# "Special Steps": An Effective Visiting/Walking Program for Persons with Cognitive Impairment

Laurie Wishart, Jean Macerollo, Patricia Loney, Anne King, Lesley Beaumont, Gina Browne, and Jacqueline Roberts

On a procédé à l'évaluation d'un programme à l'intention des personnes âgées présentant une déficience cognitive et du personnel soignant, en fonction de l'efficacité et de l'efficience en ce qui touche la charge de travail, la satisfaction et le sentiment de cohérence de même que les coûts pour le système de santé. Ce programme consistait en des visites hebdomadaires de deux heures par des bénévoles, dans le but de faire une promenade. Au cours d'une période de 9 mois en 1997, on a choisi aléatoirement parmi les personnes admissibles un nombre qui aurait accès au programme dès le début de celui-ci (groupe expérimental) et un autre qui serait placé sur une liste d'attente en vue d'y participer six semaines plus tard (groupe de contrôle). Le groupe expérimental dénombrait onze bénéficiaires et membres du personnel soignant et le groupe de contrôle, dix. Tous ont répondu à un questionnaire au moment de l'échantillonnage et à la sixième semaine. L'évaluation de la charge de travail par les membres du personnel soignant du groupe expérimental n'a diminué que de 8 % (F = 6.8, p = .02). Celles-ci ont indiqué que le soutien et les moments de répit avaient été appréciés, et que les bénéficiaires avaient pris plaisir à

Laurie Wishart, PhD, PT/OT, is Assistant Professor, Faculty of Health Sciences, School of Rehabilitation Sciences, and System-Linked Research Unit on Health and Social Service Utilization, McMaster University, Hamilton, Ontario. Jean Macerollo, RN, is Coordinator, Special Steps Program, Victorian Order of Nurses, Halton (Ontario) Branch. Patricia Loney, BA, BHSc, MSc, is a graduate student, Department of Clinical Epidemiology and Biostatistics, McMaster University. Anne King, BScN, is Manager, Volunteer Services, Victorian Order of Nurses, Halton Branch. Lesley Beaumont, RLT, is Research Assistant, System-Linked Research Unit on Health and Social Service Utilization, McMaster University. Gina Browne, PhD, RN, is Professor, System-Linked Research Unit on Health and Social Service Utilization, Department of Clinical Epidemiology and Biostatistics, and School of Nursing, McMaster University. Jacqueline Roberts, MSc, RN, is Associate Professor, System-Linked Research Unit on Health and Social Service Utilization, Department of Clinical Epidemiology and Biostatistics, and School of Nursing, McMaster University.

la visite et à la promenade. Bien que cette étude n'ait couvert qu'une brève période et porté que sur un petit échantillon, il en ressort que des améliorations ont été notées sur le plan de la charge de travail, le personnel soignant ayant exprimé sa satisfaction à l'égard du programme. Celui-ci n'a représenté aucun coût additionnel pour la structure de la santé et des services sociaux.

A program for elderly persons with cognitive impairment and their caregivers was evaluated for its effectiveness and efficiency with regard to caregiver burden, sense of coherence, satisfaction, and cost to the health-care system. The program consisted of a weekly 2-hour visit and walk by volunteers. During a 9-month period in 1997, all eligible referrals were randomly assigned to receive the service immediately (experimental group) or be placed on a waiting list to receive it 6 weeks later (control group). Eleven caregivers/recipients formed the experimental group; 10 caregivers/recipients formed the control group. All completed questionnaires at randomization and at 6-week follow-up. Perceived burden decreased by 8% only for the caregivers in the experimental group (F = 6.8, p = .02). They indicated that they appreciated the respite and support and that the care recipient enjoyed the visit/walk. Although this study was short in duration and small in sample size, improvements were noted in perceived caregiver burden and caregivers expressed satisfaction with the program. The program did not result in additional health and social-service expenditures.

#### Introduction

Special Steps is a visiting/walking program for "at risk" elderly persons with cognitive impairment who are residing in their private homes. The program consists of in-home care and supervision by a trained volunteer on a regularly scheduled basis. An integral component of each visit is physical and/or psychological stimulation in the form of a walk or outing, depending on the physical capabilities of the client. The program is designed to improve the activities of daily living and the physical and social well-being of the client as well as the emotional health of the caregiver. Its mission is to enhance quality of life for the cognitively impaired elderly living at home and their caregivers, by providing respite and thus decreasing the caregiving burden, to extend the community support network, and to reduce social isolation.

## **Background**

Living with cognitive impairment can be devastating for both the person with the impairment and his/her caregiver, and thus poses a major challenge to the health-care system. Studies on caregiving show that a majority of elderly people with dementia live at home supported by a spouse, relative, or friend. Recent research findings indicate that although families will go to great lengths to avoid institutionalization, they are overburdened in trying to care for their relative with cognitive impairment (Miller, McFall, & Montgomery, 1991). Women make up

about three quarters of all caregivers (Malonebeach & Zarit, 1991; Stone, Cafferata, & Sangl, 1987). Wives and adult daughters provide most of the care and the most difficult types of care, with sons taking on the job of caregiving in the absence of a daughter to fulfil the role (Horowitz, 1985). In addition, a study by Brody, Kleban, and Johnsen (1987) concluded that women are more susceptible to conflict between employment and elder care and often get caught in the middle — sandwiched between caring for their children and caring for their parents (Brody, 1981).

Spousal caregivers are at highest risk of caregiver burden (Cantor, 1983; George & Gwyther, 1986; Tennstadt & McKinlay, 1989), are less likely to receive assistance from secondary caregivers, and may have some functional limitations (Tennstadt & McKinlay, p. 155). Adult sons and daughters are more likely than spouses to refer to stress or burden in the caring role (Johnson, 1983; Johnson & Catalano, 1983).

With increasing knowledge of the extent to which caregivers provide care, research has begun to focus on the impact of caregiving (Tennstadt & McKinlay, 1989, p. 155). Stress and burden are associated with caring for elderly persons with dementia. According to Zarit, Reever, and Bach-Peterson (1980), caregivers of the elderly with dementia often feel isolated, fatigued, and overwhelmed by the demands of caring. These symptoms are often labelled "caregiver burden" (George, 1987; Horowitz, 1985). Caregiver burden can refer to "any negative implications for mental health, for social or recreational involvement, for financial difficulties, and/or for physical health problems" (Chappell, 1992).

Studies consistently show that caregivers experience and report negative effects such as stress, strain, and depression in relation to their helping role (Jackson, Cooney, Walsh, & Coakley, 1991; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Poulshock & Deimling, 1984; Reese, Gross, Smalley, & Messer, 1994; Zarit, Todd, & Zarit, 1986). Their physical health may also be affected (Neundorfer, 1991). These effects, however, are not experienced by all caregivers and, overall, caregivers try to adapt (Horowitz, 1985).

Most of the research on stress and burden associated with the helping role has focused on caring for persons with dementia, documenting the physical, psychological, and social implications of providing care and the importance of interventions (Zarit, Antony, & Boutselis, 1987). George and Gwyther (1986) conclude that caregivers of persons with dementia feel more burdened than caregivers of the physically frail. Although interventions to relieve caregiver burden

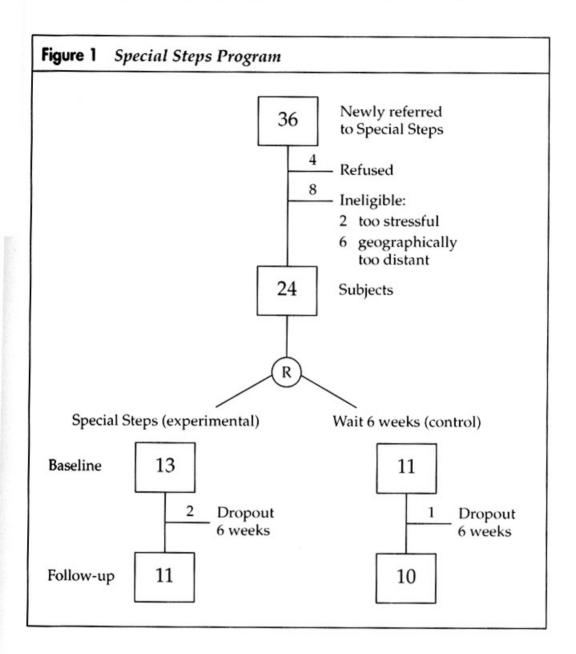
have been recommended, few studies have measured the effectiveness of such interventions using randomized control trial (RCT) methodology. The main finding of a recent review of the literature on the effectiveness of interventions for caregivers of relatives with cognitive impairment was that more research is needed; respite services for clients with cognitive impairment resulted in a reduction in nursinghome placement but little reduction in caregiver burden (Roberts et al., in press).

No evaluations of interventions using volunteers in a walking program in a home setting were found. A community-based exercise and walking program has been initiated, but efficacy results have not been published (Teri et al., 1998). Two studies evaluated walking programs in long-term-care facilities. Using an RCT design, Friedman and Tappen (1991) concluded that a walking and conversation program was beneficial for maintaining communications skills in patients with Alzheimer's disease in nursing homes. An institutionally based walking program was found to be effective, using a pre-post test design, in reducing the number of aggressive events by the client (Holmberg, 1997).

This trial was initiated to evaluate a community-based visiting/ walking program provided by volunteers to reduce caregiver burden among those caring for relatives with cognitive impairment. Since few studies have documented health-care costs, it was also intended to measure health-care utilization, which involves identifying the use of health and social services and their associated costs.

### Methodology

All clients with cognitive impairment referred to the Special Steps Program by community agencies, health professionals, or their family during the 9-month evaluation period were randomized to receive a volunteer visitor as soon as possible, usually within 2 weeks (experimental group), or later, after 6 weeks (control group). Questionnaires were completed by their caregivers at baseline and at 6 weeks (Figure 1). Randomization was carried out by computer-generated random assignment to group, and group numbers were placed in sealed opaque envelopes. Grouping was blocked after every four assignments so that groups would not differ greatly in sample size. Clients were eligible for the program if they had a caregiver, had a cognitive impairment, and were able to go on outings. Those consenting to complete the questionnaires and to participate were included in the trial.



# Research Questions

- 1. Is there a difference in mean change score (baseline to follow-up) in caregiver burden, social support, and health-care expenditures between experimental and control groups?
- 2. Are informal caregivers of persons with cognitive impairment satisfied with the Special Steps Program?

### Special Steps Volunteers

The volunteer's role was to provide assistance and companionship to an elderly person with a cognitive impairment and/or a related disorder through a visiting/walking program. The volunteer was expected to make a commitment to the client of 2 hours each week, as well as to attend two 3-hour training sessions prior to being matched with a client and to attend monthly meetings with program staff. The Victorian Order of Nurses (VON) provided ongoing support and information and were available at all times should the volunteer have any concerns or any changes to report. The two training sessions covered education in cognitive impairments, including Alzheimer's disease, and behavioural changes; the volunteers were specifically trained in walking with clients with cognitive impairments and engaging them in conversation.

The Special Steps Program was designed as a pilot project but has become part of the regular services offered by the community health agency. The volunteer continues the weekly visits for as long as the caregiver finds them beneficial. For the purposes of this study, however, the intervention was evaluated over the first 6 weeks only.

### **Experimental Group**

Thirteen clients randomized to the experimental group were matched with volunteers. Matching was based on interests and geographic proximity. The volunteers were mostly women. One third were college students; the remainder were seasoned community volunteers. The volunteers visited once a week for 6 weeks, the visits averaging 2.5 hours (range = 1-3 hours) in duration. Activities consisted of crafts, outings, and walks tailored to the client. All caregivers completed baseline measures; 11 completed the 6-week measures. Two clients with cognitive impairment did not complete the program: one died and one became too ill to participate.

# **Control Group**

The caregivers of the 11 clients randomized to the control group completed baseline measures; 10 completed the 6-week measures. Clients in the control group were placed on the waiting list for a visitor in 6 weeks, at which time five of them began the program.

#### Measurements

All questionnaires were completed in written format and sent to the university for analysis. All 24 caregivers completed the questionnaire at baseline (before randomization); 21 completed it 6 weeks after the inter-

vention. However, two caregivers did not complete the social-support questionnaire.

**Sociodemographic questionnaire.** Client data on age, gender, education, culture, income, living arrangements, and caregiver support characteristics were collected via an interview. These questions were specifically developed for this study.

Health and social service utilization. The health and social service utilization outcome variable was measured using an inventory developed by Browne (Browne, Arpin, Corey, Fitch, & Gafni, 1990) based on Spitzer's methodology. It consists of questions about the respondent's use of direct health services: primary care; emergency room; hospital episodes and days (irrespective of episode); other health professionals; and laboratory services. Psychometric information for this inventory has not been published. Inquiries were restricted to a 6-week recall span. To calculate annual utilization costs, the various spans of time were extended per category of health service and multiplied by the dollar value of the service to yield a per person/per annum cost for health and social services.

**Social support.** The 8-item Duke-UC Functional Support Questionnaire measures the functional aspects of supportive relationships on a 5-point scale under the headings *confident support* (5 items) and *affective support* (3 items), with response options ranging from "as much as I would like" to "much less than I would like." Criterion validity is considered good and test-retest reliability is r = .66 (Broadhead, Gahlback, deGruy, & Kaplan, 1988).

Client satisfaction. This 8-item questionnaire was completed by the caregiver on a scale of 1 to 4, indicating dissatisfaction or satisfaction with global and specific aspects of the program. The questionnaire was given a total score. Content, construct, and predictive validity have been reported as satisfactory, and it has good split-half reliability and high internal consistency (% = .84) (Nguyen, Attkisson, & Stegner, 1983).

Caregiver burden. This interview questionnaire has 22 items and a 5-point scale evaluating the subjective impact of caregiving. Internal consistency using Cronbach's alpha has been estimated at .88, test-retest reliability at .71 (Zarit et al., 1986; Zarit, Orr, & Zarit, 1985).

### Analysis

Experimental and control clients and caregivers were described and compared on variables at baseline. Change scores on outcome variables were compared using analysis of variance statistical analysis (ANOVA). The alpha level was set at .05 using the SPSS 8.0 computer program. At baseline, members of the control group were of a higher educational level. Since it was thought that level of education might have an effect on caregiver burden and as the sample was small, ANCOVA was used to equate the two groups on this important variable (Munro, 1997).

#### Results

### Sample

Of the 36 caregivers approached, four refused to participate because they did not have the time to complete the questionnaire and eight were ineligible (six did not live close by and two were too stressed). Thus 13 caregivers were randomized to the experimental group and 11 to the control group. At 6 weeks there were three dropouts due to death or illness, two in the experimental group and one in the control group.

Two caregivers did not give their age. The remainder had a mean age of 58 years; the majority were daughters or daughters-in-law; most had a high school education; all spoke English. They spent an average of 14 hours per day with their relative; 67% lived with the relative. Care recipients had a mean age of 80 years; 80% were women; approximately one half had an adequate income. There was equal distribution of severity of condition, with one third having mild, one third moderate, and one third severe dementia (Table 1). The two groups of caregivers were compared at baseline. A statistically significant difference was found in educational level, with the control group having more years of education (t = 2.63, p = .02) (Table 1).

# Satisfaction

The 11 caregivers in the experimental group were very satisfied with the program, indicating that the quality of the service was excellent and they would recommend it to a friend. Mean satisfaction score was  $3.62 \pm .32$  out of 4 (with 4 indicating very satisfied) (Table 2).

 Table 1
 Description of Caregiver

 and Care Recipient Characteristics

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	To:		Specia	l Steps	Con	trol	Stat	istic
	Ме	an	Mean	SD	Mean	SD	t	P
Caregivers								
Age in years $(n = 20)$	57	.6	58.2	12.4	56.8	15.5	.22	.83
Education in years	14	.3	12.9	2.4	15.8	2.7	2.63	.02*
Hours spent with relative ( $n = 20$ )	14	.0	16.9	8.7	11.9	01.8	.96	.35
Care Recipients								
Age in years $(n = 20)$	80	0.2	81.4	8.1	78.7	7.6	0.76	0.46
	N	%	N	%	N	%	x <sup>2</sup>	P
Caregivers								
Sex: Female	2e + 17	86	1e+13	91	9e + 12	80	.51	.48
English only language		76		73		80	.15	.70
Relationship Husband Wife Daughter Other		19 14 62 5		27 9 64 0		10 20 60 10	2.37	.50
Live with		67		73		60	.38	.54
Income Low Medium High		38 57 5		55 45 0		20 70 10	4.49	.21
Severity of illness Mild Moderate Severe		33.3 33.3 33.3		27 27 46		40 40 20	1.53	.47
Care Recipients								
Sex: Female $(n = 20)$	16	80	8	73	8	89	.81	.37

	Excellent		Good		Fair		Poor	
	N	%	N	%	N	%	N	%
Quality of service	10	91	1	9	0		0	
Kind I wanted	8	73	3	27	0		0	
Met my needs	4	36	6	55	1	9	0	
Recommend to a friend	9	82	2	18	0		0	
Satisfied with help	7	64	3	27	0		1	9
Helped me deal with problems	7	64	4	36	0		0	
Generally satisfied	7	64	4	36	0		0	
Would come back	10	91	1	9	0		0	

## Caregiver Burden

The statistical assumptions for ANOVA (data normalcy and homogeneity of variances) were met for the burden change score. Since there was a difference in educational level between the groups at baseline, education was used as a covariate. There was a difference of 2.5 in the burden change score, and using ANCOVA there was a statistically significant difference between groups (F = 6.8, p = .02), with those in the experimental group lowering their burden by 8% and those in the control group increasing their burden by 3% (Tables 3 and 4). The confidant social support improved for the experimental group and decreased for the control group; however, there was no statistical difference in social support change between groups (Table 3).

### Health and Social Service Utilization

Annualized average health expenditures for the two groups were compared at 6 weeks. Average expenditures for services were \$2,575 per caregiver and \$11,667 per care recipient. Interestingly, the majority of expenditures were for homemaker services. There was no statistically significant difference between the two groups.

Table 3	Comparison Between Groups of Mean Change Scores
	in Social Support and Burden

	Special Steps			Control			Statistic	
Variable	N	Mean	SD	N	Mean	SD	t	P
Social support change score								
Confidant support	9*	1.10	2.3	1010	20	2.9	1.11	.28
Affective support	9*	44	2.9		.00	2.4	.37	.72
							F	P
Burden	11	-4	6.8	10	1.51	9	6.76	.02

<sup>\*2</sup> subjects did not answer questionnaire.

Table 4 ANCOVA: Differences Between Experimental and Control Group in Caregiver Burden When Education Level Controlled

Variable	df	ms	F	P
Covariate: Education	1	241.9	4.63	0.045
Mais Effect: Groups Effort	118	353.4 52.3	6.78	0.018

#### Conclusion

Caregivers in the experimental group were extremely thankful for and satisfied with the Special Steps Program, perceiving less caregiver burden than those in the control group. Quantitative results show a significant decrease in perceived caregiver burden with the program. This finding was supported by qualitative comments by the caregivers, which were collected in an unstructured interview by the research assistant. Although no formal analysis was made of these comments, they raise interesting points. The benefits of the program are described eloquently by two of the caregivers: "As the volunteer is skilled and aware of behaviours, I have not had to worry about attending with the volunteer and it has eased my feelings of responsibility." "She helped me bear and share the shock of the change my mother-in-law was going

through and it is very comforting to know that someone was visiting her without judging her in any way." The volunteers found the training worthwhile and indicated that they enjoyed the experience, as expressed by one of the volunteers: "It is satisfying to know you have made someone's day a little brighter." Open-ended comments by clients and volunteers indicate that the program director, a VON nurse, was important to the success of the program.

#### Discussion

The results of this study indicate that the informal caregivers of older adults with dementia can benefit from a regular walking program provided by trained volunteers. This program was developed and coordinated by nurses at a community agency, who recruited, trained, and provided ongoing support to the volunteers. The volunteers were recruited through college programs, agencies such as the Alzheimer Society, and newspaper advertisements and mall displays. Most were female. They were either students, retired women, or part-time workers. Most had previous volunteer experience. The elderly clients and their caregivers were recruited on the basis of whether they were likely to benefit from the program. The Special Steps Program is relatively easy to set up and is administered through community access centres.

This study provides preliminary evidence of the benefits of a walking program provided by volunteers in the home setting. The last several years have seen the development of many formal day programs to help the elderly with dementia maintain their skills and functioning by offering them the opportunity to participate in meaningful activities. Many of these programs have not been evaluated. Results from the limited number of methodologically sound evaluations that do exist support the benefits of a variety of purposeful activities such as the walking and conversation program described in this paper (Bach, Bach, Bohmer, Gruhwalk, & Grik, 1995; Friedman & Tappen, 1991; Koh et al., 1994). For a recent review of the effectiveness of activity programs for older adults, see Occupational Therapy Evidence-based Practice Research Group, McMaster University (1999).

The results of this pilot study should be interpreted with its limitations in mind. The study, although an RCT, had the following design limitations: small sample size, relatively short intervention period, and no direct measure of the effects on the client with cognitive impairment. Of interest would be physical and emotional clinical outcomes. Despite these limitations, which affect the generalizability of results, this study

provides preliminary evidence to support the benefits of reducing caregiver burden through a relatively inexpensive program coordinated by community nurses.

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#### Authors' Note

This evaluation was supported by a New Horizons Grant, Partners in Aging Project, Health Canada, and the System-Linked Research Unit, McMaster University.

Correspondence should be directed to Jacqueline Roberts, System-Linked Research Unit, McMaster University, HSC 3N28, 1200 Main Street West, Hamilton ON L8N 3Z5 Canada. Telephone: 905-525-9140, ext. 22725. Fax: 905-521-8834. E-mail: <robertsj@fhs.csu.mcmaster.ca>.