

Perceived Support Needs of Family Caregivers and Implications for a Telephone Support Service

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Les objectifs de cette étude étaient : de déterminer les besoins de soutien perçus par les membres de la famille fournissant des soins aux personnes vivant avec une maladie chronique (physique ou cognitive) et recevant des services à domicile, et de décrire les types de services téléphoniques qui satisferaient ces besoins. L'étude qualitative a utilisé des entrevues semi-structurées. Au total 34 fournisseurs de soins (âge moyen : 62 ans) ont participé à l'étude. Les bénéficiaires (âge moyen : 78 ans) étaient surtout les époux ou épouses ou des parents des fournisseurs de soins. Les besoins des fournisseurs de soins les plus souvent exprimés ont été : une vie sociale, du soutien instrumental (une relève, de l'aide pour les soins physiques, une compensation financière), informationnel et affectif. La majorité des fournisseurs de soins ont affirmé qu'ils utiliseraient un service de soutien téléphonique fourni par un professionnel (71 %) ou par un autre fournisseur de soin (59 %), s'il en existait un. Les résultats de cette étude commandent une étude pilote et une évaluation quant à un service de soutien téléphonique destiné aux fournisseurs de soins membres de la famille.

The purposes of this study were: to identify the perceived support needs of family caregivers of persons living with chronic illness (physical or cognitive) and receiving home-care services, and to describe the types of telephone services that would meet the expressed needs of caregivers. The qualitative design used semi-structured interviews. A total of 34 caregivers (mean age 62 years) participated in the study. The care recipients (mean age 78 years) were primarily the husband / wife or parent of the caregiver. The most commonly expressed caregiver needs were: a social life, instrumental support (e.g., respite, assistance with physical care, financial compensation), informational support, and

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emotional support. Most caregivers said they would use a telephone support service provided by a professional (71%) or a fellow caregiver (59%) if available. The results of this study support a pilot study and evaluation of a telephone support service for family caregivers.

The recent restructuring of the health-care and social service systems has resulted in a major shift to care in the community, increasing the burden on informal support networks of family and friends (Grunfeld, Glossop, McDowell, & Danbrook, 1997). As the stress on caregivers grows, they are increasingly in need of support services. Telephone support offered as part of home-care services and provided by professionals or fellow caregivers may be a relatively inexpensive and effective strategy to help meet caregiver needs. However, there is limited information about the perceived needs of caregivers and their preferences with regard to telephone support services.

This paper describes a study of the perceived needs of those providing care to persons with chronic physical or cognitive illness and receiving home-care services, as well as the types of telephone support services that might meet those needs. The study was supported by a partnership of academic and community agencies in the province of Ontario, Canada, including Community Care Access Centre (a home-care agency), a branch of the Victorian Order of Nurses (VON), McMaster University, and a regional caregivers' network.

Background

Canada's growing elderly population, budget constraints, and technological advances have led to major health-care reforms (Bergman et al., 1997). Inpatient hospital stays have been reduced in length, the number of nursing home beds has decreased, and the priority in home care is shifting towards post-acute services and away from long-term care (Merlis, 2000). There has been a major shift in care to the community, increasing the burden of care on informal support networks of family and friends (Grunfeld et al., 1997). Informal caregivers are largely responsible for providing care to the increasing proportion of community-dwelling older persons who are frail and suffer from chronic illness or cognitive impairment.

Many Canadians are involved in caregiving. According to the 1996 General Social Survey (Statistics Canada), 11% of the population 15 years and over (more than two million people) provide an average of 4 to 5 hours of informal care per week to seniors with long-term health problems (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Most of

the caregivers of those with long-term conditions are middle-aged women, though many seniors also provide informal care (Cranswick, 1997). This burden on women is exacerbated by the increasing participation of women in the workforce. Chappell (1992) found that 80% of care for older seniors is provided by family and friends. Recipients of care are most frequently parents or spouses of the caregiver.

The informal caregiving networks are, however, often "overextended or at risk of breaking down" (Bergman & Beland, 2000). Caregivers bear physical, psychosocial, and economic burdens that negatively affect their quality of life (Grunfeld et al., 1997; Keating et al., 1999). The 1996 General Social Survey notes that 45% of caregivers have modified their social life as a result of caregiving duties, 44% have incurred financial costs because of their responsibilities, 29% report changes in their sleep patterns, and 21% report that their health has been affected (Cranswick, 1997). Furthermore, mental or emotional strain has been found to be an independent risk factor for mortality among older spousal caregivers (Schulz & Beach, 1999). Not only does caregiver burden reduce quality of life, it also limits the effectiveness of the informal support system for at-risk older adults, and it may contribute unnecessary costs to the health-care system.

The needs of caregivers have been examined. In a review of the 1996 General Social Survey, Cranswick (1997) found the greatest informal caregiving needs to be respite, financial compensation, information, and counselling. The support needs of informal caregivers vary with their own stage of life, the length of time they have been a caregiver, and the acuity and intensity of the caregiving situation (Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991). For example, the needs of those providing 24-hour care on a long-term basis differ from the needs of those dealing with an unexpected diagnosis or a sudden crisis for the care recipient.

The effectiveness of interventions for caregivers has been assessed in two systematic literature reviews. Knight, Lutzky, and Macofsky-Urban (1993) conducted a meta-analysis of 18 studies of interventions for caregiver distress. The interventions included respite services and individual and group informational and support services. The authors concluded that respite services and individual psychosocial interventions were moderately effective but that group psychosocial interventions were not very effective. Tilford, Delaney, and Vogels (1997) reviewed studies of the effectiveness of mental health interventions for long-term caregivers of highly dependent people. They concluded that

some psychosocial interventions to promote support and coping can help to reduce caregiver stress. Little research included in either review addressed the role of peer/volunteer support and none of the studies examined telephone support for caregivers.

Telephone support has been proposed as a cost-effective alternative means of delivering selected home-care services (Short & Saindon, 1998; Shu, Mirmina, & Nystrom, 1996). It can be delivered at convenient times, with privacy, and can be tailored to the needs of the individual (McBride & Rimer, 1999). One of the major advantages of telephone support is that it can conveniently fit into the lives of burdened caregivers who may be housebound with very little time in their day in which to seek and receive support (Goodman & Pynoos, 1990).

There have been three recent systematic reviews of the effectiveness of telephone services for various groups of people. McBride and Rimer (1999) reviewed 74 randomized trials in which the telephone was used to deliver a primary or adjunctive component of a health-related intervention. Telephone interventions were found to be most effective in promoting lifestyle changes and in appropriately reducing the number of face-to-face clinical encounters for patients with chronic illness who were high users of health services. However, most of the studies reviewed did not allow for the telephone component of the intervention to be evaluated separately from other components.

Hoxby et al. (1997) conducted a review of eight randomized trials of the effectiveness of telephone services for patients with various chronic illnesses. They concluded that the studies showed some evidence of the effectiveness of this intervention for physical and social health as well as decreased health-care utilization and costs.

Cava et al. (1999) carried out a review of the effectiveness of 12 telephone interventions within the scope of public health nursing. The results suggest a positive impact on physical health, psychological health, knowledge, health-related behaviours, and health-resource utilization. However, the methodological rigour of those study designs was limited.

While these three systematic reviews suggest that telephone interventions have a positive impact on the physical and psychological health, health behaviours, and health-resource utilization of patients, few studies have examined the effectiveness of telephone services for caregivers. A randomized controlled trial by Goodman and Pynoos (1990) compared two types of telephone intervention for caregivers of persons with Alzheimer disease. One group received a peer-support

intervention in which groups of four or five caregivers would phone each other on a rotating basis for 12 weeks. The other group had access to taped informational lectures on Alzheimer disease over a 12-week period. Both types of intervention resulted in greater satisfaction with social supports.

Other studies of the effectiveness of telephone interventions in providing caregiver support have used less rigorous designs (Brown et al., 1999; Coyne, 1991; Davis, 1998; Skipwith, 1994; Strawn, Hester, & Brown, 1998). Brown et al., using a quasi-experimental design, found that a telephone support group was as effective as an in-person support group in providing support and education to caregivers. In a feasibility study of a telephone intervention using a before/after design, Davis found a significant reduction in caregiver depression scores, an increase in life satisfaction, and increased use of social support.

Despite the limited evidence of the effectiveness of telephone services for caregivers, there is some evidence that caregivers favour them. Colantonio, Cohen, and Corlett (1997) conducted a telephone survey of 84 caregivers from the Alzheimer's Society of Metropolitan Toronto Wandering Persons Registry. Only 8% used telephone support services, but 57% of non-users said that they would like to do so.

Purpose

This paper addresses two research questions: *What are the perceived support needs of family caregivers of older persons who are living with chronic illness and receiving home-care services? What types of telephone support services would meet the perceived needs of caregivers?*

Methods

Sample

Case managers of a home-care agency in Ontario were invited by a member of the research team (also a case manager) to participate in the study. Case managers who volunteered to take part were asked to review their caseloads and identify caregivers who met the following criteria: 21 years of age or older; currently providing care for an adult (21 years or over) with a chronic illness (physical or cognitive) and receiving home-care services; has been providing care for at least 6 months; speaks English; and is not a caregiver for a person with a palliative condition such as end-stage malignancy. The intention was to select typical caregivers who provided substantial or complex care and

represented a spectrum of caregiver characteristics. Case managers referred caregivers to the project from October to December 1999. From the client lists provided by case managers, two of the investigators selected a sample that represented diversity in four major categories: caregiver gender (male and female), age (younger and older), and location (urban and rural), and care recipient age (younger and older). The case managers then called the selected individuals and, using a prepared script, asked permission to release their name, address, and telephone number to the research team. A letter describing the study was sent to each subject. The interviewer (project research assistant) contacted caregivers within 1 week of receipt of the letter to arrange a time and place for the interview. Subjects could refuse to participate at a number of points in the study: when the case manager called for permission to release their name, address, and phone number to the investigators; when the interviewer contacted them by phone; or, once the interviewer arrived, at any point before or during the interview. When a caregiver refused to participate or could not be contacted, the investigators selected another potential participant from the case manager client lists.

Three caregivers could not be contacted by the case managers, three refused to participate due to illness, and three refused to participate without giving a reason. Six caregivers who had agreed to take part could not be contacted by the interviewer. When 34 interviews had been conducted, the research team agreed that no new information was being obtained and that the topic was saturated.

Interviews

A semi-structured interview schedule was developed to provide detailed information about caregiving responsibilities, perceived needs, and preferences related to telephone support services (see Table 1 for examples of questions). The interview schedule was pilot-tested with seven members of a regional caregivers' network and was revised based on their recommendations.

Caregivers were interviewed in their homes ($n = 27$), in the VON office ($n = 4$), or by telephone ($n = 3$). Interviews lasted between 30 and 90 minutes with an average length of 60 minutes. The interviews were carried out by a research assistant (RA) with a background in gerontology. The principal investigator accompanied the RA on two interviews and provided feedback and strategies to enhance the richness of data collection. The interviews were audiotaped and transcribed.

Data Analysis

After the tapes were transcribed, the transcripts were reviewed and cleaned by the RA. Replies to open-ended questions were subjected to thematic analysis (Boyatzis, 1998). Four texts were coded independently by two members of the research team and the results were compared. Input was also received from other team members and any differences in coding resolved by consensus. A coding scheme was established and became the basis for coding the remaining texts. Additional codes were added as required. The coding scheme revealed themes identified by the interviewees and provided the structure for reporting the results of the interviews. The research team discussed and reached consensus on the themes identified. A preliminary report of the results of the study was reviewed by members of the regional caregivers' network, who confirmed the identified themes. The study received ethical approval from the McMaster University Research Ethics Board.

Table 1 <i>Examples of Questions from Interview Schedule</i>
Tell me about the kinds of care you provide.
Tell me a little about how you feel as a caregiver.
Some people find that there are both positive and negative aspects of caring. Tell me more about your experience.
What do you see as your most important needs as a caregiver?
What kinds of support do you receive to cope with these things?
In what areas would you like more support as a caregiver?
Which of the needs you identified could be met by some type of telephone support service?
Tell me about any advantages or disadvantages you see in receiving telephone support.
In what situations would a professional (or fellow caregiver) be the best person to help you?
If a telephone service was available, is there anything that would keep you from using it?

Table 2 *Characteristics of Caregivers (n = 34)*

Characteristic	Number (%) of Caregivers
<i>Age</i>	<i>Range: 34–81 years</i> <i>Mean: 62.3 years; SD = 13.6 years</i>
<i>Gender</i>	
Female	22 (65)
Male	12 (35)
<i>Marital status</i>	
Married	24 (71)
Single (never married)	3 (9)
Divorced	3 (9)
Widowed	2 (6)
Common-law	2 (6)
<i>Highest level of education completed</i>	
Less than Grade 9	5 (15)
Some high school	12 (35)
Completed high school	7 (21)
Some college or university	2 (6)
Completed college or university	8 (24)
<i>Employment status</i>	
Employed full-time	5 (15)
Employed part-time	4 (12)
Not employed /retired	25 (74)
<i>Household income</i>	
Less than \$20,000	4 (12)
\$20,000 to \$29,999	6 (18)
\$30,000 to \$39,999	9 (26)
\$40,000 to \$49,999	3 (9)
\$50,000 to \$59,999	2 (6)
More than \$60,000	3 (9)
Unknown/declined to answer	7 (21)
<i>Size of household</i>	<i>Range: 1–6 members</i> <i>Mean: 2.5 members; SD = 1.0</i>
<i>Self-rated health</i>	
Excellent	5 (15)
Very good	5 (15)
Good	16 (47)
Fair	8 (24)
Poor	0

Findings

The findings are presented in three sections: sample characteristics, perceived support needs of caregivers, and caregiver preferences related to telephone support.

Sample Characteristics

The characteristics of the 34 participating caregivers are described in Table 2. Their mean age was 62 years and most were female, married, and retired or not employed. Three quarters of the caregivers reported their health as excellent, very good, or good.

The 34 caregivers provided care for 36 care recipients, with two caregivers looking after two people. The characteristics of the care recipients are summarized in Table 3. Their mean age was 78 years and most were female and married. Most were either spouses (more husbands than wives) or parents (more mothers than fathers) of the caregivers. All had been diagnosed with a chronic physical or mental health

Table 3 Characteristics of Care Recipients (n = 36)	
Characteristic	Number (%) of Caregivers
Age	Range: 34–93 years Mean: 78 years; SD = 10.9 years
Gender	
Female	19 (53)
Male	17 (47)
Marital status	
Married	21 (58)
Single (never married)	1 (3)
Divorced	1 (3)
Widowed	13 (36)
Common-law	0
Relationship to caregiver	
Husband	12 (33)
Wife	5 (14)
Mother	12 (33)
Father	5 (14)
Child	1 (3)
Sister-in-law	1 (3)

problem. The most common condition was Alzheimer disease ($n = 13$), followed by stroke ($n = 10$), heart condition ($n = 8$), and arthritis ($n = 3$). All received homemaking services and approximately 50% received nursing services.

The caregivers had been providing care for between 1 and 15 years ($mean = 5.3$, $SD = 3.5$). Twenty-nine recipients lived with the caregiver. All the caregivers considered themselves the primary care provider but only three considered themselves the sole provider. Twenty-five caregivers (74%) said that they provided care on a 24-hour basis. Six said they provided daily care and three said they provided less than daily care. In most cases the caregiver cooked, cleaned house, shopped, took the care recipient to doctor and hospital appointments, and managed household finances. Caregivers supervised or administered medication. Some carried out health-care procedures such as suctioning and tube feeding. The most disabled recipients required assistance with the basics of self-care such as dressing, eating, washing, toileting, and incontinence care.

Perceived Support Needs of Caregivers

Caregivers reported their most important caregiving needs, which resulted in the identification of four themes: the need for a social life, the need for instrumental support, the need for informational support, and the need for emotional support. No differences in perceived support needs were found between male and female respondents. The excerpts below are taken verbatim from the record of each interview.

The need for a social life. The caregiver need most commonly expressed was the need for a social life. Many caregivers described a life of social isolation. They no longer went out in the evenings or visited with friends or family. Even when they did go out, they were often preoccupied with thoughts of the care recipient. While some caregivers had visitors, others found that their social circle had "dwindled away." Some visitors had stopped coming because they were upset by the care recipient's illness. Many caregivers could leave the care recipient only while a homemaker was present or if the care recipient went to a day program:

My social life has decreased. Even last year she couldn't get up from bed, so it was worse last year because I just couldn't go out. I was always in the house... [My social life] is nil, has decreased to nil. (Caregiver #10)

I just find they don't come around the same because my husband can't talk to the fellows, and these are friends that we've had for 35 years. That

I find the hardest part...socially... I just don't see or hear from them. They always think, "Well, I don't want to call you because [you're] busy." Well, call, I'll take 5 minutes to talk to you... And when I go out I don't want to talk about it. I'm out for a good time. I want away from it. Like, that's even these support groups. I went yesterday to see what it was about. It's how to be a caregiver and survive it. I came out shaking my head — like, why did I bother going... I want to go out and have fun for an hour. I live this all the time. I don't want to go out and live it again. (Caregiver #8)

The care recipient was usually the caregiver's most consistent companion. It is not surprising therefore that caregivers felt "like running away" or needed "space" or felt "trapped." Almost all caregivers craved more time away even if they worried about the care recipient when they were absent:

Sometimes I feel like if I could run away from home I would do it...just for more time to do a little bit with my husband...just to be able to go away for a weekend...or a couple of days and not worry. (Caregiver #9)

I have no social life. I'm really tied down... We used to square dance five to seven nights a week. Life has really changed... We don't get to go to Florida any more... All our friends were basically square dancers so I don't see them any more... I miss the social life and the friends. You feel sort of cut off. (Caregiver #31)

The need for instrumental support. The second theme related to perceived caregiver needs was instrumental support. Caregivers identified the need for increased caregiver relief, assistance in providing physical care, and reimbursement for financial costs related to caregiving. They pointed to the need for more hours of professional or non-professional support in the home:

I know I'm getting tired and I do need a break from it...I would like to see them come into the home [to give respite]... Certainly more hours [of support would help]. I'm not complaining, I appreciate what I have, but it's long days. It is long days. (Caregiver #8)

They've cut me down to 2 hours a day for 4 days only, and that's really not enough. (Caregiver #26)

Caregivers stated that they needed more support with physical care, such as lifting and moving:

The physical exertion...in the caregiving. She used to weigh 130 pounds. Now, because she's totally immobile, she's 170 pounds and it's difficult for me as an older guy, even with my size, to lift her from the bed onto the commode and back... [I would like more help with] just the physical support, somebody to do the heavier physical stuff. (Caregiver #27)

Caregivers also noted the need for financial support. They spoke about the financial impact of providing care, such as out-of-pocket expenses and lost wages:

I guess financially speaking everybody could always use a little extra, because you have a lot of expenses that you didn't realize you were going to have with this situation. I mean, just diapers are \$100 a month. Stuff which you hope you never have to need but... [When my mom] had her injury, we had to bring some aids in for her, like a bath chair. Stuff like that. We ended up buying it, so that was \$200. And her medication unfortunately isn't covered because it's viewed as a new medication. (Caregiver #16)

The need for informational support. The third theme related to perceived caregiver needs was informational support. Caregivers stated that they needed to have more information about the care recipient's illness and how to manage it:

I just want somebody...when I see that crazy sugar so high I worry about it. If I have somebody who understands about what I can do... (Caregiver #1)

I would have liked to know what other people are doing. I know each case is different, but if there's somebody else doing the same cases as my husband, what are they doing to help out? (Caregiver #3)

If there was a problem, let's say if Dad was having difficulties, cognitive difficulties like dealing with where he was, I'd like to [say] this is happening, where do I go from here?... If there was somebody in the middle of the night that you could phone...just be able to talk to somebody for a bit. (Caregiver #6)

Caregivers also indicated a need to know more about community health and social support services available to them:

Somebody's got to tell me who accepts Alzheimer patients in this area...it's very difficult to place them... [By] the same token, someone's got to tell me...on an emergency basis — if I have a heart attack or something — who steps in immediately...someone has to step in immediately, because she can't stay here alone. (Caregiver #4)

The need for emotional support. Some caregivers expressed the need for emotional support in dealing with the demands of caregiving:

You get everything inside, inside, inside, and then it has to come out. And the only way it's going to come out is if you cry and everything comes out. Yes, there are times I do need people to go to and talk about those things, to express my emotions. Yes, it's good. (Caregiver #10)

...to get emotional support in the beginning [of caregiving] because, boy, when it hits it really hits you... Everything that you were feeling, possi-

bilities of what could be done, possibilities of what could happen again. I'm not sure that it was only feelings, but just to know somebody is there that you can totally rely on, because you feel like you're going to crack up yourself. (Caregiver #18)

Caregiver Preferences Related to Telephone Support

Caregivers were asked about their previous experiences with telephone support and their opinions about such services. Three respondents had used a telephone service provided by a professional and one had used a telephone service provided by a fellow caregiver. Twenty-four caregivers (71%) said they would make use of a telephone service provided by a professional if available, seven (21%) said they would not, two (6%) were unsure, and one did not answer the question. Twenty caregivers (59%) said they would use a telephone service provided by a fellow caregiver if available, nine (26%) said they would not, two (6%) were not sure, and three (9%) did not reply to the question.

Twelve caregivers (35%) said they would like to initiate calls to a service and two (6%) said that they would like the caller to do so. Thirteen caregivers (38%) favoured a combination of the caller and themselves initiating calls. Only two of the 28 caregivers who responded to this question said they would prefer to remain anonymous while receiving telephone support. Caregivers indicated that telephone support could potentially meet some of their informational and emotional needs. Three themes related to telephone support were identified in the data: different roles of professionals and fellow caregivers in providing telephone support; preference for knowledgeable, well-trained, caring telephone service providers; and the need for after-hours support.

Different roles of professionals and fellow caregivers in providing telephone support. Caregivers saw professionals and fellow caregivers as playing different roles in the provision of telephone support. They viewed professionals as better able to offer disease-related information and assistance in emergencies. They recognized the ability of fellow caregivers to give advice based on experience and to provide emotional support:

I think a fellow caregiver would be supportive and understanding. I think the professionals would be more for specifics like medicine and finding out what agencies are out there for help. (Caregiver #15)

A fellow caregiver it would be when you have your low points you would call for support. A professional...might be the same thing, but it would

also be if anything happened, a change in condition [of the care recipient]...to confirm that I'm doing the right thing. (Caregiver #18)

Professional people are fine but they don't deal with the caregiving of a person. I'm not trying to be smart by saying that...a person who does it all the time at home knows what you feel instead of a professional who doesn't deal with it. (Caregiver #9)

The need for knowledgeable, well-trained, caring telephone service providers. Caregivers stressed that it was important the telephone service providers be knowledgeable, well trained, and caring, capable of developing rapport with the caregivers:

The person that answers the phone...has to know exactly what the person needs. He can't give him the wrong information. So it's got to be a very well trained person. (Caregiver #2)

I think that people on the other end of that service are going to have to be...understanding and caring people. (Caregiver #15)

If I'm going to phone a person up...and the other person, a caregiver, is in the same boat as I am — they don't know what they are doing — how are we going to help each other? Even the volunteers sound good, but is the volunteer, he/she, going to be trained to be able to answer...? (Caregiver #10)

The need for after-hours support. Many caregivers identified a need for after-hours support for relief and emergencies — that is, outside of the normal community agency hours of 9am to 5pm on weekdays. Many caregivers emphasized their need for help at night and on weekends:

The nights are long...if there was somebody in the middle of the night that you could phone...just to be able to talk to somebody for a bit. (Caregiver #6)

When I feel the worst is in the middle of the night when I'm having problems... There are times when I need it [support] at night, in the evenings. (Caregiver #31)

I would say 7 days a week, 24 hours a day, but that's probably not very realistic. Probably just not 9 to 5, maybe 8 to 8 or something like that...a 12-hour period. And at least 1 day on the weekend I think is important for people, especially if you emotionally need that support. Sometimes the weekends are the hardest time to get in touch with people... It would be nice to know that they are available. (Caregiver #16)

Discussion

The caregivers in this study expressed a need for a social life, instrumental support (e.g., respite, help with physical care, financial com-

pensation), informational support, and emotional support. Some of these perceived needs are consistent with the needs identified by Cranswick (1997), from the 1996 General Social Survey, as information, counselling, respite, and financial compensation. Our study, however, also identified the need for social interaction as a prominent theme in the data.

Social isolation and loneliness were significant issues for the caregivers in this study. A previous study found that peer networks of four or five caregivers engaging in telephone conversations regularly can result in improved perceived social support and satisfaction (Goodman & Pynoos, 1990). There is little research in this area, however, and it is not clear whether telephone support by either professionals or peers can address the need for a social life. Comments from many caregivers in the current study indicated a desire to more regularly leave the caregiving setting for the purpose of social interaction. Thus, telephone support may not fully meet caregivers' needs for a social life. Other types of support, such as in-home respite offered by a trusted home-care worker in order to give family caregivers the opportunity to engage in social interaction, may be more likely to meet social support needs. Clearly, however, this type of support would require changes to the home-care system.

The caregivers in this study indicated that some informational and emotional support needs might be effectively met through a telephone support service. Colantonio et al. (1997) found that only a small percentage of their sample had ever used telephone support lines staffed by professionals (8.3%) or caregivers (2.3%). Similarly, few of the caregivers in the current study had ever used a telephone support service. Colantonio et al. also found that, of those not currently using a service, 57.1% would use one if provided by a professional and 57.3% if staffed by a caregiver. These numbers are consistent with the percentages of caregivers in our study who indicated they would use a service provided by a professional (71%) or a caregiver (59%). Colantonio et al. found that caregivers did not have strong preferences concerning professional- or peer-staffed services. While that result is generally consistent with ours, we did find that caregivers had a preference for professional support regarding issues such as medications, disease processes, and community services.

Our sample was broadly representative of caregivers of home-care users in terms of demographic characteristics. However, the sample included only English-speaking caregivers who provided care in non-palliative situations. Furthermore, the sample included only those who

had provided care for at least 6 months, and long-term caregivers are more likely to require support than those providing short-term care. Due to lack of information about refusers, we are unable to compare their characteristics with those of the participants. We do know, however, that the participants were not a biased group in terms of being satisfied with their home-care services; many openly expressed concerns about the home-care services they received (e.g., lack of consistency of staff).

Nurses can play a key role in providing professional telephone support to caregivers, in helping to establish and support caregiver-led telephone services, and in advocating for effective services to meet the broad range of expressed caregiver needs. The findings of this study have a number of implications for telephone support services. These services should offer practical assistance to caregivers, including information on topics such as care recipients' disease processes, medications, placement, respite, and links to resources and services. Information about services that might support the social lives of caregivers may be particularly important in view of the results of this study.

The participants in this study emphasized the need for a telephone support service that is available evenings and weekends. Further, telephone support should include both caregiver-initiated and provider-initiated services.

The providers of the telephone service should be knowledgeable about caregiving issues and community resources and should possess effective communication skills. The particular knowledge and skill set of nurses would be especially valuable in helping to train caregivers to provide emotional and informational support to peers.

Finally, there is a clear need for rigorous evaluation of different models (professionally led and peer-led) of telephone support for caregivers (Colantonio et al., 1997; Poole, 1997). Ideally, such evaluation would use a randomized controlled design in which the effects of telephone support are assessed separately from other interventions. The evaluation should include outcomes (e.g., health, caregiver burden, costs, satisfaction) as well as process (e.g., patterns of use of the service) (Wright, Bennet, & Gramling, 1998).

The results of this study reveal that some caregiver needs (e.g., physical support in providing care, more relief hours, financial compensation) cannot be met through a telephone support service. The literature supports the existence of such caregiver needs (Litwin & Lightman, 1996; National Advisory Council on Aging, 1990). In the case

of some of these expressed needs, services are available but caregivers either do not know of their existence or do not know how to access them. Thus, improved methods for referring caregivers to existing services should be an important goal for nurses and other home-care providers. In cases where such services do not exist, professionals, caregivers, and caregiver groups should work in partnership to advocate for their establishment (Anderson & Parent, 1999).

Conclusions

This study identified the perceived needs of family caregivers of persons living with chronic illness and receiving home-care services. Caregivers identified the need for social interaction, information, emotional support, and instrumental support. Telephone support services have the potential to meet some caregiver needs for informational and emotional support, and possibly social support as well. A high percentage of caregivers indicated that they would use a telephone support service if available. Nurses can play a key role in providing telephone support services and advocating for other services to meet caregiver needs. They can also contribute to rigorous evaluation of telephone support services. Finally, it is vital that nurses work in partnership with caregivers to plan and provide caregiving services.

References

- Anderson, M., & Parent, K. (1999). *Putting a face on home care: CARP's report on home care in Canada in 1999*. Toronto: Canada's Association for the Fifty-Plus.
- Bergman, H., & Beland, F. (2000). Evaluating innovation in the care of Canada's frail elderly population. *Canadian Medical Association Journal*, 162, 511-512.
- Bergman, H., Beland, F., Lebel, P., Contrandriopoulos, A., Tousignant, P., Brunelle, Y., Kaufman, T., Leibovich, E., Rodriguez, R., & Clarfield, M. (1997). Care for Canada's frail elderly population: Fragmentation or integration? *Canadian Medical Association Journal*, 157, 1116-1121.
- Boyatzis, R.E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.
- Brown, R., Pain, K., Berwald, C., Hirschi, P., Delehanty, R., & Miller, H. (1999). Distance education and caregiver support groups: Comparison of traditional and telephone groups. *Journal of Head Trauma Rehabilitation*, 14, 257-268.
- Cava, M., Wade, K., Cho, S., Dwyer, J., Johnson, I., & Lee-Han, H. (1999). *The effectiveness of telephone intervention as a delivery strategy within the scope of public health nursing practice: A systematic overview*. Unpublished manuscript.
- Chappell, N. (1992). *Social support and aging*. Toronto: Butterworths.

- Colantonio, A., Cohen, C., & Corlett, S. (1997). *Support needs of elderly caregivers of persons with dementia*. Unpublished manuscript.
- Coyne, A.C. (1991). Information and referral service usage among caregivers for dementia patients. *Gerontologist*, 31, 384-388.
- Cranswick, K. (1997). Canada's caregivers. *Canadian Social Trends*, 47, 2-6.
- Davis, L.L. (1998). Telephone-based interventions with family caregivers: A feasibility study. *Journal of Family Nursing*, 4, 255-270.
- Goodman, C., & Pynoos, J. (1990). A model telephone information and support program for caregivers of Alzheimer's patients. *Gerontologist*, 30, 399-404.
- Grunfeld, E., Glossop, R., McDowell, I., & Danbrook, C. (1997). Caring for elderly people at home: The consequences to caregivers. *Canadian Medical Association Journal*, 157, 1101-1105.
- Hoxby, H., Roberts, J., Browne, G., Pallister, R., Gafni, A., & Streiner, D. (1997). *Telephone nursing support: Let's talk*. Working paper 97-2. Hamilton, ON: System-Linked Research Unit, McMaster University.
- Keating, N., Fast, J., Frederick, J., Cranswick, K., & Perrier, C. (1999). *Eldercare in Canada: Context, content and consequences*. Catalogue #89-570-XPE. Ottawa: Housing, Family and Social Statistics Division, Statistics Canada.
- Knight, B.G., Lutzky, S.M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *Gerontologist*, 33, 240-248.
- Litwin, H., & Lightman, E. (1996). The development of community care policy for the elderly: A comparative perspective. *International Journal of Health Services*, 26, 691-708.
- McBride, C.M., & Rimer, B.K. (1999). Using the telephone to improve health behavior and health service delivery. *Patient Education and Counselling*, 37, 3-18.
- Merlis, M. (2000). Caring for the frail elderly: An international review. *Health Affairs*, 19, 141-149.
- National Advisory Council on Aging. (1990). *The NACA position on informal caregiving: Support and enhancement*. Ottawa: Author.
- Norbeck, J.S., Chafetz, L., Skodol-Wilson, H., & Weiss, S.J. (1991). Social support needs of family caregivers of psychiatric patients from three age groups. *Nursing Research*, 40, 208-213.
- Poole, J. (1997). *Family caregivers' support network: Evaluative project activity report April 1, 1995, to March 31, 1997*. Unpublished manuscript.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282, 2215-2219.
- Short, L.A., & Saindon, E.H. (1998). Telehomecare: Rewards and risks. *Caring*, 17, 36-42.
- Shu, E., Mirmina, Z., & Nystrom, K. (1996). A telephone reassurance program for elderly home care clients after discharge. *Home Healthcare Nurse*, 14, 155-161.

- Skipwith, D.H. (1994). Telephone counselling interventions with caregivers of elders. *Journal of Psychosocial Nursing*, 32(3), 7-12.
- Strawn, B.D., Hester, S., & Brown, W.S. (1998). Telecare: A social support intervention for family caregivers of dementia victims. *Clinical Gerontologist*, 18, 66-69.
- Tilford, S., Delaney, F., & Vogels, M. (1997). Mental health promotion in high risk groups. *Effective Health Care*, 3(3), 1-12.
- Wright, L.K., Bennet, G., & Gramling, L. (1998). Telecommunication interventions for caregivers of elders with dementia. *Advances in Nursing Science*, 20, 76-88.

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