-list control. The results revealed a statistically significant decrease in depression (BDI) and increase in morale as measured by the Philadelphia Geriatric Center Morale Scale for the treatment groups while the caregivers in the waitlist experienced no change in these measures. Although the program was targeted to a mixed group-caregivers of frail older adults- 40% of the caregivers were caring for someone with a moderate to severe memory impairment due to Alzheimer's Disease, Parkinson's, stroke or other dementing illness.

Self-efficacy and Educational Programs Targeted to Homogeneous Groups

Of the 20 homogenous caregiver group programs, only two included caregiver-self-efficacy as an outcome measure of their evaluation (Steffen, 2000; Van Den Heuvel, 2001). Steffen (2000) measured the effects of an anger management series on anger intensity, depression (BDI short version from Beck & Beck 1972) and caregiver self-efficacy. The intervention consisted of instruction and homework assignments on awareness training, tension-reduction, cognitive restructuring, and assertion skills. It included an anger management video series with a workbook. There were 33 participants randomly assigned to three conditions: 1) home based viewing with a telephone check-in (n=12); 2) class-based viewing led by a facilitator (n=9); and 3) a waitlist control (n=12). Twenty-eight participants completed the study.

Post-treatment anger scores (caregiver anger interview) for home viewers and class viewers were significantly lower than the control group. Measures of depression for home viewers were significantly lower than the control group. However, there were no significant differences between the class viewers and control group.

Self-efficacy for Disruptive Behaviour (Steffen et al., 2002) was statistically significant for the class and home groups compared to the control group. Caregivers in both treatment conditions had lower post-treatment levels of anger and depression and higher ratings of caregiver self-efficacy. Due to the small sample size, the researcher was unable to perform multivariate analysis.

Van Den Heuvel, de Witte, Nooyen-Haazen, Sanderman, and de Jong (2000) report on an education intervention for caregivers of stroke care-recipients (Please refer to Appendix C). The education series is based on Lazarus and Folkman's (1986) stress coping model. The workshops focused on the feelings associated with caregiving, information about strokes, the caregiver and care-recipient relationship, lifting techniques, recognizing and handling stress, and how to organize support. The intervention consisted of eight to 10, two-hour sessions. Caregivers were randomly assigned into three groups: 1) group support (n=130), 2) home support (n=78), and 3) control group (n=49).

The research reported an increase in self-efficacy in knowledge about patient care (intervention vs. control) (p<= .001 for group and p<=. 05 for home intervention). There were non-significant differences reported for coping, physical well being, social support, satisfaction with social support, or assertiveness. A summary of the significant results was provided earlier on Table 5.

Summary

There were very few education interventions that looked at caregiver self-efficacy (Lovett & Gallagher, 1988; Steffen, 2000, Van Den Heuvel et al. 2000). None have specifically emphasized self-efficacy training in the content of their programs. The curriculum for the current educational program focused upon increasing pleasant events (Lovett & Gallagher, 1988, Teri et al. 1997), behaviour management (Robinson & Yates 1994), developing social support (Barusch & Spaid, 1991; Greene & Mohanan, 1987; Toseland et al. 2001 Robinson & Yates 1994), and relaxation training throughout the sessions (Green & Mohanan, 1989; Hepburn et al. 2001). Thus, besides developing the curriculum through self-efficacy training, it also carried the relevant aspects of other programs that have reported successful outcomes on depression, and burden[13].

Hypotheses

The study was designed to test three hypotheses;

1) Caregiver self-efficacy will increase as a function of receiving a caregiver education program.
2) Depression and burden will decrease as a function of receiving a caregiver education program
3) The increase in caregiver self-efficacy will be greatest in persons with low levels of burden and low levels of depression at the start of the program.

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[13] None of the findings for burden reached 80% statistically significant power

Method

Overview of the Research Design

Based on the systematic analysis, it was hypothesized that the intervention would have medium to large effects. Thus, the sample size should be between 26-64 for control and treatment groups to detect a medium to large effect size (0.5-0.8) with an alpha set at .05, and the power of the test to be 80% (Cohen, 1992). In the original proposal, about 26-64 participants were to be selected to receive the intervention. The comparison group was also to consist of 26-64 caregivers in the community who were attending support groups in the Lower Mainland. Other support group facilitators have identified a class size of between 15-25 as ideal, although the lower number was suggested for more individual attention. Thus, the education series would be run more than once to reach sufficient sample size and to have an ideal class size. The program was to be advertised through local media, health care centres and adult day programs. When signing up for the program, caregivers were to be asked to be involved as study participants. The comparison group was to be recruited through adult day programs and support groups throughout the Lower Mainland until a comparable number was found. Table 8 provides an overview of the original study design.

Table 8: Research Design

	Treatment Group n=26-64	Non-Equivalent Control Group n=26-64
Baseline Survey (Time 1)	Yes	Yes
Receive Education Series	Yes	No
Repeat Survey (Time 2)	Yes	Yes

According to the literature there are recruitment biases in self-care and health promotion interventions. The literature suggests that participants are more healthy (although Elward, Wagner, and Larson (1992) report participants to be less healthy), have more education and higher incomes when compared to those who do not participate (Wagner, Grathaus, Hecht, & LaCroix, 1991; Bruchner & Pearson, 1989, Rakowski, 1986). Although the above research refers to several types of interventions, it was assumed that the recruitment practices for this project would attract a non-representative, biased sample of caregivers.

A proposal for a cross-over design, also termed a “delayed intervention” (Rakowski, 1986) design, had been proposed to the funding organization. However, the request was not granted as this project was considered a pilot-test and no commitment could be made to offer the series again either in the near future or in a year. Thus, the evaluation was to consist only of a pre-test and post-test with a comparison group.

Intervention

Number and Duration of Sessions

The intervention consisted of 10, two hour education sessions delivered weekly for ten weeks. The number and duration was consistent with programs found in the literature and in the local community. As indicated in Appendices B and C, they range from four to 18 sessions (average of about eight sessions), with session length ranging from one and one-half hours to three hours.

The Curriculum

The curriculum content was based on the literature review, interviews conducted with professionals involved with caregivers, as well as in consultation with a Steering Committee. Representatives from the Caregiver's Association of BC (CABC), the Alzheimer's Society, the VON Family Respite Centre (FRC) and a family caregiver were invited as members of the Steering Committee. The Steering Committee consisted of one member from the Caregivers Association of British Columbia (CABC), an educator from the Alzheimers Society, the Director of Community Health Services from VON British Columbia, an RN from the VON Family Respite Centre, a previous family caregiver from the community, and the project co-ordinator. The Steering Committee met two times as a group. By the second meeting, the family caregiver had dropped out due to health reasons, and the representative from the Alzheimers Society restricted her input to the dementia-related curriculum, which was later decided to be included as optional sessions to the program. The staff member from the VON Family Respite Centre was unable to leave work to attend the two meetings, but stayed involved through contact with the project co-ordinator. A new representative from the CABC, the VON staff member and the project co-ordinator were involved in the final editing of the curriculum which was completed in June 2002. By October 2002, the VON Director of Community Health Services had completed her evaluation of the curriculum. The Steering Committee was not involved in the implementation or the evaluation of the project.

The ten curriculum topics for the caregiver series were as follows; 1) Introduction to Caregiver Issues; 2) Role Changes, and Self-Care; 3) Accessing and Developing your Resources; 4) Stress Management; 5) Practical Techniques to Care; 6) Medication and Medication Management; 7) Understanding Behaviours and the Role of the Environment; 8) Financial and Legal Matters; 9) Residential Planning; and 10) How to Involve your Family Member in More Activities. The caregivers were provided with handouts that would be given out at each session.

In introducing the program, the author highlighted the fact that there are other factors involved in the care-recipient and caregiver relationship that are out of the control of the caregiver: social support from family, health of the care-recipient, or income, for example. This project did not aspire to put more pressure on the caregiver by inadvertently appearing to blame the caregiver for incidents, or problems in the care-recipient relationship. Caregivers also need to know that there may be times when they are unable to act until a crises occurs and to feel that this is not a result of their performance, but due to a challenging situation (Schmall, 1995). Since this education series was provided for caregivers and not the care recipients, it focused on the variables that were within their range to influence such as behaviour change, knowledge, skills, and self-efficacy i.e. confidence of the caregiver.

Table 9: Curriculum Content for the Education Series
Session 1: Introduction to Caregiver Issues Introduction and Overview of the sessions, Goals of group members and group introductions, What do caregivers do?, Sources of frustration,
Session 2: Role Changes and Self-Care Role Changes, Acknowledging and coping with the feelings of caregiving: guilt, helplessness, grief, depression; Self-Care, Self-care assessment for caregivers, Consequences of not looking after yourself, How to start caring for yourself
Session 3: Accessing and Developing Your Resources What are your needs, Barriers to accepting help, Accessing your support network, Guidelines for navigating the system, Community resources: support groups, home health services, respite, Developing your resources.
Session 4: Stress Management Review of List of needs previous session, Identifying stress and types of stress, Burden, Tried and true methods from other caregivers on stress management. Introduction to Stress Monitoring, Progressive Relaxation, Visualization exercises.
Session 5:Practical Techniques to Care Follow-up on session 4 stress monitoring, relaxation exercises, Approaches to caring for someone with cognitive impairment, hearing impairment, Communication verbal and non-verbal, Touch and reflex, Personal Care and Cognitive Impairment (Optional), Transfers :Bed transfers/turning/changing sheets , Bathing Tips (Optional), Nutrition, Conclusion with Deep Breathing Exercise
Session 6: Medications and Medication Management Pharmacare program, Questions to bring to the professional, Keeping records of medications, Polypharmacy: herbal, over-the counter, prescribed medications, How to administer a medication, Identifying pain in older adults: verbal and non-verbal symptoms.
Session 7: Understanding Behaviours and the Role of the Environment Follow-up on Session 4 stress monitoring and exercises, Some causes to changes in behaviour, Strategies of managing wandering, difficulty eating, undressing, Incontinence, Approaches to Communication, Environmental changes to manage behaviour, Environmental adaptations to promote Safety, Conclusion with relaxation exercise.
Session 8: Financial and Legal Matters Power of Attorney, Representation Agreement: things to consider, decisions to make, Resources, Questions and Answers, Deep-breathing exercise
Session 9: Residential Planning When is it time to stop caregiving at home, Review signs of burnout, Public long-term residential Care: eligibility and the process, Private Residential Care, Supportive Housing, Questions and Answers, Conclusion with relaxation exercise.
Session 10: How to Involve your Family Member in More Activities. Benefits of activity, Guidelines for selecting an appropriate activity, How to set the stage, Types of Activity: sensory stimulation, Solo activities, Reminiscence, Word Games, Art ideas, Music, Physical exercise, Activity Demonstration, Conclusion of program, evaluation.

The Facilitator

Originally, VON Family Respite Centre (FRC) staff were to teach the sessions and the project co-ordinator would conduct "a train the trainer" workshop. However, the Director of VON British Columbia decided to hire one external facilitator with expertise in the topics to teach all ten sessions. The facilitator also conducted a final edit of the curriculum. A facilitator with vast experience in support group and counselling was hired two weeks before the sessions began. Due to her schedule, guest facilitators were found to deliver session five, *Practical Techniques to Care,* and session six, *Medication Management.* Speakers were invited to supplement the curriculum for sessions eight, *Legal and Financial Matters* and session nine, *Facility Care.* Unfortunately, a pharmacist could not be found to facilitate session five, *Medication Management.* Instead a social worker from New Westminster Home Health facilitated this session. The project co-ordinator met with the facilitator regularly throughout the series to discuss the facilitation of upcoming sessions and final edits to the curriculum.

Dependent Variables

The primary dependent variable was caregiver self-efficacy as measured by Steffen, McKibbin, Zeiss, Gallagher-Thompson, and Bandura (2002) and Fortinsky, Bowman, Burant, Caban, Kercher and Rosenblatt (1998). The literature shows a relationship between caregiver self-efficacy and both depression (Chou, 1997; Haley, Levine, Brown & Bartolucci, 1987; Lovett & Gallagher, 1988; Steffen, 2000; Zeiss et al.,

1999) and burden (Chou, 1997;Gastman, 1994; Zeiss et al., 1999) in caregivers. Therefore, both depression and burden also served as dependent variables.

Self-efficacy

Self-efficacy is not a global or invariant expectation about one's ability to perform: self-efficacy varies across place, task, and situations (Bandura, 1977; Gignac & Gottleib, 1996). Four task specific self-efficacy measures were chosen for this project. They are as follows:

- The Revised Self-efficacy Scale for Obtaining Respite (Steffen et al., 2002);
- The Revised Self-efficacy Scale for Controlling Upsetting Thoughts (Steffen et al., 2002)
- Self-efficacy for Accessing Support Services Scale (Fortinsky et al. 1998),
- Self-efficacy Medication Scale (Fortinsky et al., 1998)

The Revised Self-efficacy Scale for Obtaining Respite (Steffen et al., 2002) has a test-retest reliability r_{12}=.76, and coefficient alpha of .85-.88 (Steffen et al., 1994; cited in Pennington-Costa, 1997). Self-efficacy for obtaining respite was chosen as it related to the content of session three, *Accessing and Developing your Resources.* In particular the session assisted participants in identifying the benefits and barriers in using respite services. It also focused on how to access respite services and allotted time for discussion of others' experience in using respite.

The Revised Self-efficacy Scale for Controlling Upsetting Thoughts (Steffen et al., 2002) has a construct validity of r=-.62, a test-retest reliability of r_{12}=.76 and a coefficient alpha between .82-.89 (Steffen et al., 1994; cited in Pennington-Costa, 1997), and .89 (Gastman, 1994, original scale. This scale was included as it corresponded with the curriculum introduced in session five, exercises for visualization and progressive relaxation. The two exercises provided skills training in redirecting negative and distracting thoughts to the breathing exercises and positive visualizations and were practiced throughout the education series.

There is limited information on the reliability or validity of the Fortinsky et al (1998)'s scales. However, the scale for self-efficacy of Medication (Fortinsky et al., 1998) was chosen because it included items on understanding side effects, the purpose and management of medications, as well as confidence in finding answers to medication questions, which directly related to the content in session six, *Medications and Medication Management*. The scale for self-efficacy for Accessing Support Services Scale (Fortinsky et al. 1998) was chosen as the items corresponded to the curriculum of session three, *Accessing and Developing your Resources.* This session focused on the benefits and barriers to using community and family resources and how to access community resources.

Burden

The scale developed by Montgomery, Gonyea, and Hooyman (1985) was used to measure burden. A copy of this scale is included in Appendix D. Montgomery et al's (1985) measure of burden consists of a 5-point 9-item inventory for objective burden and a 13-item 5-point inventory for subjective burden. Subjective burden was adapted from the Zarit, Reever and Back-Peterson (1980) 29-item inventory. Objective burden was derived from other researchers who have identified the areas most disrupted by the caregiving experience (Montgomery et al., 1985). Montgomery's version was chosen because it is sensitive to change and widely used (Knight et al., 1993). The meta-analysis performed by Knight et al. (1993) reveals that the Zarit Burden Interview is not sensitive to change.

The Montgomery objective and subjective measures of burden have sufficient reliability comparable to the Zarit Burden Interview. The Zarit Burden Interview has been reported to have a coefficient alpha between .79 - .88 (Bergstone et al., 1988; Zarit, 1982; Gallagher et al., 1985). The Montgomery Objective burden scale reports a coefficient reliability of about .85 (Montgomery et al., 1985) and .87- .92 for the 6-item version (Edelman, 1997; Gonyea , 1991). The Subjective Burden Scale reports a coefficient alpha of .86 (Montgomery et al., 1985; Edelman, 1997, 7 item version).

Montgomery et al. (1985) defined subjective burden as the respondent's attitudes toward or emotional reactions to the caregiving experience. Objective burden is defined as the extent of disruptions or changes in various aspects of the caregiver's life and household. Through the education series, this project aspired to effect caregiver' s subjective burden, but it is also possible to have an effect on objective burden. For example, the caregiver may use more support services such as respite due to attending the series, and possibly have lower measures of objective burden at post-test. Thus Montgomery's burden seemed most appropriate for this project.

Depression

Depression was measured by the Centre for Epidemiological Studies Depression Scale (CES-D) because it was designed for research purposes and not as a diagnosing tool (Radloff, 1977). The CES-D reports a coefficient alpha of .70- .92 (Lawton et al. 1991; Radloff, 1977).

Independent Variables

Consistent with the literature, data were collected on age, gender, caregiver place of residence, amount of assistance provided, number of years caregiving, health measures, self-care, care-recipient health and functioning (Barusch & Spaid, 1991; Gallagher, & Hagen, 1996). The data were collected using the questionnaire shown in Appendix D.

Recruitment

VON partnered with New Westminster Home Health in recruiting caregivers and providing home support hours to the caregivers during the sessions. Since New Westminster Home Health had recruited and selected caregivers of their clientele, issues of confidentiality arose, which affected the evaluation process. VON had not emphasized or included the evaluation process as part of their discussions with New Westminster Home Health. On March 13, 2003, the project co-ordinator and the Director of VON Health Services met with New Westminster Home Health to discuss the outcome surveys. The tools and process for the evaluation were limited and stipulated by the New Westminster Home Health Unit.

Originally, the outcome survey was to be delivered by phone prior to session one and after session 10. The Fraser Health Authority felt it could not release the names of the caregivers to the project co-ordinator and felt very strongly that the project co-ordinator should not attend the series as a co-facilitator as it may pressure their clients into filling out surveys. It was decided that the co-ordinator would attend the first session, present the surveys and collect the surveys at the next session. At the request of New Westminster Home Health, the participants were to be given the option of completing the outcome survey at home on their own - not during the session - or by telephone with assistance from the project co-ordinator.

A list of 25 people had been compiled by New Westminster Home Health. VON British Columbia contacted them by letter and the facilitator called each person on the list and was able to speak with 20 people. The facilitator tracked the number of participants. A pre-test, post-test survey measuring demographic variables and outcome variables, self-efficacy, depression, and burden, and the consent forms were distributed at the first session. The participants were asked to complete the survey and sign a consent form and return it the next session, or to complete the survey over the phone with the assistance of the co-ordinator. At session two, the facilitator collected the surveys and the signed consent forms and offered the surveys to newcomers and to those who did not fill out a survey from session one. Seven participants completed the first survey. At the ninth session all participants were asked to complete the survey. Four were collected at session 10. The remaining three participants who did not fill in the second survey were contacted by phone. One more survey was completed by phone, one person had dropped out of the education series and one person did not respond. A total of only five participants completed both surveys.

It was originally intended that the education series be formally evaluated through a statistical analysis of observed changes between the pre and post-tests of caregiver self-efficacy. However, due to the large attrition and low participation in the surveys, there were insufficient numbers of caregivers to rely solely on the self-efficacy data to evaluate the program. Interviews and satisfaction surveys were employed as this would assist in the evaluation of the series and provide qualitative feedback to the organization who may want to continue running the series. In summary, the evaluation of the education series was based on the self-efficacy data, the project co-ordinator's field notes of the first session, an interview with the facilitator, a caregiver satisfaction survey, and interviews with two caregivers. A copy of the Caregiver Satisfaction Questionnaire is included in Appendix E. Key themes were identified from the surveys and interviews.

Results

The evaluation is based on the pre-test survey, the project co-ordinator's field notes of the first session, the interview and report of the facilitator, interviews with two caregivers, and a satisfaction questionnaire.

Attendance

As shown on Table 10, 14 people attended the first session. The group consisted of four men and 10 women. Five participants were adult children caring for a parent (one male and four females). The other participants were spouses. These caregivers were dealing with several illnesses in their families including Dementia, Stroke, Huntington's Disease, and Parkinson's Disease. Two of the male participants dropped out as one was going on holiday and the other stated he was managing well without the program.

There were 14 participants for the second session: the two newcomers were women. Although participants were offered the opportunity to attend the sessions that interested them, new participants were not encouraged to attend after the second session, as it was seen to disrupt the bonding of the group members. For the majority of sessions eight were represented. There were six who attended session four and 10 caregivers who attended session 10.

Table 10: Attendance

Session	Number of Participants
1	14
2	14[14]
3	8
4	6
5	8
6	8
7	8
8	8
9	8
10	10

Socio-demographic Characteristics

As shown in Table 11, seven participants provided socio-demographic information. Their average age was 68.6 with a range of 60-78 years. Six were female and one was male. Four of the caregivers were looking after their spouse, two were looking after their parent, and one was looking after another type of relative. Six of the seven lived with the care-recipient. Four were caring for someone with dementia as well as another disability or disease.

Five of the seven rated the care recipient's cognitive status as moderate (middle) to advanced (late) stages. Of the people living with the care-recipient, the caregivers were spending 10-24 hours per day caregiving. Five of the seven rated their own health as poor or fair.

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[14] Two were new Attendees

Table 11: Caregivers' Socio-demographic Characteristics (n=7)

Age	
Average	68.6
Range	60-78
Gender	
Female	n=6
Male	n=1
Cognitive Status	
Moderate-Advanced Stage	n=5
Early Stages	n=1
Hours Spent Caregiving per Day	
5-9 hours	n=1
10-24	n=6
Caregiver Health	
Good	n=2
Fair/Poor	n=5
Care-recipient's Major Health Problem	
Dementia	n=4
Stroke	n=1
Huntington's Disease	n=1
Other-not specified	n=1

Depression, Burden, Self-efficacy

Pre-test Survey

The Self-efficacy scales range from 0-100% confidence. The scores for Self-efficacy for Obtaining Respite reveal a group average of 34.5% and range of 16% to 66% confidence. The scores for Self-efficacy for Controlling Upsetting Thoughts result in a group average of 49.5% with a range of 0% to 84%. The scores for Self-efficacy for Accessing Social Support result in an average of 52% with a range in scores of 36% to 70%. The scores for self-efficacy for Medication Management average 79% with a range from 0 to 100%. Participants were also asked to indicate their general confidence in caring for their relative or friend. The scores for global confidence range from 50 to 90% with an average of 69%.

Due to the small numbers of caregivers who completed the education program (8 completed) and low participation in the final survey (5 out of 7, 1 dropped-out of program), a statistical comparison of scores between pre-test and post-test on depression, burden, and self-efficacy was inappropriate. Since the test group was small and a statistical comparison of scores would not be done, the recruitment of a comparison group was suspended.

Field Notes

I attended the first session and recorded my observations. The session began with an introduction to the program and introduction of the facilitator. Each participant introduced him or herself and described their caregiving situation. A few caregivers broke into tears when describing their situation. During the introductions, three caregivers discussed their hesitation in attending the series, and that after hearing others' situations they indicated their situation was "not so bad". The facilitator encouraged these caregivers to attend the sessions as they may find information relevant to them. She easily built rapport with the group and redirected the caregivers to the topic at hand. A few caregivers arrived late and a few left early as they expressed problems with the timing of the home support worker or with transportation. One male caregiver said he would be leaving early as he did not want to leave his wife too long.

There were 14 caregivers for the first session. Two men dropped-out of the series: one caregiver was going on holidays and said he would try to attend the last couple of sessions, another man caring for his wife in the advanced stages of dementia, said he was managing well and did not need this program. These observations reveal some of the difficulties of attracting and retaining caregivers in the program. Many expressed concern at being present, concern with whether this was an appropriate program for them, and concern with leaving the care-recipient at home.

Outcome Evaluation

Interview with the facilitator

An interview was conducted with the facilitator, three weeks after the series was complete. She also submitted her own evaluation based on her observations. Key themes from her evaluation and from the interview were identified and are presented below.

The Curriculum Content

Generally, the facilitator's comments indicated that she felt that there was too much material to cover, and that the curriculum should be set up so that caregivers were able to choose topics of interest at the beginning of the series. She observed that giving the material to caregivers to read at home worked well. The caregivers had a variety of interests in the curriculum: some people were interested in communication techniques, one in respite, and some in legal issues. The facilitator thought the topics were universal across caregiving situations, and found that caregivers who were not caring for someone with dementia were very supportive of those who were. She also observed that it gave them a sense of empowerment to help someone else. She noted that loss and frustration were common issues for all caregivers, but that people varied in the degree of their experiences.

Development into a Support Program

The facilitator reported that the initial structure of the program was one of information but over the course of the series it expanded to become more of a support group. She felt this evolution was necessary, as it addressed the different needs of participants: some were looking for information and some were looking for social and emotional support. She said the feedback from the participants and from New Westminster Home Health indicated that the information component was valued, but that the group members were looking for a place to share their experiences.

As well, all of the facilitators and presenters commented on how interactive and talkative the group became. In general, they observed that the caregivers left the sessions feeling they could continue talking about the subject. This led the facilitator to present the topic at each session and ask the participants if they wanted to review the chapter and handouts systematically, or spend the group time in discussion and sharing. After the third week, most often, the discussion option was the one selected. When this was the case, the facilitator then focused on a few of the core ideas from the chapter which she felt the participants needed most to hear about and the rest of the content was seen as 'homework' for the next session. In the next class she would review the handouts. She further observed that once the caregivers had built a relationship with each other, they only wanted to talk about issues and there was an abundance of sharing. The interpersonal support was more important than the actual learning component, and she felt she could not generalize the results of the evaluation to an education program.

The group started to "regulate" itself, that is, the group started to make its own rules for members; as an example, the group provided feedback to a member who was not contributing by offering solutions to others. The group members suggested that he /she make contributions to the group. The person who received the feedback continued to attend the sessions, and the facilitator took the person out for coffee to debrief.

At session nine, the participants were given the option of continuing the program as a support group to meet after the series was completed. Nine participants chose to continue to meet. The social worker from New Westminster Home Health, who helped to set up the sessions, agreed to be the professional contact for the group after the 10 weeks had finished.

Program Strength

The facilitator said that advertising the series as an education-based program may be less threatening and more effective at attracting caregivers who could benefit from support than if advertised as a support program. According to her report, "beginning the group as an information series was helpful for some of the participants in creating a level of comfort. After the first few sessions this level of comfort and focus on emotional safety allowed the participants to share more specific situations about their lives."

The facilitator offered how to the program could be used to set-up future support/education programs. In order to accomplish this, she suggested that the program begin with a professional facilitator for the first few sessions and introduce the curriculum as a resource manual, with the intention of the group being self-run.

In-depth Interview

One of the caregivers completed the second survey by phone and also provided more insight into the education series. This participant indicated wanting more education on a specific disease, but also wanted the support group aspect. The caregiver did not feel the exercises on stress management were helpful and commented that a few others had taken similar workshops before, but stated that others in the program "did get something out of it". This participant reported feeling he/she had acquired "quite a bit of knowledge on most subjects" and would "like to take the group to another level to advocate for services for caregivers and for funding medications".

What is known about the drop-outs?

Fourteen people attended the first session. At this session two men caring for their spouses dropped out. One participant indicated that he was going on holidays and the other felt he was managing well without the program. Since caregivers could attend sessions of their choice, some only attended one or two. There was a core group of eight that attended each session. It would be appropriate to interview those who left the program to see why they left the program, i.e. if they were wanting a curriculum-based program, or whether they left due to personal circumstances. I asked the facilitator to attempt to contact those who dropped out and ask the reasons they left. According to her report, several left the program as they had attended the first one or two sessions and decided they were looking for a support and discussion group more than an education series. Another participant did not return to the group because she was looking for a place where people could focus on political advocacy around health care issues. One person cited the difficulty of leaving her husband and getting out of the house as the problem, which prevented her from attending the meetings.

I was able to interview one person who attended only two sessions. She was unable to attend more sessions due to personal circumstances. On the day the sessions were held, she explained that she attends a music class for her relaxation. As well, the home support worker that her spouse is most comfortable with was not available on the day the sessions were held. She said that she has since changed her schedule as she hopes to attend the ongoing support group. She said that she found it helpful to hear about other peoples situations, "good to know that others are in the same boat". She also said that hearing others stories made her depressed and in effect turn to other methods to cope such as relaxation exercises as well as continue with her music class. She also relayed that at this point her husband, although moderately cognitively impaired, did not have some problem behaviours that others had to deal with.

It thus appears that the people who left the program did so for personal reasons, or because they did not perceive themselves as needing assistance. According to the facilitator's report, it appears that some who dropped out of the first session when the program was more curriculum focused, had left as they were wanting a support program.

Satisfaction Questionnaire

A satisfaction questionnaire was distributed in session 10 and collected by the facilitator. All 10 who attended the final session completed the survey, although one did not answer all the questions. A summary of the questionnaire findings is as follows.

The Delivery of Sessions (n=9)

The quality of instruction was rated as good or excellent by eight respondents and fair by one. The effectiveness of the facilitator in communicating the material covered was rated as good or excellent by all respondents. The material/information presented was also rated as good or excellent by nine of the nine respondents.

Length and Number Sessions (n=10)

The number of sessions was rated as good or excellent by nine of the nine responding participants. The length of each session was rated as good or excellent by nine and fair by one respondent.

Curriculum (n=10)

The topics covered were rated as good or excellent by nine of the nine who responded to this question. The organization of topics was rated as good or excellent by 10 of 10 respondents. When asked: "Was the material covered in this workshop relevant to your particular problems and concerns as a caregiver?" all ten indicated that the material was relevant to their particular problems and concerns as a caregiver.

One of the caregivers commented "Almost every week I received some information that was useful /important to my situation".

Some people had specific comments to this question. An important theme emerged in terms of an appreciation of the support aspects. One caregiver said, "Being of the sandwich generation, I liked the reality of the experiences of the group as well as the facilitator". Another person identified a general appreciation of the content, but also emphasized the support aspects “On a whole, the subjects were very good. It was nice to see the friendship with all members and our leader. I’m very pleased that I was asked to be here.” Another said “I found it very interesting to listen to caregiving ideas, feelings, and problems”. It was interesting that none of the comments discussed particular curriculum that was learned. Instead, they relate to the interpersonal support needs of the group. The next question asked participants to rate the relevance on each of the 10 individual sessions. The results are shown in Table 12.

Table 12: Perceived Relevance of Individual Sessions (n=10)

	Least Useful/ relevant	Some-what Relevant	Very Relevant	No Answer
Session 1 Introduction to Caregiving		1	5	4
Session 2 Role Changes, Acknowledging your feelings, Self-Care		1	7	2
Session 3 Accessing and developing your resources			9	1
Session 4 How to identify stress, Stress test, Stress management Progressive Relaxation, Visualization, Relaxing Events		1	8	1
Session 5 Practical techniques to care, personal care, personal hygiene, transfers (Guest Speaker)	1	1	7	1
Session 6 Medication Management (Guest Speaker)	1	1	4	4
Session 7 Understanding behaviours, behaviour management, environmental adaptations		2	7	1
Session 8 Legal and financial matters: Power of Attorney		1	8	1
Session 9 Facility care/ End of life decisions and planning		2	6	2
Session 10 Appropriate Activities: how to involve your family member in more activities		1	4	5

For some sessions, a smaller number of participants attended the session than the number who indicated their satisfaction with that session. For example, session four was attended by six people, but nine people evaluated the session. Sessions five, seven, and eight were attended by eight people but nine people evaluated the session. Since the caregivers were provided with their own participant manual they may have answered these questions after reading the sessions they did not attend, or they simply indicated whether this topic was relevant to them regardless of whether they were present for the session or not. This suggests that the question was not worded clearly to the participants. In general, the topics were rated as very relevant by the majority of participants.

Participants were asked if "there were any topics that they wanted to spend more time on". Three cited the session on medication. It should be noted that there was a problem recruiting a speaker for this session (a guest facilitator talked about general medication management strategies). Two participants cited legal issues, one on self-care, one indicated all topics, and one wanted more time for others to speak. In general the responses reflect their diverse needs.

They were asked to suggest future topic areas. The responses indicated a need by some for more disease-specific or individual topics: one person requested she would like additional information on Alzheimer's disease, another wanted more information on strokes and third person, on bereavement. These three needs could be met by other agencies that already provide caregiver education on these topics. The resources for these agencies were included in session three and perhaps this indicates a need to review the session on resources. In fact, one person I had interviewed who attended session three, did not know of the Alzheimer support program in New Westminster, which was explicitly mentioned in the session on resources. This may reflect that caregivers are in different stages of learning and have different needs at different times. This type of changing need may be addressed in a support program.

Other

The facilities were rated as good or excellent by eight respondents and fair by two. The breaks and refreshments were rated as good or excellent by nine of nine who responded. Nine of 10 indicated that the time of day of the sessions was convenient or very convenient; one person said somewhat convenient.

Future Programming

The participants were asked "What, if anything, would you change about the program?" The responses further reflect the diverse needs of the caregivers. At least two people wanted to spend more time on the curriculum; two indicated that they wanted more time to talk; "more time for individual concerns"; three indicated nothing to change; and two referred to the session on medication management and suggested teaching the next session when a speaker is unavailable. One person indicated a need for more control in staying on the topic "sometimes stories are interesting, but often time consuming from subject".

Recommend to others

When asked "Would you would recommend this education program to any other caregivers you know?" all who answered (eight) responded "yes". One person stated "because of the educational value as well as feedback and common sharing".

Goal and Goal Attainment

The participants were asked, "What was your goal/ reason for taking this series? Did you meet your goal?" For the first questions, coping was indicated by two participants, education and information with no specific topic by three, and education and socializing by one person. Two respondents did not have a specific goal but had appreciative comments, one person indicated she was "talked into coming", but was also appreciative of being "signed up". Although there was a diverse range of goals all caregivers who answered (nine) indicated that their goal had been met. The responses to this question also indicate that the participants had not conceptualized specific education goals when deciding to take the series.

Additional comments

The comments were very positive toward the facilitator, to VON and to New Westminster Home Health/Continuing Care for sponsoring the program. Overall, the program was rated as good or excellent by nine respondents and fair by one respondent.

Summary of satisfaction questionnaire

The questionnaire asked participants to rate the facilitator, material, number of sessions, topics, and organization. All aspects were rated good or excellent except for quality of instruction, the length of sessions, and overall evaluation of the program. These items were rated "fair" by one respondent. All stated that the program was relevant to their particular problems and concerns as a caregiver. As well, all who responded indicated they had reached their goal for taking the series. There were comments that revealed that some appreciated and valued the support aspects whereas one person commented that there was too much time spent on discussion.

Key themes identified

Responses from the interview with the facilitator and from the satisfaction questionnaire were categorized into common themes.

Interview with facilitator:

Words pertaining to support aspects were mentioned seven times (words such as interpersonal support, sharing, discuss, talk, support, continue talking).

Participants' Response

Participants also expressed satisfaction with support group aspects and referred to needing more time to talk five times, with references to friendship and sharing five times. One person mentioned that too much time was spent talking. Participants cited the benefits of education/information five times.

The data suggest that both the caregivers and facilitator consider the support aspects of the program as beneficial. The education components were commonly cited amongst the caregivers.

Discussion

The systematic review indicated that a medium to large effect size was reasonable to determining sample size. In general the studies utilized small sample sizes, that could only result in medium to large effect size. The review identified relevant aspects of studies that met methodological rigor and produced statistically significant results at 80% power with an alpha set .05. These elements were sessions relating to the emotional aspects of caring and coping, relaxation training, and comprising a strong support aspect. These elements were included in the current intervention in addition to self-efficacy training.

Delay of the Program and Data Collection

The decision to conduct the education series as a support group was in response to the needs of the participants, which in turn led to a more qualitative evaluation than was originally intended. However, there were other contributing factors that led to a delay in the project, and change in type of evaluation that relates to the recommendations following this discussion.

When conducting research for an agency[15], the researcher is dependent on the agency in terms of timelines and key decisions, which can challenge the research process. At the start of this project, I was hired by the Executive Director, who was the key person involved in developing the outline for the education series. Soon after being hired for this project, the Director went on-leave. The person who assumed her responsibilities had yet to be orientated to the organization as well as to the project which led to a delay in the project. As well, a key program of the organization (Family Respite Program) was in the process of relocating and much of the new Director's time and energy was spent on the day to day running of the Family Respite Program and the upcoming move. This led to a further delay in the final editing of the curriculum, in hiring the facilitator, and in making choices of where the sessions were to be held.

Originally, the project co-ordinator was to market the series by advertising to local agencies and through caregiver organizations. The Director of VON British Columbia had been meeting with New Westminster Home Health to find a possible location to hold the series. On February 26, 2003, the Director informed the project co-ordinator that through a partnership with New Westminster Home Health, 25 caregivers were signed up for the series. Since VON partnered with the health authority who recruited the participants, the research process also had to meet the health authorities' needs. The survey, although adapted to be self-administered, was designed to be administered over the phone or in person. This may have led to such small participation rate of the outcome survey. If the co-ordinator had been involved at the time of recruitment of caregivers, information could have been collected on the participants at the time of sign-up and it would have been possible to keep track of those who dropped out of the program.

Similar to other programs, (Gallagher & Hagen, 1995), the evaluation of the VON Caregiver Education Series relies on qualitative measures rather than outcome measures. The caregivers evaluated the project positively in terms of topics and instruction, and meeting their goals. However, as the series was not conducted as an education series, it

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[15] The funding for the development of the education series and evaluation of the project has been provided by VON Canada.

could not be evaluated as an education-based program, and suffers from type III error (Windsor et al. 1994)

Project Coverage

The VON Caregiver Series Pilot project was successful in starting up a support group program for a diverse group of caregivers in an area not served by a support program for a mixed group with diverse needs. The Alzheimer's Society and the Brain Injury Association do operate support programs in New Westminster, however, these programs may not meet the needs of caregivers who are not looking after someone who is brain injured or has dementia. During an interview with one of the caregivers, I referred the person to the support group offered through the Alzheimers Society as the person wanted to be around others who were caring for someone with Alzheimer's Disease as well as attend the ongoing support program from this project.

Management did not stipulate the clear goals of the program with New Westminster Home Health. When I had met with the manager and staff of New Westminster Home Health, their major concern was the support aspect of the program: they expressed the need amongst caregivers to have time for discussion. The Community Health Centre had already spent numerous work hours trying to recruit participants and had already signed 25 participants for the program. Caregivers in need were identified and encouraged to attend the series by case managers who they know, and perhaps may have not attended without that encouragement. As it turned out, the caregivers signed up for the series were clearly needing a support program rather than an education-based program.

Retention

People will drop out of programs that do not meet their needs. It could be a timing issue, due to a personal reason, or some other important reason. The importance to the effectiveness of an intervention is to determine why the needs were not met by the program. We can infer from the facilitator's comments that people dropped out for reasons that were personal, due to the timing of the sessions, or due to health status, but it is not known for certain. The facilitator stated that the participants dropped out because they wanted a support group, as some caregivers had called into the Home Health Unit during the first couple sessions to express their needs for support. This feedback, led to the change in the format of the program, but how many people actually felt this way is unknown. There were 25 who were signed up and a core group of eight who attended the majority of sessions. Surveying the group who dropped out may have provided important information to assist in developing future educational programs.

According to Windsor et al. (1994), a Quality Assurance Review will look at many aspects of the program to figure out the process of the program. An evaluator may use focus groups, interviews, or surveys for example. At the minimum, the Quality Assurance Review would analyze the evaluations and interviews and then make a set of recommendation to improve the intervention.

Unfortunately, the program suffers from type III error (Windsor et al. 1994) which refers to the failure of implementing the program. The education program was not implemented. The participants clearly were more interested in support aspects, drawing out session topics into discussions and it was not taught in a structured format. When partnering with another organization for recruitment, the goal of the program should be made clear to the partnering organization who recruited the participants. The health unit recruited participants identified by case managers who they felt could benefit from the program. There are certainly clear benefits in utilizing this type of recruitment, as some of the participants probably would not have attended the program if not encouraged by the social workers and case mangers. There were clear benefits to those who did participate; however, the evaluation was not designed to capture an evaluation for a support group.

Conclusion and Recommendations

The series was intended for caregivers of diverse age and with diverse needs. The caregivers ranged in age from 60 to 78 and were looking after family members with diverse needs: some had Parkinson's Disease, Huntington's Disease, stroke, dementia, and heart problems. However, this education series was also intended to meet the needs of caregivers wanting more in-depth information than existed in a support program. I attended an excellent education program run by the Alzheimers Society-White Rock Chapter. The White Rock Chapter had two programs that ran simultaneously, one curriculum-based, that I attended, and one a support program. Some caregivers attended both, while some attended just one. When I surveyed caregivers in the Richmond support group four indicated that they had previously attended an education series for caregivers. These caregivers were wanting more skill-based training and specific curriculum than offered in a support group. The education program that was the focus of my study was developed to run as an education series, not as a support group program. However, the caregivers attending this series were clearly interested in the support aspects of meeting as a group and not in the curriculum. When asked about their goals for taking the project, none specified a particular education topic. This also reveals the fact that the caregivers who attended this series were not ready for an education program, but were indeed ready for a support program. As a result, the curriculum was distributed as a handout and not the focus of the group discussion. In summary, the series served a diverse group of caregivers with diverse needs, but it did not run as an education program

The project partnered successfully with New Westminster Home Health Unit and with the City of New Westminster Parks and Recreation in use of Century House to hold the sessions and provide snacks and refreshments. A secondary benefit was that the program was well-timed in developing a support group in the City of New Westminster, which will be further supported by the New Westminster Home Health Unit. Although, the impact of the project was positive, the following recommendations are offered to the sponsoring organization:

Recommendations

1) Offer a caregiver program to an existing caregiver support group for use with caregivers wanting more support /education than they currently receive.

2) It would be a more appropriate use of time and energy for VON British Columbia to partner with other organizations who also provide services to caregivers. More specifically, while it was a unique opportunity to involve key members of the caregiving community in the development of the project, it would have been more appropriate for VON British Columbia to accept the education program already developed and operated by VCHA that was evaluated by Gallagher and Hagen (1996) and developed by the Caregivers Association of BC.

3) The VON Family Respite Centre Staff have hands-on experience in providing activity, social programs, and physical care to clients attending their Adult Day and Overnight Respite Program. Their valuable experience and skills could be shared with family caregivers through workshops on topics not offered by VCHA. Originally, VON British Columbia staff were to be more involved in the development of the curriculum, as well as facilitating the sessions. Now that the respite centre has finished its move and the overnight respite program has been operating for several years, staff could be involved in evaluating this curriculum or developing their own

workshops on topics they perceive as needs for caregivers who they interface with daily.

4) The education series should be run again, in under-served areas, advertised as an education program, and evaluated as an education program with a qualitative evaluation component and outcome evaluation component focussing on key knowledge areas and self-efficacy.

5) With the next implementation of the program, administration should ensure that all staff and partners understand the goal of the program and the need and purpose of an evaluation.

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Appendix A

SIMON FRASER UNIVERSITY

OFFICE OF RESEARCH ETHICS

BURNABY, BRITISH COLUMBIA
CANADA V5A 1S6
Telephone: 604-291-3447
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April 17, 2003

Ms. Teresa Snider
Graduate Student
Gerontology
Simon Fraser University

Dear Ms. Snider:

Re: Effect of a 10 Week Education Program on Caregiver Self-Efficacy

The above-titled ethics application has been granted approval by the Simon Fraser Research Ethics Board, at its meeting on March 17, 2003 in accordance with Policy R 20.01, "Ethics Review of Research Involving Human Subjects".

Sincerely,

Dr. Hal Weinberg, Director
Office of Research Ethics

Appendix B: Study Characteristics, Measures, and Outcomes: Mixed Caregiver Groups

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
1. Barusch & Spaid, (1991).	RCT	Coping Inventory Subjective Burden Objective Burden	Developed by author ZBI Montgomery et al., (1985)	T1: In-Class attended alone(n=37) T2: At home sessions attended alone (n=22) T3: In Class sessions-attended with family(n=33) T4: At home sessions: attended with family (n=3)	Six weekly, 2 hour sessions	Coping SS increase for In-class T1 + T3 vs. In-home groups T2 +T4 Subjective Burden NS Objective Burden SS increase for Family T3+T4 vs. Individual groups T1+T2	No Risk of Type I error
2 Greene & Mohanan. (1989)	Quasi-Exp.	Subjective Burden Anxiety Depression Hostility Subscales	ZBI SCL-90 (Derogatis, 1977)	T = Education Series (n=127) C= Control (n=81)	Eight weekly, 2 hour sessions	Anxiety SS Depression SS decrease for T Dependent on participants with high pre-test scores (regression to the mean) Hostility NS	Yes for anxiety, and depression, however validity threat (selection & regression to the mean)

Appendix B: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
3. Montgomery & Borgatta (1985)	RCT	Subjective Burden Objective Burden	Developed by Author	T1: received respite (n=76) T2: Education series (n=74) T3: education series and respite (n=77) C= 78	Six weekly, 2 hour sessions	NS for education group, but Burden SS for respite only group	Risk of Type II error
4 Kaasalainen, Craig, & Wells (2000).	Quasi-Exp.	Morale	POMS measures Anxiety, depression, anger, activity, fatigue, confusion	T= Education Series (n=23) C= Matched Comparison (n=23)	Eight weekly, 2 Hour sessions	Morale : NS	Risk of Type II error

Appendix B: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
5. Lovett & Gallagher, (1988)	RCT	Depression	BDI	T1: Increase life satisfaction skills (n=23)	Ten weekly, 2 hour sessions	Morale : SS increase for T1 and T2 Depression: SS decrease for T1 and T2	Yes for depression, No for Morale
		Morale	PGCMS				
		Problem solving Self-efficacy	Developed by Authors	T2:problem solving skills (n=20)			
		Pleasant events self-efficacy	Developed by Authors	C: Waitlist Control (N=19)			
		Perceived Stress Scale	Cohen et al. (1983)				
6. Schwiebert & Myers (1994).	Quasi-Exp.	Caregiver Burden	CBI	T= Treatment (n=29) C= Control (n=22)	Four weekly, 2 hour sessions	Coping SS Increase Burden: NS	No Risk of Type I error
		Coping	CRIS				

Appendix B: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
7. Steffen et al (1998)	Quasi-Exp.	Depression	BDI	T1= Individual psychotherapy (n=28)	10 weeks	Depression: NS Burden: NS	
		Burden	ZBI				Risk of Type II
				T2=psycho-educational classes (n=24)			
8. Toseland et al. (2001).	RCT	Psychosocial well-being	GHQ	T =Education Program (n=58)	Eight weekly, 2 hour sessions plus ten, 2 hour monthly follow-up sessions	Depression SS decrease NS on other measures and subscales	Yes for Depression
		Burden	MBBS	C= Usual Care from HMO (n=47)			
		Pressing Problems Index	PPI				

NR= Non-Random; Quasi-Exp. = Quasi Experimental Design, RCT= Random Controlled Trial; ZBI= Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980), NS= Non statistically Significant, SS Statistically Significant; POMS= Profile of Mood States (McNair, Lorr, & Droppleman, 1981). BDI= Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961); PGCMS= Philadelphia Geriatric Center Morale Scale (Lawton, 1972) CBI= Caregiver Burden Index (Novak & Guest, 1989); CRIS= Coping Resources Inventory for Stress (Matheny, Curlette, Aycock, Pugh & Taylor, 1987). GHQ =General Health Questionnaire, (Goldberg & Hillier, 1979); MBBS= Montgomery-Borgatta Burden Scale (Montgomery & Borgatta, 1986); PPI= Pressing Problems Index (Toseland et al. 1989)

Appendix C: Study Characteristics, Measures, and Outcomes: Homogeneous Caregiver Groups

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
1. Brodaty & Gresham, (1989).	Quasi-Exp.	Psychological Stress	GHQ	T1= Training program (n=33) T2: memory training for Care recipient and 10 days respite (n=31) C= waitlist control (n=32)	10 days plus regular telephone follow up for 1 year	Psychological Stress: SS Depression: NS	Yes
	Measured at 12 months post-test	Depression	ZDS, coded as Hamilton (Hamilton (1960)				
2. Brodaty, et al. (1994).	Quasi-Exp.	Burden	ZBI	T1= completed 5 sessions (n=33) T2=non-completers (n=22) C= waitlist control (n=26)	6 weekly sessions	NS	Risk of Type II error
		Positive and Negative Affect	PANAS (Watson, 1988)				
3. Chiverton & Caine (1989).	Quasi-Exp.	Health Specific Family Coping Index	HSFCI (Choi et al, 1983)	T = 20 C = 20	3 weekly, 2 hour sessions.	HSFCI: SS improvement for therapeutic competence, knowledge , emotional competence subscales. Other subscales: NS	No Risk of Type I error

Appendix C: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
4. Gallagher-Thompson, Arean, Rivera & Thompson (2001)	Quasi-Exp.	Depression Burden Anger	GDS Given et al., (1990) STAXI	T=43 C=27	8 weekly, 2 hour sessions	Depression: SS Burden: NS STAXI: NS	Yes for Depression
5. Gendron et al. (1996)	RCT	Distress Depression Coping Burden	HSCL ATQ JCS ZBI	T=18 C= Support Group (n=17) Tested at post-test, 3 months, 6 months	8 weekly 1.5 hour sessions	NS on criteria measures	Risk of Type II error
6. Haley, Brown & Levine (1987). Haley (1989)	RCT	Depression Life Satisfaction Impact on caregiver family relationship	BDI LSIZ ECR (Poulshock & Demling, 1984).	T1 : education series (n=14) T 2: same as T1 plus stress management skills.(n=17) C: Waitlist control (n=9)	10 weekly, 1.5 hour sessions	NS on criteria measures	Risk of Type II error

Appendix C: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
7. Hebert et al. (1993)	RCT Measured at post-test and 8 months	Burden Depression / Anxiety	ZBI BSI	T=23 C= support group (n=18)	8 weekly, 3 hour sessions	NS	Risk of Type II error.
8. Hebert, et al. (2003).	RCT	Reactions to C-R Behaviours Burden Anxiety Affect Personal efficacy	RMBPC ZBI STAXI Bradburn, (1969) Bandura, (1977)	T= 60 C= Support Group (n=58)	15 weekly, 2 hour sessions	Reaction to behavioural problems: SS NS on criteria measures	No Risk of Type I error
9. Hepburn et al. (2001)	RCT Measured at 5 months post-test	Depression Burden Beliefs about Caregiving Scale	CES-D (Radloff,1977) ZBI BACS (Phillips et al., 1989)	T=60 C= waitlist control (n=34)	7 week 2 Hour weekly	Depression: SS Decreased Burden :SS decreased BACS subscale nurturing and reaction to C-R's behaviour: SS Monitoring subscale : NS	No Risk of type I error

Appendix C: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
10. Kahan, et al (1985)	Quasi-Exp.	Burden Depression	ZBI ZDS	T=22 C=18	8, weekly, 2 hour sessions	Burden: SS decrease Depression: SS decrease	No Risk of type I error
11. Marriott et al. (2000)	RCT Post-test (9 months after entry), f/up (12 months)	Depression	BDI	T1: Family intervention (n=13) C1 : Received no interventions, received CFI interview (N=14) C2 received no intervention, no CFI interview (n=14)	14 weekly sessions on Education, topics, stress management , and coping	Depression: SS difference between Control (C1 and C2) and T at 12 months	Yes For T vs. C1
12. Mittelman et al., (1995).	RCT 8 months Post test	Depression	GDS	T= intervention includes education, counselling, and support group (n=103) C=103	Multi-component 10 weekly sessions plus support group and counselling sessions	Depression: SS decrease at 8 months post test	No Risk of type I error
13. Ostwald, et al., (1999).	RCT Post-test, and 5 months post test	Revised Caregiver Burden Scale Depression	(Zarit, Orr and Zarit 1987) CES-D	T=50 C= waitlist Control (n=30)	7 weekly, -2 hour sessions	Burden: SS decrease at 5 month post test, suggests a delayed treatment effect.	No Risk of type I error

Appendix C: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
14. Ripich et al. (1998)	Quasi-Exp.	Subjective Well-being Depression Stress and Burden	PANAS, (Kercher, 1992), CES-D (Caregivers Hassles Scale) Kinney & Stevens, 1989).	T=19 C=18	4 weekly sessions communication training	NS on criteria measures when confounding variables were controlled	Risk of Type II error
15. Robinson (1988)	RCT	Self-esteem Social skills Subjective and objective burden	Self-esteem Scale, (Rosenberg, 1968) Assertion Inventory (Gambrill & Rickey, 1975) Montgomery et al. (1985)	T=11 C =9.	4, weekly, 2 hour sessions 2	NS	Risk of Type II error
16. Robinson & Yates (1994).	RCT for first session	Subjective and Objective Burden	Montgomery et al, 1985	T1= Social skills training (n=10) T2= Behavioural management (n=11) C= control (n=12)	6 bi-weekly, 1.5 hour	Objective burden: SS improvement for twice trained vs. C (12 sessions, n=6 no longer RCT)	No Risk of Type I error

Appendix C: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
17.Steffen (2000)	RCT	Anger	Developed by author)	T1: home based viewing with telephone check in (n=12)	8 weekly video series	Anger: SS decrease for T1 and T2	No [16] Risk of Type I error
		Depression	BDI			Depression: SS decrease for T1	
		Caregiver Self-efficacy Scale for disruptive Behaviour	Developed by author	T2: Class based viewing led by facilitator (n=9)		Depression: NS for T2 Self-efficacy: SS improvement for T1 and T2	
				C: Waitlist control (n=12)			
18. Teri et al., (1997).	RCT	Depression	HDRS	T1: skills training in maximizing pleasant events (n=23)	9 weekly, 1 hour sessions	Depression: SS decrease for T1 and T2	Yes
		Burden	ZBI	T2: Problem Solving skills training (n=19)			
				T3: Typical Care: received advice and support (n=10)			
				C: Waitlist control: (n=20)			

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[16] Home-based treatment group reaches statistical power, but this treatment group does not meet criteria for inclusion in the systematic review.

Appendix C: Continued

Study	Design	Outcome Measure	Instrument	Group Allocation (sample size)	Length of Program	Findings	Evidence of statistical power (yes/no)
19. Van Den Heuvel et al. (2000).	RCT	Confidence in knowledge to being a caregiver Coping	Developed by author Utrecht coping list (Schreurs et al, 1988),	For caregivers of stroke care-recipients T1: In class (n=110) T2: In home (n=60) C= control (n=42)	8-10 weekly 2 hour sessions	Confidence in knowledge about patient care: SS increase Coping: NS	No Risk of Type I error
20. Zanetti, et al. (1998).	Quasi-Exp. Matched control group	Depression Burden Quality of life (LEIPAD, De Leo et a., 1994)	BSI Memory and behavioural checklist, (Rankin et al., 1992)	T =12 C=11	6 weekly 1 hour sessions	Burden: SS decrease	No Risk of Type I error

NR= Non-Random; Quasi-Exp. = Quasi Experimental Design, RCT= Random Controlled Trial; NS= Non statistically Significant, SS= Statistically Significant; GHQ= General Health questionnaire (Goldberg, & Hillier, 1972); GDS= Geriatric Depression Scale; ZBI= Zarit Burden Interview (Zarit, Reever, &Bach-Peterson, 1980) PANAS (Watson, 1988); GDS= Geriatric Depression Scale (Yesavage et al.1983);RMBPC: Revised Memory and Behaviour Problem Checklist, Teri et al. (1992). STAXI (Speilberger et al., 1985), HSCL= Hopkins Symptom Checklist (Derogatis et al., 1974) ATQ= Automatic Thoughts Questionnaire (Hollan & Kendall, 1980) JCS= Jalowiec Coping Scale (Jalowiec, 1988); LSIZ= Life Satisfaction Index (Wood et al., 1969); BSI= Brief Symptoms Inventory (Derogatis, & Cleary, 1977).IPSI= Ilfeld Psychiatric Symptoms Index (Ilfeld, 1976); ZDS= Zung Depression Scale (Zung (1967) HDRS= Hamilton Depression Rating Scale, Hamilton, 1960),

Appendix D: Outcome Survey

ID # ____________ (Please write the number found on your Work Book. If you did not complete the first survey in the first session, you may not have an ID number, please ask the facilitator if you have any questions.)

Thank-you for choosing to fill out this survey. The information that you provide will help us evaluate the project and provide useful feedback for future education workshops. This survey can also be a way for you to monitor how you are doing. It will take approximately 30- 40 minutes to complete. Please remember that your participation is completely voluntary, you may withdraw at any time and the information you provide will be kept confidential.

If you have questions or would like to complete the survey over the phone, please feel free to call me, Teresa Snider at (604) XXX-XXXX between 9-4, Monday-Friday.

The following questions are basic personal questions to determine how your needs and access to services differ based on your gender, or relationship to the care-recipient, for example. Please check (√) or circle your answer.

---

1. Age at last birthday? ______________

2. Gender? Please check (√) or circle your answer.

☐ Female ☐ Male

3. What is your educational background? Please check (3) or circle your answer.

☐ Primary School

☐ Some high-school

☐ High-school grad

☐ Some college/university

☐ College/university degree

4. How are you related to the person you provide care to? I am his/her

☐ spouse

☐ child

☐ other family

☐ friend

☐ Other (please specify) ________________

5. What is your total annual household income? Please check (√) or circle your answer.

☐ 0-$5,999

☐ $6,000-$9.999

☐ $10,000-$19,999

☐ $20,000-$29,999

☐ $30,000-$39,999

☐ $40,000-$59.999

☐ $60,000 or more

6. What are the living arrangements of the person you care for? Please check (√) or circle your answer.

☐ Lives in same household as me

☐ Lives in a different household than I, lives with others

☐ Lives alone

☐ Lives in a care facility i.e. nursing home. How long has your friend/family member lived in the care facility? ____________________

☐ Other (please specify) ___________________________

7. What is the major health problem(s) that has caused the person you care for to require your help? You can have more than one answer

☐ Alzheimer's disease /dementia
☐ Parkinson's disease
☐ Heart problems
☐ Stroke
☐ Accident (please specify e.g. hip fracture)________________
☐ Cancer
☐ Other (please specify)__________________________

8. In regards to their cognitive status, what stage is your friend/family member considered to be in. Please check (√) or circle your answer.

☐ Mild Stages (early)
☐ Moderate (Middle)
☐ Advanced (Late Stages)
☐ Not Applicable

9. What types of activities does your friend or family member need help with usually? Please check (√) or circle more than one answer if applicable.

☐ Dressing
☐ Bathing
☐ Transferring i.e. helping move in and out of bed and chair
☐ Toileting i.e. needs help going to the toilet and using toilet
☐ Continence care i.e. more than one occasion, does not control bladder or bowel movements and needs help cleaning-up
☐ Feeding
☐ Walking
☐ Shopping
☐ Banking
☐ Laundry
☐ Taking medications
☐ Other (please specify _

10. About how many hours do you spend caregiving?

a. per day________?
b. per week _______?

11. How would you describe your health at the present time?

☐ Excellent ☐ Good ☐ Fair ☐ Poor

12. Do you have someone you can trust and confide in?

☐ Yes ☐ No ☐ Don't Know

13. Which of the following services and programs do you currently use or have recently used (in past 3 months) to support you or the person you care for? (Please check (√) or circle)

☐ Home support services i.e. home care

☐ Other services from Home Health such as Home Care Nurse, Occupational therapist, physiotherapist

☐ Adult Day Program

☐ Educational workshops related to caregiving (other than this one)

☐ Support group

☐ Respite services (out of home)

☐ Meals-on wheels or other grocery delivery programs (Safeway, IGA delivery)

☐ Peer Counselling or other counselling

☐ Other (please list)

____

____

____

____

14. On a scale of 1 to 5, how satisfied are you with the support you receive from others? Please circle your response.

Very unsatisfied 1 . . . . . 2 . . . . . .3. . . . . 4 . . . . . 5. . . . . . very satisfied

The following questions relate to how you are managing emotionally

For the following 20 items, please select the choice that best describes how you have felt over the past week: Please check (√) the most appropriate column. Over the past week.	Rarely or none of the time (<1 day)	Some or a little of the time (1-2 days)	Occasion-ally or a moderate amount of the time (3-4 days)	Most or all of the time (5-7days)
1) I was bothered by things that usually don't bother me.				
2) I did not feel like eating: my appetite was poor.				
3) I felt that I could not shake off the blues even with help from family and friends.				
4) I felt that I was not as good as other people.				
5) I had trouble keeping my mind on what I was doing.				
6) I felt depressed.				
7) I felt that everything I did was an effort.				
8) I felt hopeless about the future.				
9) I thought my life had been a failure.				
10) I felt fearful.				
11) My sleep was restless.				
12) I was unhappy.				
13) I talked less than usual.				
14) I felt lonely.				
15) People were unfriendly.				
16) I did not enjoy life.				
17) I had crying spells.				
18) I felt sad.				
19) I felt that people disliked me.				
20) I could not get "going".				

Please check (√) the most appropriate column.

For the following items, ask yourself the extent to which caring for your relative/friend has brought **(A lot more, A little more, Same, A little less, or A lot less) changes to . . .**	I have a lot more (better) 1	I have a Little More 2	About the Same as before 3	I have a Little Less now (Worse) 4	I have a lot Less now (Worse) 5
1) The Amount of Time you have to yourself?					
2) The Amount of Privacy you have?					
3) The Amount of Money you have to meet expenses					
4) The Amount of personal freedom you have					
5) The Amount of energy you have					
6) The Amount of time you spend in recreational and/or social activities					
7) The Amount of vacation activities and trips you take					
8) Your Relationships with other family members					
9) Your health					

For the following items, ask yourself how often you experience the following. Please check (√) the most appropriate column.	Rarely/ Never 1	Little of the time 2	Some-times 3	Often 4	Most of the time 5
1) I feel it is painful to watch my relative/ friend age					
2) I feel useful in my relationship with my relative/friend					
3) I feel afraid for what the future holds for my relative/friend					
4) I feel strained in my relationship with my relative/friend					
5) I feel that I am contributing to the well-being of my relative/friend					
6) I feel that my relative/friend tries to manipulate me					
7) I feel pleased with my relationship with my relative/friend					
8) I feel that my relative/friend doesn't appreciate what I do for him/her as much as I would like					
9) I feel nervous and depressed about my relationship with my relative/friend					
10) I feel that my relative/friend makes requests which are over and above what s/he needs					
11) I feel that I don't do as much for my relative/friend as I could or should					
12) I feel that my relative/friend seems to expect me to take care of him/her as if I were the only one s/he could depend on					
13) I feel guilty over my relationship with my relative/friend					

These last set of questions ask about how confident you are that you can keep up your own activities and also respond to caregiving situations. Please think about the questions carefully, and be as frank and honest as you can about what you really think you can do. The items cover activities and thoughts that could come up for you as a caregiver. Please think about each one and answer how confident you are that you could do each item. Rate your degree of confidence on a scale of 0 to 100.

0 ⇒ 10 ⇒ 20 ⇒ 30 ⇒ 40 ⇒ 50 ⇒ 60 ⇒ 70 ⇒ 80 ⇒ 90 ⇒ 100

Cannot do at all	Moderately certain I can do	Certain I can do

For example, a rating of 20% confidence means that it is unlikely, but not totally out of the question for you to be able to perform the activity. A rating of 100% means that you are absolutely certain that you could perform the activity whenever you wished. A 50% confidence rating would mean that if you gave it your best effort, chances are about 50-50 that you could perform the activity. You can use any score between 0 and 100 (10, 20, 30, etc.) to express your confidence.

Please make all your ratings based on what you could do TODAY as the person you are NOW rather than on the person you used to be or the person you would like to be. Just rate how you think you would do as you are TODAY.

A. PRACTICE RATING

"If you were asked to lift objects of different weights right now, how confident are you that you can lift each of the weights described?" Ask yourself "How confident are you that you can..." before every item.

"How confident are you that you can	**CONFIDENCE (0-100)**
1) . . . Lift a 10 pound object?"	100 (Would mean I am 100% confident that I could lift the object)
2) . . . Lift a 50 pound object?"	50 (Would mean I am 50% confident that I could lift a 50 pound object)
3) . . . Lift a 100 pound object?"	0 (Would mean I am 0% confident that I could lift a 100 pound object)

Self-efficacy for Obtaining Respite

Please use any score between 0 and 100 (10, 20, 30, etc.) to express your confidence.

"How confident are you that you can . . .	**CONFIDENCE (0-100%)**
1) . . . ask a friend/family member to stay with (the person you care for), for a day when you need to see the doctor by yourself?"	
2) . . . ask a friend/family member to stay with the (person you care for) for a day when you have errands to be done?"	
3) . . . ask a friend or family member to do errands for you?"	
4) . . . ask a friend/family member to stay with (the person you care for) for a day when you feel the need for a break?"	
5) . . . ask a friend/family member to stay with (the person you care for), for a week when you need the time for yourself?"	

All caregivers sometimes have negative thoughts about their situation. Some thoughts may be brief and easy to get rid of. Other times, thoughts may be hard to put out of your mind, just like a silly tune is sometimes hard to get out of your mind. We would like to know how well you can turn off any of the following thoughts. Use the same confidence rating. Don't be concerned about how often the thoughts come up. We want you to rank your confidence that you can turn off or get rid of each type of thought when it does come up.

Self-Efficacy for Controlling Upsetting Thoughts about Caregiving

"How confident are you that you can control . . .	**CONFIDENCE (0-100%)**
1) . . . thinking about unpleasant aspects of taking care of your friend/family member?"	
2) . . . thinking how unfair it is that you have to put up with this situation (taking care of your relative / friend)?"	
3) . . . thinking about what a good life you had before your friend/family member's illness and how much you've lost?"	
4) . . . thinking about what you are missing or giving up because of friend/family member?"	
5) . . . worrying about future problems that might come up with friend/family member?"	

Accessing Support Services Scale

"How confident are you right now that you can	**CONFIDENCE (0-100%)**
1) . . . care for your relative without help from organisations or agencies that provide services?"	
2) . . . find organisations or agencies in the community that provide services to help you care for your relative?"	
3) . . . Get answers to all of your questions about these services?"	
4) . . . Arrange for these services yourself?"	
5) . . . Find ways to pay for these services	

Self-efficacy Medication Scale
0 (not at all certain) to 100(very certain)

"How certain are you right now that you . . .	CONFIDENCE (0-100%)
1) . . . understand possible side effects from medications your friend/family member is taking?"	
2) . . . know how many different medications that your friend/family member is taking?"	
3) . . . understand how your friend/family member should take his/her medications?"	
4) . . . understand why a new medication is prescribed for your friend/family member?"	
5) . . . can get answers to all of your questions about medications your friend/family member is taking?"	
6) . . . know the purpose of all of the present medications that you are taking?"	

In general how confident are you in taking care of your friend/family member? __________ CONFIDENCE (0-100)

Please Indicate the Number of sessions that you attended for this Education Series? _______________ (1-10) (Survey #2)

Do you have any other comments that you feel we should know e.g. what other kinds of service you would need)

____

____

____

Thank-you very much for your time and for the information that you have provided. If you have any questions please feel free to contact me at the above number. Please return this survey and your signed consent form at the next session.

Appendix E: Satisfaction Survey

Thank-you for being a participant in the VON Caregiver Education Series. We need your honest feedback about this program as we revise it for future presentation.

Please take a few minutes to answer the following questions. There are no right or wrong answers and your answers will remain strictly confidential. You will not be identified personally in any way.

Please rate the following aspects of this education program by placing a check (√) in the appropriate box:

	Poor	**Fair**	**Good**	**Excellent**
1. Quality of instruction				
2. Effectiveness of the facilitator in communicating the material covered?				
3. Material/Information Presented				
4. Number of sessions				
4. Length of each session				
5. Topics Covered				
6. Organisation of topics				
7. Facilities				
8. Breaks/Refreshments				
9. Overall rating				

10) Was the material covered in this workshop relevant to your particular problems and concerns as a caregiver?

a. Yes

b. No

Please explain

____

____

____

11) How convenient for you was the time of day at which the sessions were offered?

a. Very Convenient

b. Convenient

c. Somewhat

d. Not very

12) Would there have been a better time of day to attend? (Please be specific)

____

13) Here is the list of sessions that we have covered in the last 10 weeks. Please rate how useful or relevant to your caregiving experience. Please rate on a scale of 1 to 5. Please circle the number, with 1 representing the least useful or relevant and 5 as most useful or relevant.

least useful ☐ very useful

Session 1 Introduction to Caregiving	**1**	**2**	**3**	**4**	**5**
Session 2 Role Changes, Acknowledging your feelings, Self-Care	**1**	**2**	**3**	**4**	**5**
Session 3 Accessing and developing your resources	**1**	**2**	**3**	**4**	**5**
Session 4 How to identify stress, Stress test, Stress management Progressive Relaxation, Visualization, Relaxing Events	**1**	**2**	**3**	**4**	**5**
Session 5 Practical techniques to care, how-to techniques for personal care, personal hygiene, transfers (Guest Speaker)	**1**	**2**	**3**	**4**	**5**
Session 6 Medication Management (Guest Speaker)	**1**	**2**	**3**	**4**	**5**
Session 7 Understanding behaviours, behaviour management, environmental adaptations for behaviour and safety.	**1**	**2**	**3**	**4**	**5**
Session 8 Legal and financial matters: Power of Attorney	**1**	**2**	**3**	**4**	**5**
Session 9 Facility care/ End of life decisions and planning	**1**	**2**	**3**	**4**	**5**
Session 10 Appropriate Activities: how to involve your family member in more activities	**1**	**2**	**3**	**4**	**5**

14) Are there any topics that you would like more time spent on?

If yes which one (s)?________________________________

15) What, if anything, would you change about the program?

____

16) Would you recommend this education program to any other caregivers you know?

Yes (please comment) ____

No (please comment) ____

17) What was your goal/ reason for taking this series?

____

____

18 a) Did you meet that goal?

____

18 b) If no, what could be improved so you could meet that goal?

____

____

19) What other topic areas would you like to know about or be interested in future education series?

____

____

20) Please use the space below for any additional comments that you would like to make.

____

____

____