

Peer Visitor Support for Family Caregivers of Seniors with Stroke

Miriam J. Stewart, Susan Doble, Geraldine Hart,
Lynn Langille, and Kathleen MacPherson

Les objectifs de cette étude d'intervention subventionnée par de multiples organismes canadiens étaient de : (1) mettre en place un programme de soutien fondé sur des visites à domicile menées par des paires compétentes et destinées aux soignantes naturelles des personnes âgées ayant subi récemment un accident cérébrovasculaire; (2) surveiller, décrire et évaluer l'intervention de soutien; et (3) mesurer l'impact de l'intervention de soutien menée par des paires sur les perceptions des soignantes naturelles concernant le soutien qu'elles reçoivent de la collectivité, leur fardeau, leur stress et leurs compétences, ainsi que l'utilisation des services de santé par les survivants d'un accident cérébrovasculaire. Les deux premiers objectifs constituent le point de mire de cet article. Vingt soignantes naturelles ont d'abord été visitées par une professionnelle de la santé (infirmière, ergothérapeute) pour une évaluation, puis par une paire (soignante naturelle ayant vécu la même expérience), à une fréquence de deux fois par semaine, pendant 12 semaines. Les transcriptions d'entrevues enregistrées qui ont été menées auprès des participantes peu de temps après l'intervention et aussi quelque temps après (trois à six mois), et les cahiers d'écoute des professionnelles et des paires ont été soumis à une analyse de contenu. Les paires visiteuses offraient, aux soignantes naturelles, un soutien émotif, ainsi qu'un appui sur le plan de l'information et de l'affirmation. Les soignantes naturelles ont affirmé que l'intervention était satisfaisante en ce qui avait trait à leurs besoins en soutien, qu'elle contribuait à une diminution de certaines de leurs demandes en soins de santé et consolidait leur confiance personnelle et leur capacité d'adaptation.

The objectives of this nationally funded intervention study were to: (1) implement a home visiting support program for family caregivers of seniors with a recent stroke using experienced peers; (2) monitor, describe, and evaluate the support intervention process; and (3) measure the impact of the peer support intervention on caregivers' perceptions of their social support, burden, stress, and competence and the use of health-care services by stroke survivors. This paper focuses on the first two objectives. Twenty family caregivers were visited initially by a health professional (nurse, occupational therapist) for assessment, and thereafter twice weekly for 12 weeks by a peer (experienced family caregiver).

Miriam Stewart, M.N., Ph.D., is Professor, Faculty of Nursing, and Director, Centre for Health Promotion Studies, University of Alberta, Edmonton. Susan Doble, M.Sc., Ph.D.(Cand.), is Associate Professor, School of Occupational Therapy, Dalhousie University, Halifax, Nova Scotia. Geraldine Hart, M.N., is Associate Professor, School of Nursing, Dalhousie University, Halifax. Lynn Langille, M.A., is Research Associate, Atlantic Health Promotion Research Centre, Halifax. Kathleen MacPherson, M.D., M.P.H., is Coordinator, Geriatric Program Development and Research, Centre for Health Care of the Elderly, Queen Elizabeth II Health Science Centre, Halifax.

Transcripts of audiotaped post-intervention and delayed post-intervention (3 and 6 months) interviews with participants and the diaries/logs of professionals and peers were subjected to content analysis. Peer visitors offered emotional, informational, and affirmational support to family caregivers. Family caregivers reported that the intervention met their support needs, lessened some of their caregiving demands, and enhanced their confidence and ability to cope.

Older Canadians are more likely than others to suffer from chronic conditions (Health Canada, 1997) that restrict their activities (Rosenberg & Morre, 1997). Most Canadians living with chronic conditions (Statistics Canada, 1997) and most elderly people (Canadian Study of Health and Aging Working Group, 1994) are cared for and supported by family members. Stroke is a common chronic condition that afflicts the elderly, results in disability and caregiver burden, and accounts for a significant proportion of hospitalizations and deaths among seniors. Stroke represents 19% of all deaths from cardiovascular diseases; stroke was the cause of 7% of deaths in Canada in 1994 and accounts for 40% of patient days in hospital (Heart and Stroke Foundation of Canada, 1997). Whether or not survivors are discharged to their home depends upon the severity of stroke deficits and the willingness and ability of family members to help them to live in the community (Macnamara, Gummow, Goka, & Gregg, 1990).

Studies suggest that family caregivers of elderly persons with stroke need support and guidance as they cope with the demands of the caregiving situation (Anderson, Linto, & Stewart-Wynne, 1995; Smurawska, Alexandrov, Bladin, & Norris, 1994; Williams, 1994). Demands encountered by caregivers relate primarily to the stroke survivor's behaviour and physical care (Macnamara et al., 1990; Williams). Confidence in their ability to handle the challenges of the caregiving role may diminish. Furthermore, the caregiver's relationship with their elderly relative with stroke may suffer. Caregivers face adjustment difficulties following a family member's first stroke (Schultz & Tompkins, 1990). Given the stress associated with their new caregiving role, they may experience negative mental and physical health outcomes (Canadian Study of Health and Aging Working Group, 1994; Statistics Canada, 1997; Tyman, 1994).

Given the potential deficits in support from the natural network and the need for support specific to caregiving demands, support interventions for the family caregivers of stroke survivors are important. Such interventions can modify or mobilize natural networks, create new sources of support, decrease conflict, enhance the quality of support (Barrerra, 1991; Maguire, 1991), or moderate the costs of providing and seeking support (Fisher, Goff, Nadler, & Chinsky, 1988).

Support interventions are most useful when they enhance role functioning, develop new skills, enable coping (Heller, 1990), or alleviate social isolation (Maguire).

The support portion of intervention programs for caregivers of seniors is typically not explicated and not matched to caregiving burdens or demands. Furthermore, intervention programs have emphasized professional rather than lay/peer support (e.g., Forster & Young, 1996). Finally, support intervention studies for family caregivers of the elderly have not focused explicitly on caregivers of stroke survivors.

Objectives

The objectives of this nationally funded intervention study were to: (1) implement a home visiting support intervention, delivered by experienced peers, to address the caregiving demands and support needs of family caregivers of seniors with a recent stroke; (2) monitor, describe, and evaluate the support intervention processes; and (3) measure the impact of the peer support intervention on caregivers' social support, caregiving demands, stress, and competence and the use of health-care services by stroke survivors. This paper focuses on the first two objectives and the evaluation of the support intervention process.

Research Questions

1. What types of social support are provided by the peer visitor intervention?
2. What are family caregivers' perceptions of the support intervention processes?
3. What are family caregivers' perceptions of the impact of the support intervention on their caregiving demands, support needs, and coping?

In order to document the caregiving demands and support needs discussed with peer visitors (intervention processes) and to provide background information for the perceived impact of the intervention on caregiving demands and support needs, supplementary research questions were posed:

4. What caregiving demands are experienced by new family caregivers of seniors with stroke?
5. How do family caregivers of seniors with stroke appraise their support needs?

Theoretical Context

Partners/spouses, family members, friends, neighbours, and coworkers (House, Umberson, & Landis, 1988) may all be sources of support to those caring for elderly persons with stroke. The four specific functions or types of social support are: emotional, instrumental (practical), informational, and affirmational (House et al.). By communicating information, esteem (affirmation), aid (practical support), and emotional help, support providers may enhance the caregiver's ability to cope, moderate the impact of perceived stressors, and promote health (Stewart, 1993).

Integration in a social network and ability to draw support resources from the network can help maintain health and facilitate physical recovery (Bloom, 1990). However, not all persons caring for an elderly person with stroke have people in their social network who are willing and able to provide support. Health and illness can affect the availability and quality of social support. The continued need for social support in chronic stressful situations like illness and caregiving can deplete support and drain the social network of resources that contribute to support (Stewart, 1993).

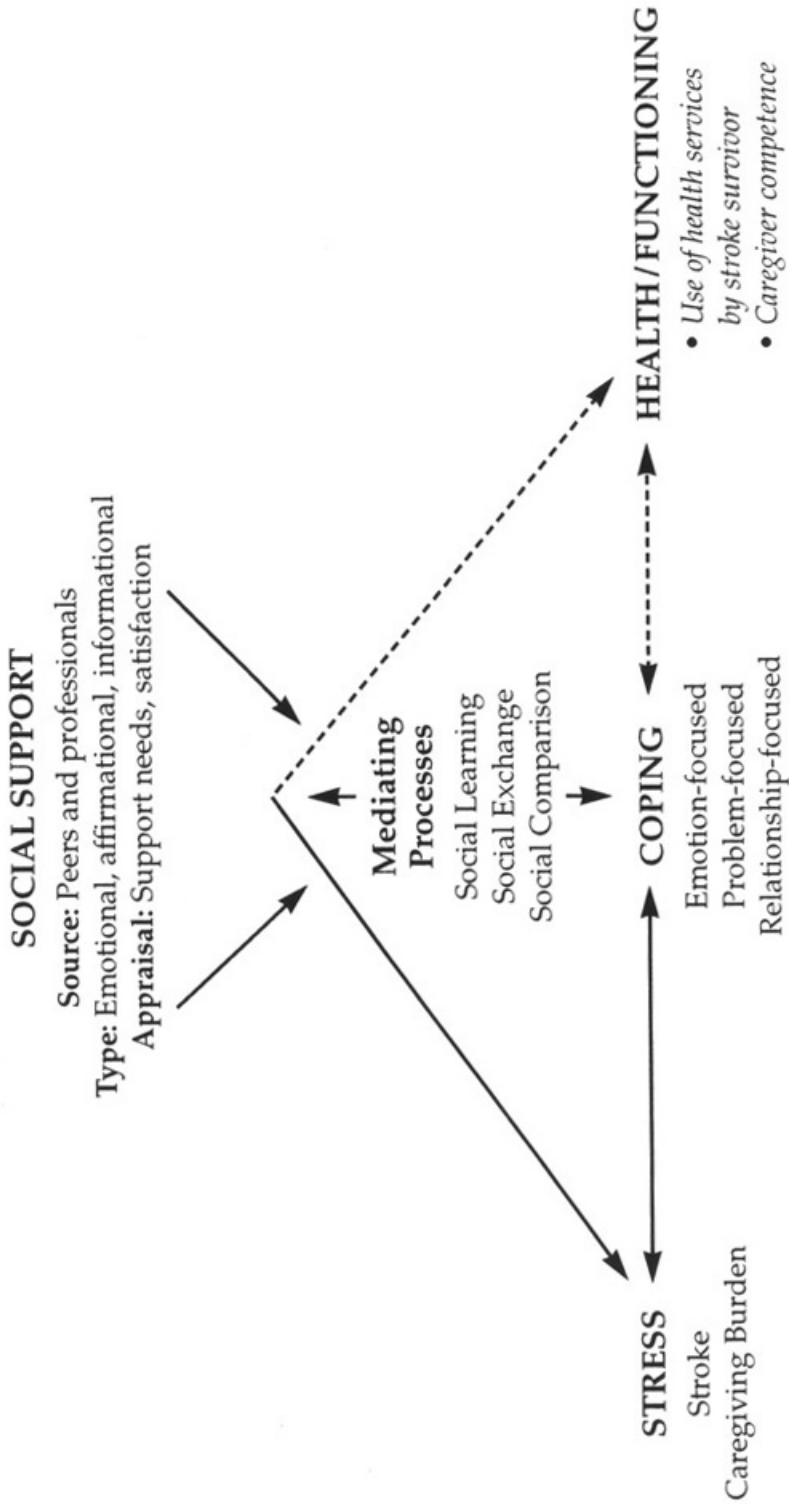
Support functions will be most effective if they are matched to specific stressors encountered (Cutrona, 1990). Furthermore, specific types of support are most effective when they are provided by sources that are perceived by the recipient as supportive (Dakof & Taylor, 1990). Thus, even when caregivers have supportive persons in their networks, these persons may not be able to provide them with the specific support they need to manage their caregiving demands. Their support efforts may have negative effects (Brenner, Norwell, & Limacher, 1989). Indeed, most social relationships have supportive and stressful elements (Rook, 1990). Even successful relationships involve lapses in support, miscarried efforts (Sarason, Sarason, & Pierce, 1990), and failed support modes or functions (Eckenrode & Gore, 1990). These negative effects are most likely to occur when there is a continued need for social support in chronic stressful conditions such as caring for a senior with a stroke. Moreover, negative interactions are more predictive of poor emotional health than supportive interactions (House et al., 1988; Rook). These drawbacks of support affect both support providers and support recipients.

Social support is conceptualized as a coping resource or coping assistance (Thoits, 1986). Supportive persons can alter appraisal of caregiving stressors, sustain coping efforts, influence choice of coping strategies, augment coping resources available to deal with stressful encounters, and change the trajectory of coping. Moreover, perceived availability of social support has been linked to coping effectiveness (Bennett, 1993). Conversely, the ways in which the caregiver copes may provide important clues to potential supporters about whether support is needed and, if it is, about the types of support needed (Silver, Wortman, & Crofton, 1990). Coping with caregiving can be conceptualized as managing distress (emotion-focused), completing instrumental tasks (problem-focused) (Lazarus & Folkman, 1986), and attending to each other's needs in the caregiver/stroke survivor relationship (relationship-focused) (Coyne & Smith, 1991).

This intervention focused on provision of peer support to supplement the depleted or strained networks of family caregivers, by offering emotional, informational, and affirmational assistance (House et al., 1988). Peer support has a potential effect on coping efforts, and may influence the choice of coping strategies (Folkman et al., 1991). Furthermore, peer support may influence the use of health services by stroke survivors.

Three mediating processes were anticipated within this support intervention. The process of *social comparison* occurs among peers, and, depending on the direction and dimension of comparison, will influence emotions and coping effectiveness (Gottlieb & Selby, 1989). Norms of equity or *social exchange* suggest that support should be bidirectional (Tilden & Galyen, 1987). However, persons who are ill and their caregivers frequently form non-egalitarian, non-reciprocal relationships (Tilden & Galyen). As social exchange and equity theories indicate, support may involve benefits and costs for both recipients and providers. Yet reciprocity is neglected in many social-support studies (Winemiller, Mitchell, Sutcliffe, & Cline, 1993). Interventions involving peers typically promote reciprocity (Katz, 1993). *Social learning* theory posits that people's perception of their capabilities (self-efficacy) affects their behaviour, thinking, and emotional reactions in stressful situations (O'Leary, 1985) and that personal and situational influences alter coping behaviour (Bandura, 1986). Thus family caregivers may learn from peer visitors as role models.

Figure 1 *Conceptual Framework*



(Italics = quantitative results reported in a separate paper)

Methods

Intervention Design

This intervention introduced guidance and information around caregiving within the context of a supportive relationship with an experienced peer. As family caregivers themselves, the peers had an understanding of the caregiver's situation and an appreciation of the caregiver's concerns about caregiving demands and about her/his performance. Participants received two home visits per week for a period of 12 weeks. The support intervention was implemented soon after the elderly person who had an initial stroke was discharged from hospital. This is the point at which new caregivers may be most fearful, lacking in confidence, in need of someone to ease their apprehensions about caregiving demands, and in need of ongoing reinforcement in performing specific caregiving tasks.

The professional completed a preliminary assessment of the stroke survivor's functional status in the home and accompanied the peer at the first intervention session. Once the professional withdrew, she/he was on call (as a consultant) to deal with problems or concerns raised by either the peer or the family caregiver.

The peer visitor conferred periodically with the professional; provided ongoing emotional, informational, and affirmation support; and monitored the caregiver's needs and the unanticipated effects of the intervention for both the caregiver and the stroke survivor.

The specific types of support provided by peers and professionals, and the support processes inherent in the intervention, are delineated below, in the third and fourth subsections of the Results. The conceptual underpinnings of the intervention are described above, in the section entitled Theoretical Context.

The guide for peer visitors encompassed specific issues and strategies pertaining to each of four caregiver burden domains — physical care, changes in family life, changes in caregiver roles, and emotional needs of caregivers — that might be raised in peer-caregiver interactions. The peer visitor listened carefully to the caregiver, offered suggestions concerning coping with different burden domains, encouraged problem-solving, and dealt with interpersonal tensions between the caregiver and the care recipient that might reduce the efficacy of caregiving.

Several steps were taken to control sources of bias and other potential problems. The professionals received specific project-related train-

ing in observation techniques and evaluation criteria. Both professionals and peers received empathy training. Peer visitors were taught how to document the delivery of support in diaries. All participants were encouraged to refrain from discussing details of the intervention with other caregiving families during the study period.

Family caregivers were assured that their participation was voluntary, that they could withdraw at any time, that confidentiality and anonymity would be protected, and that only group data and anonymous quotes would be presented in reports of results. The project received ethical approval from the research team's university.

Project Personnel

The health professionals — nurses and occupational therapists — were recruited to provide ongoing support and guidance to the peer visitors. The health professionals used their assessment, communication, teaching, and supervisory skills to help the peer visitors to: (a) maintain the major focus on the family caregivers' needs; (b) encourage the caregivers to share their experiences; and (c) provide emotional support by listening to the caregivers' stories. By providing situation-specific feedback, the professionals enabled the peers to hone their interaction skills and boost their confidence in their ability to provide effective support.

All peers had experience caring for a relative or another elderly person recovering from stroke. Most had cared for mothers; a few had cared for husbands. Although this was not a criterion, all of the peers selected were women. All had well-developed communication skills. Selection of peer visitors was based in part on whether they lived reasonably near a caregiver.

Potential peer visitors and professionals for the intervention study were easily identified through stroke clubs and newspaper advertisements.

To prepare peers and professionals for the program, a one-day training session was held, focusing on how personal beliefs might affect peers' ability to provide support, ways of using personal strengths or obtaining assistance from professional partners, and strategies for creating supportive partnerships that might reduce caregiver isolation and build caregiver competence. Simulated situations and role playing were used. Strategies were identified for assisting individuals who might need more support than the intervention could offer.

Sample Selection and Recruitment

The convenience sample was drawn from family caregivers and elderly stroke survivors across Nova Scotia and New Brunswick. The inclusion criteria for persons with stroke were: men or women 55 years or older who had experienced a stroke for the first time, had been recently discharged from hospital to the community, and continued to have a deficit or range of deficits. The inclusion criteria for family caregivers were: spouses or children who either lived with the elderly person or visited on a daily basis and saw themselves as the primary caregiver.

The convenience sample was recruited through numerous community sources, including professional associations, practitioners, consumer groups, non-governmental organizations (NGOs), and public avenues such as the media. To ensure recruitment of a sufficient number of caregivers, multiple avenues (print and electronic media, church bulletins, neurologists and family physicians, stroke clubs, hospitals, Victorian Order of Nurses, Heart and Stroke Foundation, etc.) were used. Although interest was expressed by all groups, few referrals resulted. The lack of initiative on the part of the health professionals approached for referrals may have been a result of their busy schedules and other priorities. For example, calls to 900 family physicians resulted in only three referrals.

Evaluation of Intervention Process: Data Collection and Analysis

The provision or delivery of support was documented. After each visit, the peer helper recorded the diary account of the visit, describing subjects of conversation and documenting types of support provided. The professionals kept records of contacts with peers and family caregivers. The family caregiver also commented on types of support received and satisfaction with the intervention during the post-intervention interviews and interviews 3 and 6 months later.

Transcripts of the audiotaped post-intervention and delayed post-intervention (3 and 6 months) interviews of participants (family caregivers) and the peer and professional diaries/field notes were content analyzed using a category system that was developed inductively from the data by the research team. The research assistant coded the data in consultation with the principal investigator. The data were analyzed for both manifest and latent content. The units of analysis were full references to any content related to: (1) nature of the demands involved in caring for an elderly relative with a chronic condition; (2) caregivers' reactions to those demands; (3) types, sources, and appraisal of support

from social networks and from peers; (4) support intervention processes; and (5) impact of the intervention. Each category and subcategory was fully and clearly defined and categories were mutually exclusive. Frequency counts of categories and subcategories were identified using *Ethnograph*. (Five measures — social support, caregiving confidence, caregiver burden, global perceived stress, and use of health services — were administered pretest, post-test, and delayed post-test [3 and 6 months]. These quantitative results, which address the third objective, are reported in a separate paper.)

Profile of Family Caregivers

All 20 caregivers were women, average age 58.8 years ($SD = 10.66$). Most caregivers (90%) were married, and the spouse of the stroke survivor (65%). The remainder were daughters (20%), daughters-in-law (5%), and other relatives (10%) of the stroke survivor. Over half (60%) of the caregivers had not completed a high school education. Generally, the caregivers provided care to older ($M = 70.8$ years, $SD = 12.54$) males (90%) with whom they lived (85.5%). On average, those caregivers who lived with the stroke survivor had lived with them for over 30 years. The average interval between the time of the stroke and the start of the support intervention was 9 months ($SD = 4.61$), although some caregivers were visited as early as 3 months following the stroke ($range = 3$ to 18 months).

Results

The key themes and sub-themes identified in peers' diaries, professionals' field notes, and interviews with the caregivers are summarized below. Pertinent quotations from family caregivers, peer visitors, and project professionals are interspersed throughout.

Demands of Caregiving (RQ4)

These new caregivers of stroke survivors eloquently described the primary demands of caregiving to peer visitors and during post-intervention interviews. These demands included providing physical care, managing emotional and behavioural reactions of the stroke survivor, coordinating the health care of the stroke survivor, and facilitating the occupational and social functioning of the stroke survivor.

All caregivers expressed considerable concern to peer visitors about managing the symptoms and deficits experienced by their family member with stroke. They worried about the effects of the stroke, the

Table 1 *Primary and Secondary Demands of Caregiving*

Primary Demands	(N = 20)
A. Physical Care	
Managing/worrying about symptoms/deficits	20
Constancy of care/constant responsibility	15
Assisting with activities of daily living	10
Adhering to a schedule/routine of care	8
Managing crises	5
B. Dealing with Emotional and Behavioural Reactions of Stroke Survivor	
	17
C. Coordinating Formal and Social Health Care of Stroke Survivor	
Interacting with health professionals and/or health-care system	14
Making appointments	8
Negotiating/clarifying caretaking roles with family	5
Arranging for community services	3
Advocating for stroke survivor's care	2
D. Facilitating the Occupational and Social Functioning of Stroke Survivor	
	8
Secondary Demands	
A. Personal Needs of Caregiver	
Respite/time off	17
Fatigue — getting rest/sleep	16
Managing own illness(es)	13
Dealing with own emotional reactions or concerns	12
Planning for the future	4
B. Effect on Family	
Finances	9
Family relationships	8
Marital relationships where stroke survivor is a spouse	6
Housing requirements	4
Loss of friendships	3
Marital relationships where stroke survivor is not a spouse	2
C. Family Caregiver Role Involvements	
Other caregiving commitments	8
Paid work outside home	5
Household maintenance and responsibilities	3

deterioration of the survivor's health, and the possibility of another stroke. Many caregivers (75%) spoke of the constancy of worrying about the stroke survivor and their vigilance concerning symptoms, medication use, and other aspects of care. They were reluctant to leave the stroke survivor alone and felt "tied down." Caregivers fulfilled a variety of physical functions, including changing dressings and treating minor physical problems. Many caregivers (50%) assisted the stroke survivor with dressing, eating, getting to the bathroom, washing, and other personal activities of daily living. Other physical care demands included adhering to a routine of care (40%) and managing crises (25%). The following examples were documented in the peer visitor diaries.

CG can't go unless stroke survivor (SS) is okay. She can't stay too long. Meals are prepared around what SS can eat and when. [peer visitor — PV]

CG is sure her mother is going to have another stroke as her blood is changing every test and that is what it did before. It will be a year in April and she can't shake the feeling. [PV]

In the initial post-intervention interview, one caregiver said:

The thing is she's on my mind whether she falls or if she has more strokes, which could happen any time... [caregiver — CG]

Caregivers reported to peer visitors that they found it difficult to deal with the emotional and behavioural reactions of the stroke survivor (85%). Caregivers indicated that sometimes stroke survivors behaved towards them in ways that were unkind, unappreciative, and even abusive. Problems with memory presented concerns. In the first interview post-intervention, one family caregiver said:

I shouldn't say this but I feel there is another man, another person, inside his body. [CG]

Caregivers also reported negative experiences in their interactions with health professionals and the health-care system (70%). Other sources of stress pertaining to coordination of care included arranging for appointments (40%), arranging for community services (25%), and advocating for the health care of the stroke survivor (10%).

CG is angry with medical professional about dumping her mother from the hospital when discharged and not telling CG what to do or how to cope. [PV]

Caregivers indicated that they wished stroke survivors would "do more for themselves" and that they attempted to facilitate the

survivor's participation in self-care, meaningful activities, and social activities (40%).

CG was going to get SS to help her put windshield washer fluid in the car after his nap. She tries to get him to do things like this so he'll feel like it is a help to her. [PV]

Secondary caregiving demands described by these caregivers included the devastating impact of the stroke on their own personal needs and role involvements and on the family unit (see Table 1). In addition to their caregiving responsibilities, caregivers had to balance the demands of other roles, such as caring for elderly parents, spouses, children, and grandchildren (40%), paid work (25%), and household maintenance (20%). Family caregivers contended that the additional role of caregiver interfered with their rest. Caregivers (85%) indicated that they did not get enough time to participate in personal activities and social interactions. The types of respite activities engaged in by caregivers included hobbies, walking, going to the library, and shopping.

Her mom thinks she should take the phone to the bathroom with her. CG was very upset... It's that she isn't getting enough time to herself. [PV]

One family caregiver said:

I do everything for him that I can. Many times I feel worn from it... sometimes I'm downright exhausted. [CG: Int2]

Another caregiver commented on the need for respite:

I started taking him to the Adult Day Care one day a week... He enjoys that in there, and I can leave him and have the day to do whatever I want to do. [CG: Int2]

Over half (65%) of the caregivers revealed to peer visitors that they had health problems of their own (e.g., arthritis, diabetes, anxiety). Consequently, they had to cope with their symptoms and navigate the health-care system. Many caregivers were concerned about the impact of their health problems on their ability to care for the stroke survivor. They also had to deal with their own emotional reactions to their caregiving responsibilities (60%) and changes in their relationship with the stroke survivor (13%).

CG just recently had a heart attack. She tires out quite easily and feels that sometimes she doesn't have the energy to put towards helping stroke survivor. [PV]

A major effect on the family unit involved finances (45%). Changes in financial circumstances resulted from several factors. Income was

depleted as a result of the loss of the stroke survivor's income and/or the loss of the caregiver's income, as many caregivers quit work in order to care for the stroke survivor. New expenditures for services that the stroke survivor had formerly provided, and for respite care and medications, also placed a strain on the family finances. Caregivers expressed concerns related to family relationships and strategies for reducing and managing real or potential familial conflict (40%).

Caregivers' Appraisal of Support Needs (RQ5)

Caregivers spontaneously discussed their support needs, arising from gaps and deficiencies in support, with peers. While people in their network, such as family members and friends, provided physical care of stroke survivors and transportation (instrumental support), 40% of the caregivers indicated that they did not have people available who could meet their needs for emotional, affirmational, and informational support. Even when potential support providers were available, 35% of the caregivers reported that persons in their network either were unable to provide help or provided insufficient help. Another 15% reported that they did not believe the support they received from family and friends was helpful (i.e., miscarried helping).

During caregivers' discussions with peer visitors, several referred to inadequate support and stressful interactions with family members. Support was either absent, insufficient, or miscarried. Many family caregivers referred to the absence of support during interviews:

Don't mention Homecare... They interviewed us, and we had meetings at the hospital when [the stroke survivor] was being discharged. That was last May, and there has been nothing. Absolutely nothing. And we're just getting by. But we've had absolutely no help from all this. [CG: Int2]

I don't have any family so it makes it hard. And at one time we used to have more neighbours around... They had to move. And all Mom's friends are gone. And all the ones that are left here, they are never home. They are working all the time. So there isn't anybody I can depend on. [CG: Int1]

Other caregivers indicated that network members were unable to help:

My brothers and sisters live about 100 km from here. They are not actually able to drop in and help... And my in-laws are just too old to be helpful. [Int3]

Some caregivers referred to insufficient support:

When Mom came home at first, she [sister] was there two afternoons a week when she thought it was a lot. To me it was wonderful. It wasn't

enough but it was all I had so I would grab it... But two weeks before Christmas that ended. [CG: Int1]

Many caregivers had experienced miscarried helping.

She [sister] said, "Why don't you just pack him off to a nursing home? You would have a good rest." And I think, "Yes, I know. That is fine for you to say." [CG: Int3]

Finally, caregivers encountered stressful interactions:

You can tell family members, they don't understand. They make you feel that they don't believe you. [CG: Int2]

Clearly, the caregivers had unmet emotional, affirmational, and informational support needs. There was a strong need for the supplementary support provided by the project peer visitors and professionals.

Types of Social Support Provided by Intervention (RQ1)

Peer visitors provided emotional, affirmational, informational, and occasional instrumental support. Project professionals offered primarily informational support (see Table 2).

Emotional support. All caregivers indicated that they received emotional support from peers during the intervention. Listening was a central component of every caregiver/peer relationship. The presence of the peer provided caregivers with an opportunity to tell their "stories" and to vent their anger and frustrations. Caregivers confirmed that understanding was a very important element in the support provided (90%). The peers' common experience as caregivers was identified as the basis for their understanding. Aside from caregiving concerns, caregivers and peers talked about a wide variety of topics: interests, hobbies, people they knew in common, families, cooking, and work. These exchanges allowed the caregiver to build rapport and develop a foundation for the relationship with the peer. Interactions served as a point of social comparison regarding the behaviour and functioning of their relative.

I thought she was a good listening presence. [CG]

Before she started coming I...didn't have anybody to really talk to that would understand. [CG]

Peer visitors expressed concern primarily about the caregivers' own health — getting sufficient rest, exercise, and time for themselves (70%). The peer visitors attempted to create an atmosphere in which caregivers would feel comfortable expressing themselves, sometimes by asking

Table 2 <i>Types of Support Provided by Peer Visitors and Professionals</i>		
Types of Support	(N = 20)	Source of Support
A. Emotional Support		
Listened	20	Peer visitors
Conveyed understanding	18	Peer visitors
Provided companionship	16	Peer visitors
Expressed concern for caregiver as a person	14	Peer visitors
Encouraged expression of emotions and recounting of experiences	12	Peer visitors
Provided comfort	10	Peer visitors
Conveyed empathy	10	Peer visitors
Provided reassurance	7	Peer visitors
B. Affirmational Support		
Positive feedback or encouragement	18	Peer visitors
Affirmation that decisions made or strategies used are appropriate	16	Peer visitors
Sharing of feelings and experiences	16	Peer visitors
Affirmation that caregiver is not alone	12	Peer visitors
C. Informational Support		
Information about community resources	15	Peers & Professionals
Oral explanations about stroke	12	Peers & Professionals
Explanations about coping	11	Peer visitors
General information about caregiving	11	Peers & Professionals
Print material	6	Peers & Professionals
Access to other caregivers or self-help groups	6	Peer visitors
D. Instrumental Support		
Locating of equipment	8	Peer visitors
Coordination of care	3	Professionals
Transportation	1	Peer visitors

questions, other times through "active" listening (60%). Peer visitors often provided comfort (50%), in conjunction with listening, understanding, sharing similar experiences, and "just being there." Finally, peer visitors were empathetic towards the caregivers (50%); the foundations for empathy were similar experiences and having "been there."

Affirmational support. Most caregivers indicated that they received affirmational support from the peers. Positive feedback or encouragement sometimes focused on particular aspects of caregiving or specific caregiving activities. In addition, peer visitors offered affirmation that caregivers' decisions or strategies were appropriate and that they were not alone in their caregiving experiences and feelings. Peer visitors also related difficulties they had experienced so that caregivers could see that they were handling similar situations effectively.

CG called homecare to talk about services available for her. I complimented her on doing this. [PV]

I mention it is common for caregivers to be hard on themselves and think that others would do a much better job in the situation. [PV]

Peer would offer advice or something that had happened in her situation that was similar. [CG]

Informational support. The caregivers received informational support from peers and/or professionals. The peers provided informational support based on their own experiential knowledge (*social learning*). The professionals provided information either directly to the caregiver or indirectly through the peer. The peers offered information about local day programs, home-care or homemaker services, library resources, "friendly visiting" programs, financial assistance, transportation options, and seniors' housing (75%). In many cases caregivers were not aware of the resources available in their communities and/or how to access them. Oral explanations about stroke and treatment of stroke focused on stroke symptoms, problems associated with the effects of stroke, therapy, modifications to living spaces, and enabling self-care (60%). The peers suggested strategies for managing the emotional and behavioural reactions of stroke survivors, respite, caregiver stress, family conflict/demands, and for enhancing the self-confidence of the stroke survivor. They offered problem-specific suggestions for meaningful activities for stroke survivors and suitable "solutions" to caregiving problems or concerns (55%). Peer visitors also recommended equipment and strategies regarding the safety and comfort of the stroke survivor.

I did not know that homecare workers would come for nominal fee. I found out through peer. [CG]

Instrumental support. Project personnel offered practical/instrumental support infrequently. On a few occasions, peers assisted with housework, took the stroke survivor for an outing, stayed with the stroke survivor, checked on the stroke survivor when the caregiver was out, visited with the stroke survivor, and took the caregiver for outings. Even these small periods of respite were greatly appreciated by caregivers.

Caregivers' Perceptions of Intervention Processes (RQ2)

Most support from peer visitors was viewed as supportive, reciprocal/bidirectional, appropriate, and timely.

She was very respectful of my emotions. She didn't offer me advice except if it was solicited. [CG]

I almost felt like I was giving her as much as she was giving me. [CG]

Peer visitor support increased caregivers' self-esteem and made them feel more capable (30%).

I was feeling most inadequate.... I found her affirming. [CG: Int2]

Probably self-confidence. That she helps you feel that yes, you can handle this. That life goes on, and you'll be able to cope better and still have a life for yourself outside of looking after this person 24 hours a day.... I guess she gave me some self-confidence, and thinking about yourself again. [CG: Int3]

Caregivers (30%) noted that peer support helped them to feel more confident in their role.

I think it just made me stronger and firmer so that I don't allow her to rule me any more. [CG: Int3]

The main thing she did for me was to give me confidence so I wouldn't feel so guilty being away from my mother. [CG: Int3]

I think that she probably has made me more confident that I could get a job and carry on. [CG: Int1]

Some caregivers (25%) explained that peer support had reduced the uncertainty they felt in their role as caregiver.

At first, I didn't know whether I was coming or going so she told me what to expect. I'm okay now. [CG: Int2]

Peer Visitor Support for Family Caregivers of Seniors with Stroke

[When stroke survivor had seizures] I was a little bit more prepared because [peer visitor] said that her father had had them. [CG: Int2]

Caregivers referred to the importance of the personal characteristics of peers (60%), caregiver/peer match (50%), comfort in the relationship (50%), caregiver/peer friendship (50%), and opportunity for communication (45%). Many caregivers indicated that the personality of the peer visitor contributed positively to the relationship.

I thought she was nice. Very caring. [CG]

Elements contributing to the success of a caregiver/peer match included similarities in caregiving experience, personality factors, age, and interests (*social comparison*). A feeling of mutuality or reciprocity (*social exchange*) in the relationship was also important.

You just feel connected to other people who are going through the same thing. I felt connected to peer. [CG]

Also significant were the comfort of the caregivers in talking freely and openly with the peers and the process of establishing a level of comfort in the relationship. Trust developed over time. Many caregivers reported that they became friends with their peer visitor during the intervention. They looked forward to the visits as an opportunity to talk openly about caregiving with someone who understood their feelings and concerns. Peers' efforts to interact with the stroke survivor were very important to some caregivers.

I felt more at ease each time she came. Because I'm not much one for talking to strangers about things. So it kind of helped a lot there after a while. I kind of opened a bit more. [CG]

Peer was a very good listener. ... she didn't try to interrupt or give advice. ... after you had explained things, she might have some ideas as to some other things to try but she wasn't trying to impose her solutions on you. She just let you talk. [CG]

I was talking to peer and she realized that I was doing more than... I expected a lot from myself. ... talking to her, I knew that I had to start taking more time for me. It was good to have somebody that wasn't in the family that you could vent your frustrations and you knew that they weren't going back and telling. [CG]

Many family caregivers saw the professional as a source of information and liaison with the peer, although others noted that the professional's role seemed to be restricted to initial assessment. Family caregivers were asked, during the post-intervention interviews, whether they would choose a peer or a professional visitor in a future

intervention. Of those who responded, 67% indicated a preference for a peer visitor and 33% indicated a preference for both a peer and a professional, while none indicated a preference for a professional alone.

I just think that somebody who is living with it, day in and day out, sees it on a different level because they have to experience the emotional side of it, not just the clinical side of it. [CG]

Some peers and family caregivers found it difficult to terminate the visits. Some peers indicated that they were aware that caregivers did not have other sources of emotional, affirmational, and emotional support following the termination of the intervention program. About half of the caregivers indicated that they were not receiving any formal support services. However, in an effort to fill the void, several reported joining peer-support groups or exploring respite-care possibilities. During the follow-up interviews most caregivers said that they still kept in touch with their peer visitors.

She keeps in contact with me though, like through the phone just to say "Hi" ... It's good that you can feel that you can talk to her from time to time. [CG]

Caregivers and peer visitors recommended that, in future projects, the peer be matched as closely as possible to the family caregiver, specifically in terms of the experience with similar stroke disability (e.g., gait impairment, aphasia, memory impairment) and the relationship of the caregiver to the stroke survivor (i.e., spouse, daughter, daughter-in-law). Peer visitors who had previously cared for persons with dissimilar levels or types of stroke disability, or who had a more peripheral relationship with a person with stroke, were uniformly viewed as being less effective than those who had similar personal experiences with a relative with stroke. This reflects the importance of *social comparison*. Caregivers also suggested that the intervention start within a month after the stroke survivor is discharged from hospital, as this was when they experienced the greatest uncertainty.

Caregivers' Perceptions of Impact of Intervention on Caregiving Demands, Coping Strategies, and Support Needs (RQ3)

Some caregivers reported lessening of burden during and after the intervention. More indicated improvement in the stroke survivor (e.g., acceptance of functional deficits, improvements in self-care, engagement in physiotherapy or speech therapy).

Oh, easier... I would say [the peer] made it easier. [CG]

Yes, [the intervention] did lighten my load. [CG]

During their discussions with peer visitors, caregivers reported using a wide array of coping strategies — help-seeking (problem-focused), protective buffering (relationship-focused), and acceptance (emotion-focused).

Caregivers sought practical and emotional support from members of their network such as family and friends. They managed their relative's behaviour with a range of verbal strategies (e.g., rational explanation, changing the subject, reassurance, use of a calm approach and instruction). Caregivers hid concerns, denied worries, and yielded to the stroke survivor to avoid disagreements (i.e., protective buffering). Caregivers accepted their relative's illness and behaviour and the necessity of caregiving.

There are days I'm really, really nervous with him. Not that I can't care for him.... But my nights are worse. I go to bed and I wake up, and I hear him also coughing.... I'll get up and see if he's alright. That is just what goes on with me. That's the way it's going to be. [CG]

Avoidance or escape (emotion-focused) coping was evident in a few caregivers who physically withdrew from caregiving for short periods and/or avoided thinking about the stroke survivor.

In summary, the family caregivers appeared to engage primarily in emotion-focused coping (i.e., acceptance) and relationship-focused coping (i.e., protective buffering) to manage the primary and secondary demands associated with caregiving. Some engaged in problem-focused coping (i.e., help-seeking).

When asked, at the end of the intervention and again months after the intervention had finished, whether the support program had made it easier or harder for them to care for the stroke survivor, nearly all of the caregivers responded that it had made it easier. Eight caregivers reported that the visits by peers offered a distraction from their caregiving roles.

It made it easier because I had somebody to talk to. I didn't know where I was going from one day to another, so it was nice. It would relieve some of the pressures. I guess it helped me in different ways. It helped me to understand stroke survivors' problems. [CG]

Other caregivers commented on changes in emotion-focused coping strategies following the intervention:

I was certainly being very hard on myself and thinking that I wasn't doing enough or I wasn't doing it right. There were kind of negative thoughts... I'm much more at home in the circumstances. I am much more accepting of my dad in light of how he is today. I am a little better

with the unpredictability of what I may encounter on any given day because I am aware now that is the disease. I am less demanding. [CG]

Summary of Results

The major burdens experienced by the family caregivers in caring for their elderly relative with stroke seemed to pertain to the cognitive and emotional impact of the stroke and the requisite constancy and vigilance in managing symptoms and deficits during everyday and crisis situations. Thus the key primary caregiving stressors appeared to be situational and derived directly from the day-to-day care of their relative. The family caregivers described the impact of caregiving responsibilities on their other responsibilities, roles, and relationships within and outside the home. The key impact of caregiving was on their ability to get enough rest and respite to fulfil their caregiving and other responsibilities. Most stressful interactions and instances of inadequate support concerned relationships with family members. These stressful situations and support deficits confirmed the need for this intervention.

In the support intervention, peer visitors provided informational support by explaining and offering information about other sources of support and resources in the community and potential coping strategies based on their experiential knowledge. Peer visitors frequently offered positive feedback and affirmed the family caregiver's decisions, actions, and perceptions. Affirmation among peers, based on social comparison, can help to diminish stigma and assure people that they are not alone in a situation. Listening was the primary type of emotional support provided by peer visitors. Other types of emotional support were understanding, sharing of feelings, and companionship. Most of the supportive interactions involving the peer visitor were considered appropriate and reciprocal. The peers also reinforced self-esteem and confidence and offered support at appropriate times in the caregiving trajectory. The intervention was designed to offer support during a particularly difficult transition, and peer visitors were trained to provide "appropriate" assistance and types of support. The family caregivers appraised their relationship with the peer visitors as very positive. Trust, closeness, and comfort level developed over time, influenced by the personal characteristics of the peers.

Limitations

Some peer visitors were not as well matched with the caregiver as others, in terms of length of time since diagnosis of stroke, relationship with the