

Barriers and facilitators to caring for individuals with stroke in the community: The family's experience

By Carole L. White, Nicol Korner-Bitensky, Nathalie Rodrigue, Christina Rosmus, Rosa Sourial, Sylvie Lambert and Sharon Wood-Dauphinee

Abstract

Purpose: This project explored caregivers' perceptions regarding the barriers and facilitators to undertaking the post-stroke caregiving role, particularly as related to the health care system, with the ultimate goal of identifying potential strategies that would assist families in successfully undertaking the role.

Method: A qualitative study consisting of focus groups and individual interviews with caregivers of persons with stroke. Participants were asked about their needs in managing the care of their family member and the factors that facilitated and/or hindered the transition to the home and influenced them in maintaining their role.

Results: Information from 14 caregiver participants identified the following as primary barriers to undertaking and maintaining the caregiving role: lack of collaboration with the health care team, the intensity of the caregiving role, the negative impact on the caregiver, and the lack of community support for the caregiving role. Caregivers identified the following factors as facilitative: coordination of care, progress of the patient towards normalcy, mastery of the caregiving role, supportive social environment, and accessible community resources.

Discussion and conclusions: The results indicate there are facilitators that caregivers perceive as important both to undertaking and to sustaining the caregiving role. Consideration of these results in the design of interventions may lead to more effective interventions to support caregivers in undertaking and continuing in the caregiver role.

Key words: family caregiving, stroke, facilitators, barriers, health care system, interventions

Background

In today's health care system, the onus on the family is increasing (Canam & Acorn, 1999). Nowhere is this more apparent than in families who are attempting to support their loved ones after a stroke (Adams, 2003; Robinson, Francis, James, Tindle, Greenwell, & Rodgers, 2005). The trend towards shorter hospital stays results in individuals returning home sicker and more limited in their activities of daily living than any previous cohort of stroke survivors. Because the incidence of stroke increases with age (Kwakkel, Wagenaar, Kollen, & Lankhorst, 1996), many caregivers are themselves elderly and may be taking on a major new role while attempting to cope with their

own health problems. Compounding the problem is the sudden and unexpected nature of stroke that leaves families with little time to prepare. Thus, family members are typically forced into a new caregiving role while at the same time having to work through their own grief over the stroke event, and all of the losses that a stroke usually implies.

Research has repeatedly demonstrated the burden that caregiving places on the family, and its effects on physical and psychological well-being (Han & Haley, 1999; Low, Payne, & Roderick, 1999; Schulz & Beach, 1999; Jones, Charlesworth, & Hendra, 2000). To address these negative effects, a variety of interventions for family caregivers, both educational (Mant, Carter, Wade, & Winner, 1998; Rodgers, Atkinson, Bond, Suddes, Dobson, & Curless, 1999; Smith, Forster, & Young, 2004) and service-based in content (Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; Lincoln, Francis, Lilley, Sharma, & Summerfield, 2003; Kalra et al., 2004), have been designed and evaluated. Unfortunately, educational interventions for family members have shown only modest effects on knowledge acquisition and no significant effect on reducing emotional distress or improving health outcomes. Indeed, three reviews on the provision of stroke-related information to stroke patients and their caregivers concluded that the effectiveness of information provision remains equivocal (Korner-Bitensky, Tarasuk, Nelles, & Michallet, 1998; Rodgers, Bond, & Curless, 2001; Forster, Smith, Young, Knapp, House, & Wright, 2006).

While psychosocial interventions, such as those provided through family support groups represent another potentially effective intervention, formal evaluation of effectiveness is limited. The most common intervention examined has been discharge-related services aimed at improving the transition from the hospital to the community (Forster & Young, 1996; Dennis, O'Rourke, Slattery, Staniforth, & Warlow, 1997; Rudd, Wolfe, Tilling, & Beech, 1997; Grant, 1999; Anderson, Mhurchu, Rubenach, Clark, Spencer, & Winsor, 2000; Grant et al., 2002; Lincoln et al., 2003; Kalra et al., 2004). These services most often include regular home visits by health care professionals to offer information, and/or counselling to the stroke survivor and the family, along with physical therapy. The number of contacts was usually at the discretion of the health care professional. The majority of these post-discharge intervention studies have not shown significant differences in outcomes between the control and the intervention groups for reducing caregiver distress and improving health-related

quality of life. Counselling, provided on a fixed schedule, has been included as a component in several studies (Evans, Matlock, Bishop, Stranahan, & Pederson, 1988; Grant, 1999; van den Heuvel, de Witte, Nooyen-Haazen, Sanderman, & Meyboom-de Jong, 2000; Grant et al., 2002) and has shown some positive effects on family functioning and emotional state (Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005).

It has been suggested that one of the reasons for this general lack of success in finding effective interventions is that most interventions have been planned without a clear understanding of caregivers' needs (Robinson et al., 2005). Not only do we have limited knowledge about the factors that will facilitate the transition back into the community, but also we do not know the factors that will help sustain family support of the individual who has experienced a stroke over the long term.

Thus, the purpose of this study was to explore the perceptions of caregivers of persons with stroke regarding the barriers and facilitators to undertaking the caregiving role, particularly as related to the health care system, with the ultimate goal of identifying potential strategies that could be implemented within the health care system to assist families in successfully undertaking the role. The specific research questions were: i) what factors do caregivers perceive as barriers to undertaking the caregiving role post-stroke? ii) What factors do caregivers identify as facilitators to undertaking this role?

Methods

A qualitative thematic study was undertaken to address the research questions (Sandelowski & Barroso, 2003). Focus groups were deemed the most appropriate data collection method for this study as it was anticipated that the interactions among care providers would create more possibilities for spontaneous exchanges of ideas and experiences than individual interviews (Kitzinger, 1995). Two individual interviews were also conducted when only one participant arrived for the focus group.

Study sample

Medical records of individuals who had experienced a stroke and were discharged to the community or to a rehabilitation centre from a number of acute care urban university teaching hospitals in Montreal, Canada, between 2003 and 2004 were reviewed and contact information was obtained. Individuals with stroke were contacted by telephone by a research assistant, information about the study was provided, and if interested and agreeable, the respondent was asked to identify a primary support person. A primary support person (caregiver) was eligible to participate if the following criteria were met: i) had cared for or was currently caring for a stroke survivor who had not returned to baseline function; and ii) able to communicate in French or English. Caregivers, who were relatively new to the role, as well as those who had been caring for their family member for a longer period of time, were recruited. Information was provided to the potentially eligible

caregiver and his or her consent to participate in a focus group was requested: those who agreed provided written consent at the time of the focus group meeting. This study was approved by the Research Ethics Committees of all participating hospitals.

Data collection procedures

The focus groups and individual interviews were held in a conference room outside the hospital to provide a more neutral setting, as participants may have felt restrained in sharing information in the setting where their family member had been hospitalized. The participants attended a scheduled French or English focus group, according to their preferred language. The intent was to recruit four to six caregivers per focus group. However, due to various difficulties, groups ranged from two to four members.

The focus groups lasted between two and 2.5 hours. An experienced moderator ran each group, with an observer taking notes. All focus groups and individual interviews were audiotaped.

A series of specific questions, designed by a group of health care professionals with expertise in stroke care were used to guide the discussion. Participants were asked about their needs in managing the care of their family member and the factors that facilitated and/or hindered the transition home and influenced them in maintaining their role. Sample questions included, "What made the difference for you to be able to take your family member home?" "Do you think anything else could or should have been done to assist you in taking your family member home?" and, "What are the things that have made it difficult for you in managing the care of your family member since the stroke?" In addition, specific information was elicited on characteristics of the health care system that potentially influence success in assuming and maintaining the caregiving role. Caregivers were also encouraged to discuss anything they thought relevant to their experience in caring for their family member at home that was not addressed in the specific questions provided by the moderator. Before the groups began, the participants completed a short demographic questionnaire providing information about their age, gender, relationship to the person with the stroke, their caregiving activities, and lifestyle changes since assuming the role.

Data analysis

The interviews were transcribed verbatim from the audiotapes and examined for recurrent themes using a content analysis procedure (Dilorio, Hockenberry-Eaton, Maibach, & Rivero, 1994). First, the entire research team met to analyse one focus group transcript and to develop both the process for coding and the set of initial codes based on the themes found in the transcript. To clarify, we together reviewed the first transcript line-by-line and excerpts of the transcript that described facilitators or barriers to the caregiving role were highlighted and written in the margin of the transcript. Words or sentences representing the same

idea were grouped together and labelled (i.e., codes). Codes were discussed among the team to ensure a similar understanding of the meaning of the code. Subsequent to this session, the transcripts were divided among the research team and each member of the team reviewed two to three transcripts, with each transcript reviewed independently by at least two members of the research team. The team members discussed their coding, particularly focusing on any differences in the coding. New codes were integrated to the original list as the analysis proceeded and new themes emerged.

Results

A total of 74 caregivers were contacted with 27 found to be ineligible for the following reasons: person with stroke was back to baseline so the caregiver was no longer performing any caregiver activities (n=12), stroke survivor had died (n=5), or caregiver did not speak French or English (n=10). Of the 47 eligible caregivers, 33 refused to participate because they stated they were too busy or were not interested. This left 14 caregivers who consented and participated. The majority was over 50 years of age, the spouse of the person with stroke, and about 50% were female. About half of the group had been in the role less than six months and the other half, on average, for one year. All participants reported being very involved in the direct care and/or support of their loved ones with stroke and more than 40% viewed caregiving as their primary daily activity.

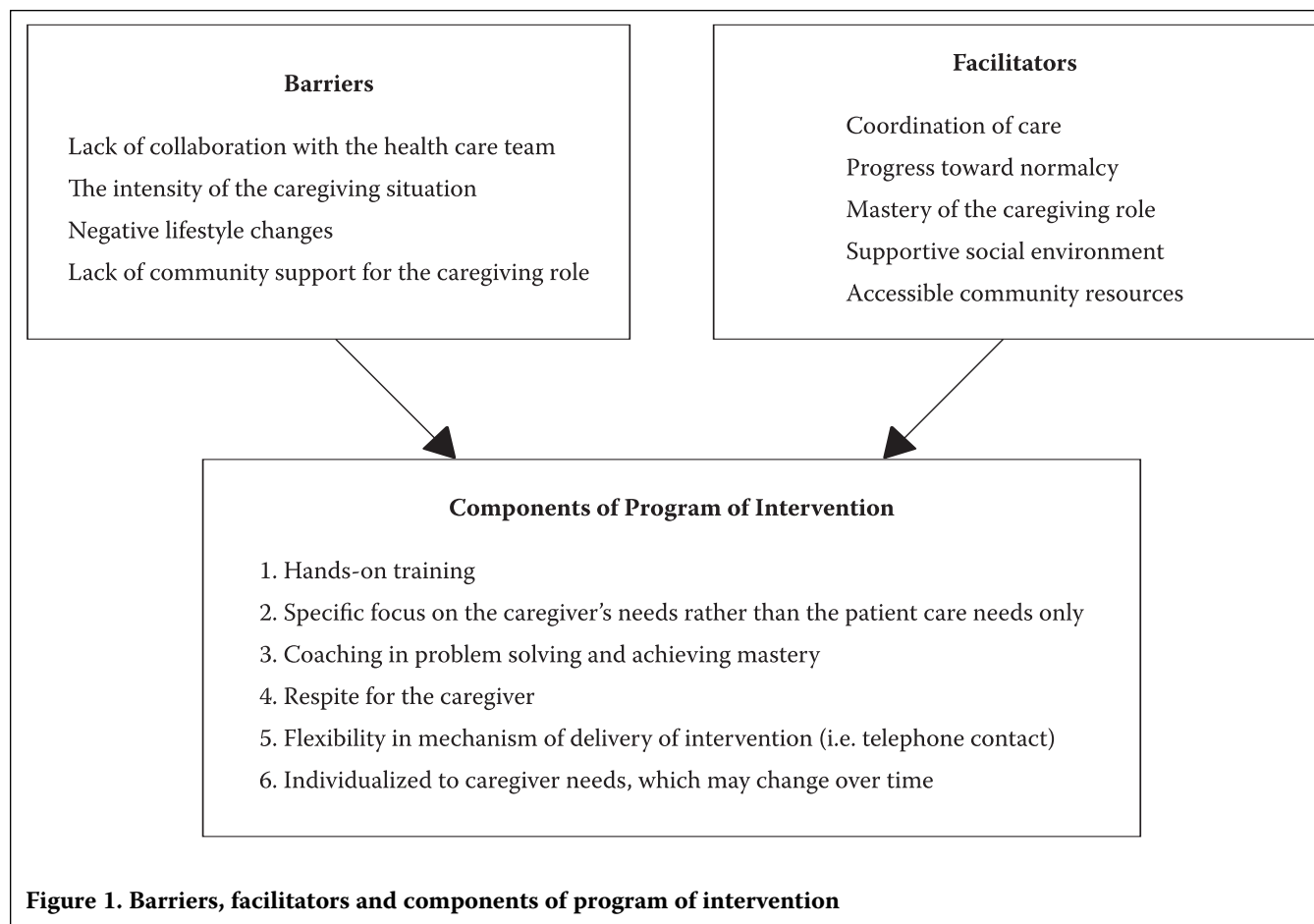
Barriers and facilitators to caring for individuals with stroke in the community

The results are presented according to the themes that surfaced, with quotations that highlight the salient points within a theme. Interestingly, caregivers often described factors along a continuum such that the presence of a factor was perceived as a facilitator, whereas its absence was seen as a barrier. For example, when there was a perceived lack of collaboration with the health care team this was seen as a barrier, whereas when caregivers were included as part of the team, this was viewed as facilitative. No caregiver described only barriers or only facilitators, but rather, there were elements of both in all situations. Figure 1 presents a summary of the barriers and facilitators, as well as potential strategies based on the results that could be implemented within the health care system to assist families in successfully undertaking the role.

Barriers

Lack of collaboration with the health care team

Caregivers repeatedly described the importance of collaboration with health care professionals and its perceived absence created anxiety and was viewed as detrimental to their success in the transition from hospital to home. One woman described it as *“being an outsider”*. Caregivers acknowledged difficulty in accessing information, and this was identified as a significant barrier in preparing to take their family member



home. A female spouse said: *"There is so much worry – it is all unknown. We didn't get answers, which creates anxiety because we didn't know how to plan."* Caregivers were also frustrated by what they perceived as a lack of coordination of care: *"They were busy doing their things. But you know, we had to call. Who's in charge of him? Who is his doctor? I didn't feel I was in the loop."*

Some caregivers described limited involvement in the discharge process: *"Well, the hospital said that they didn't want to keep him any longer so I had to take him home."* *"Yes, that's right! They tell you when it's time to go home!"* A son who was assisting his mother in the care of his father described the following: *"They sent my father home too quickly and we did not have the capability to care for him so they were sending him home to an environment that was not safe for him."*

Intensity of the caregiving situation

The limited time to acquire the necessary skills for this new role, particularly where the stroke was severe with a high demand for personal care was perceived as a barrier. A spouse described her difficulties in taking on this new role: *"You know I never had children so this is difficult for me at my age to start doing all these things. Everything is new."* Particular concerns were expressed related to safe mobilization of the person with stroke and having sufficient preparation to deal with wheelchairs, transfers, and managing in the event of a fall. Another female caregiver commented on her lack of preparation for managing falls: *"And it's not something that we did at the rehab centre, falling and getting up and stuff like that."* Most caregivers described the behavioural changes resulting from the stroke as particularly challenging, even more so than the physical changes. *"She's like a child sometimes. I find it hard. It's pretty hard sometimes."*

Caregivers emphasized the high need for their presence, particularly in the early period after discharge, described by one caregiver as *"feeling like a prisoner in your own home"*. When they did go out, caregivers rushed through their errands and constantly worried about their family member's safety. Caregivers changed their routines to be more present and if out, telephoned home frequently. This was highlighted during the focus groups when several caregivers paused from the discussion to telephone their spouses to ensure their safety.

Negative lifestyle changes

Participants described the lifestyle changes resulting from the stroke and the caregiving situation including changes to their health, socialization, physical environment, and finances. The negative effects on their physical and emotional health were seen as significant barriers to their success in the role. Fatigue was common in caregivers and the majority described times in their caregiving role when they felt completely overwhelmed. One woman described how she was feeling early in the caregiving role: *"I thought I was going to collapse physically, my knees were going on me, I thought I was getting a hernia, my back was hurting. I just thought if I collapse, what's going happen to the two of us. It's very scary, very scary."*

Many participants described changes to their social life and their subsequent feelings of isolation. They talked about not being able to go on vacations, having less contact with their friends, and less involvement in activities that were important to them. One male spouse stated: *"My personal activities have changed so that I cannot be away so much. It's hard. The days pass well, but I go out less often and have many less outside activities than before."*

Although home adaptations were seen as a necessary inconvenience to being able to care for their family member at home, these modifications also created stress for caregivers, particularly for the female spouses, and one described it in the following way: *"Well, my home is not how I like it because everything is rearranged. I have the bed in the living room, all my carpets are rolled up...it's just a mess... I mean it's just not my home! My environment is very important to me."*

Regardless of their financial capacity, caregivers commented on the expenses, including paying for services (if they could afford to do so), medications, home modifications, equipment, special clothing, and transportation, associated with the stroke. One caregiver commented: *"stroke is an expensive illness"*.

Lack of community support for the caregiving role

Participants described the lack of resources in the community and the difficulty of identifying and accessing available resources as important barriers to continuing in the caregiving role. Many of the caregivers described spending valuable time *"fighting the system"* to get help and their frustrations at the long waiting lists for services and limitations to what some services could offer. One caregiver commented on her application for home modifications: *"So I applied and I got a note from the government agency saying there was a two-year waiting list. So you know, you can die before you get any assistance in this regard."*

Participants also acknowledged a lack of support in the community for family caregivers, including psychological support, and emphasized that the needs of the family caregiver must be addressed independent of the needs of the person with stroke. One son, who was caring for his mother, stated that help should be focused on the family members who are providing this care as they are undertaking more and more given the current state of the health care system.

Facilitators

Coordination of care

Caregivers were aware of the organization of care on the nursing unit and identified factors such as a coordinator of care and family meetings as important for sharing information and critical in their preparation for discharge. One spouse clearly articulated the need for better coordination of care: *"I would have liked a project coordinator who would have talked to us weekly or regularly about what was happening. I didn't quite know what was happening or where we*

were going... there are all kinds of people, they change over time. But nobody to really talk to – to pull it all together, to say this is where we are now. This is what is going to happen, this is what you can expect.” In contrast, another spouse described how helpful it was to have someone who was in charge of her husband’s care and could provide her with information: “Well, he had one different hours, but one was the head one for him. Head nurse, I mean, she’s the one that was always at the meetings and the one that planned his care.” Caregivers valued timely information, advice, and anticipatory guidance from health care professionals in both hospital and community settings. The family meeting, where the whole team was present, was identified as an important source of information for making plans for discharge, “they lay everything out for you...they call that a family reunion”.

Caregivers identified information about stroke and the opportunity to learn care techniques, trial weekends, and a home inspection prior to discharge as critical in the preparation for discharge. One female caregiver described her preparation: “I worked with the nurses. When he took a shower and different things, helping to get dressed, his exercises...I practised all that before he came home...And then the two weekends that he came home...I thought that was pretty good. And then they took care of the CLSC [Quebec community health service] and then there’s the exercise program that I have to do with him at home. I think I was pretty well prepared in a way.”

Progress toward normalcy

Participants described important lifestyle changes brought about by the stroke and the caregiving situation. Their ability to integrate these changes and make the necessary adjustments toward a “more normal life” served as a facilitator to continuing in the role. Participants described having the time to attend to their own health needs, getting back to some previous activities, although perhaps in an altered format, and making future plans. Progress toward normalcy motivated both the caregiver and care recipient and provided them with a sense of hope for the future: “It seems that we are moving forward and we have friends who come in to visit and things seem more normal.”

Most caregivers described the vital connection between their family members’ improvement and the betterment in their quality of life, “He’s improving so I am improving.” Seeing improvement lessened their workload and also helped to maintain a sense of hope, critical to continuing in the caregiving role.

Mastery of the caregiving role

Learning to solve problems and master new roles and tasks contributed to feelings of empowerment and was viewed as facilitative to continuing in the role. One male spouse caregiver talked proudly about learning many of the household tasks that he had never before done: “I have done so many things that I never thought that I would be able to do around the house – the banking, the shopping, the cooking, giving my wife a shower, making the bed. I’ve never done a lot of work

around the house, just something I’d never done...I’ve learned a lot of things.” A difficult aspect of the caregiving role was the navigation of the health care system and knowing what resources were available and how to access them. One son described his mastery in this area: “I spend time trying to understand the health care system so that I am able to access certain things quickly.”

Supportive social environment

Caregivers identified the importance of a supportive social environment, “you know people sort of rallying around”, particularly early after the stroke. One female caregiver described the support from her son: “He’ll take him for the day. It gives me a chance to relax. I can sit and read and I don’t have to worry about what he is doing and where he’s going.” This emotional and instrumental support often provided needed respite to help the caregiver to continue in the role.

Caregivers also described a supportive relationship with their recipient of care and appreciation on the part of the care recipient for the care provided by the caregiver as contributing to a positive social environment. Even though the person with stroke may be unable to contribute to the relationship in ways that he/she may have in the past, reciprocity was important in the relationship and fostered an attitude toward one another of flexibility and being able to adapt together to the different situations. One male spouse put it this way: “It brought us closer together...it’s not as sexy as it used to be, but we are still close. We exchanged one thing for

Neuroscience Nursing
Expand your mind...
your career
your skills
your opportunities

The Advanced Studies in Critical Care Nursing certificate program – Neuroscience Nursing stream – is open to registered nurses or senior undergraduate nursing students.

- Distance delivery with computer access
- Part-time flexibility for busy schedules
- CNA certification exam preparation
- Receive course credit for CNA Neuroscience Nursing certification

Enroll today in our new Neuroscience certificate at Mount Royal College

MOUNT ROYAL COLLEGE
Calgary, Alberta

For more information visit
www.mroyal.ca/noon or call 1-888-248-2782
For Calgary & area call (403) 440-4755

the other. I have arthritis in my legs, my hands, but we help one another. I think it brings you closer, being with the person all the time."

Accessible community resources

Caregivers identified the importance of knowing what resources are available and being able to access those resources. They talked about the competency of the help that was available in the community and the importance of having well-trained help. Several caregivers described value of telephone contact with a health professional, particularly when it was difficult to leave the home: *"The nurse was really helpful, anytime... I knew if she was busy she would get back to me...I had her that I could reach out to."*

Adaptive devices were viewed as necessary for managing the care of the person with stroke (i.e. blocks under the sofa, raised toilet seats), as was the accessibility of medical care including home visits by physicians. Caregivers also indicated resources such as meals-on-wheels, transportation to day hospitals, and lifelines as facilitative. Respite, for a few hours or a longer period of time when the caregiver could focus on activities important to him/her, was seen as critical to continuing in the role. A male caregiver described how respite was important both for the caregiver and the recipient of care: *"Day hospitals give you free time and change the mind and the surroundings of the person with stroke. This is very, very important."*

Discussion

Despite an abundance of studies highlighting the anxiety, distress, and burden associated with caring for a family member following stroke, there continues to be a lack of evidence-based interventions to sustain family caregivers. Furthermore, although national stroke guidelines recommend collaboration and partnership with the families of stroke survivors to support them in undertaking the caregiving role (Greshman, Duncan, Stason, Adams, Adelamn, & Alexander, 1995), as recently as 2007 (Mackenzie, Perry, Lockhart, Cottee, Cloud, & Mann, 2007; Rodgers, Francis, Brittain, & Robinson, 2007) and now again in our study, caregivers still describe a lack of collaboration with the health care team and limited involvement in the discharge process.

The results of our study offer insight into why previous interventions may have failed and suggest elements that should be included to promote success of a post-stroke caregiving intervention program. First, the limited effectiveness of previously attempted educational interventions (Mant et al., 1998; Rodgers et al., 1999; van den Heuvel et al., 2000; van den Heuvel, de Witte, Stewart, Schure, Sanderman, & Meyboom-de Jong, 2002; Smith et al., 2004; Larson, Franzen-Dahlin, Billing, Arbin, Murray, & Wredling, 2005) indicates that we need to identify more appropriate educational strategies that families feel are beneficial (Forster et al., 2006). The caregivers in our study were very specific about the value of "hands on training" in helping prepare them for the caregiving role. There is often a lack of recognition by the health care team regarding the complexities of the caregiving role and the number of new skills caregivers must learn within a short

period of time (Brereton, 1997; Visser-Meily, Post, Gorter, Berlekom, Van Den Bos, & Lindeman 2006). A recent trial incorporating hands-on training in addition to instruction by health care professionals (Kalra et al., 2004) was effective. Specifically, those in the intervention group achieved independence at an earlier stage, their mood and quality of life and that of their caregiver was improved, and the cost of care was reduced (Kalra et al., 2004; Patel, Knapp, Evans, Perez, & Kalra, 2004). These results taken together with the information from our focus groups provide support for the inclusion of practical hands-on-training as a necessary component of educational interventions, rather than the more commonly provided written and lecture formats.

A number of studies have tested the effectiveness of a health professional, or someone identified as a family support organizer, making regular contact with the dyad to identify unmet needs and to provide information and advice (Forster & Young, 1996; Dennis et al., 1997; Rudd et al., 1997; Mant, Carter, Wade, & Winner, 2000; Lincoln et al., 2003; Tilling, Coshall, McKeivitt, Daneski, & Wolfe, 2005). For the most part these interventions have not impacted on caregiver distress, burden, or health. Caregivers in our study emphasized that their specific needs must be addressed independent of the needs of the person with stroke. There are several recent studies that targeted the caregiver with a problem-solving intervention where the caregiver is coached to define problems, identify possible solutions, and then choose and test the best solutions (Grant et al., 2002; King, Hartke, & Denby, 2007). The content of these problem-solving interventions has included a critical focus on the caregiver's own emotional responses to the caregiving role. Results are promising with the intervention groups reporting decreased depression (Grant et al., 2002; King et al., 2007) and improved quality of life (Grant et al., 2002). In our focus groups, being able to solve problems and master new situations was identified as facilitative to sustaining the caregiving role. Thus, it would seem clear that intervention programs should be designed to include coaching of caregivers to achieve mastery in situations where they are facing difficulties rather than providing them with information only. This is supported by an early study (Evans et al., 1988) where education plus counselling to solve problems occurring in the home led to better outcomes than education alone.

Caregivers described the high need for their presence, particularly in the early months, which made it difficult for them to attend to other activities that were important to them. The availability of someone to watch over their loved one, even for a few hours, was perceived as very beneficial. Nieboer, Schulz, Matthews, Scheier, Ormel, and Lindenberg (1998) examined the relationship between the number of caregiving tasks, caregiver activities, and depression. Their results suggested that when caregivers were able to combine caregiver tasks with their usual important life activities, their well-being did not deteriorate. However, when the demands of caregiving imposed restrictions on their ability to carry on these activities, their depressive symptoms increased. To date, interventions typically have not included respite, but our results substantiate the need for respite that enables caregivers to maintain their important life-activities.

Participants in our study described their own need for support, including the availability of psychological services. They discussed their difficulties in leaving the house and identified the importance of telephone contact with a health professional. In a recent trial, caregivers were asked to evaluate the intervention and as did the caregivers in our study, they recommended that future interventions should include telephone consultations with a professional (Schure, van den Heuvel, Stewart, Sanderman, de Witte, & Meyboom-de Jong, 2006).

Focus group members described the wide variety of situations that they face and how their needs changed over time. To understand the failure of their intervention to impact on caregiver well-being, Tilling et al. (2005) undertook a content analysis of the notes describing the delivery of the intervention. This analysis revealed that the family support organizer did not always target interventions to need but rather used a protocol approach. King et al. (2007) suggested that the success of their intervention may have been related to the use of a program that allowed tailoring to individual caregiver needs. Our study participants also indicate that generic interventions will most likely have limited benefits.

Limitations

Our findings reflect the views of a small sample of caregivers. Some bias may have occurred, as those who were very much locked into the caregiving role were unable to attend even one focus group. Yet, we did have a number of participants who, while currently able to leave their home, would have been unable to do so several months earlier. These caregivers were extremely articulate in describing the barriers and facilitators they had experienced when they were too busy in the caregiving role to leave their homes. Thus, we feel that the results represent the diversity of the caregiving situation. Furthermore, with the 14 participants, the last two transcripts revealed no new categories, suggesting that we had reached saturation in terms of new themes.

Conclusion

In the U.S. and Canada alone almost six million individuals are living with the effects of a stroke (Mayo, Wood-Dauphinee, Cote, Durcan, & Carlton, 2002; Rosamond et al., 2007). Caregivers are giving us a clear message indicating that

they can only undertake and sustain this enormous responsibility if we as members of the health care system address their needs. Ensuring that effective strategies are included in a comprehensive program of support is likely to impact substantially on the ability of those with stroke to remain within their family structure.

Acknowledgements

We gratefully acknowledge the financial support for this study from the Division of Nursing Research, McGill University Health Centre. We are appreciative of the family members who shared their caregiving experiences with us.

About the authors

Carole L. White, RN, PhD, Department of Neurology, University of Texas Health Science Center at San Antonio, San Antonio, Texas. Correspondence regarding this article should be addressed to Carole L. White, SPS3 Coordinating Center, 4647 Medical Drive, San Antonio, Texas, US, 78229 Tel: 1-210-592-0404, Fax: 1-210-592-0552, Email: whitec2@uthscsa.edu

Nicol Korner-Bitensky, PhD, School of Physical and Occupational Therapy, McGill University, Montreal, Quebec, Centre de recherche interdisciplinaire en réadaptation du Montréal métropolitain.

Nathalie Rodrigue, RN, MSc, Department of Nursing, McGill University Health Centre, Montreal, Quebec, School of Nursing, McGill University, Montreal, Quebec.

Christina Rosmus, RN, MSc, Department of Nursing, McGill University Health Centre, Montreal, Quebec, School of Nursing, McGill University, Montreal, Quebec.

Rosa Sourial, RN, MSc, Department of Nursing, McGill University Health Centre, Montreal, Quebec, School of Nursing, McGill University, Montreal, Quebec.

Sylvie Lambert, N, PhD(c), School of Nursing, McGill University, Montreal, Quebec.

Sharon Wood-Dauphinee, PhD, School of Physical and Occupational Therapy, McGill University, Montreal, Quebec.

References

- Adams, C. (2003). Quality of life for caregivers and stroke survivors in the immediate discharge period. *Applied Nursing Research*, *16*, 126-130.
- Anderson, C., Mhurchu, C.N., Rubenach, S., Clark, M., Spencer, C., & Winsor, A. (2000). Home or hospital for stroke rehabilitation? Results of a randomized controlled trial: Cost minimization analysis at six months. *Stroke*, *31*, 1032-1037.
- Brereton, L. (1997). Preparation for family care-giving: stroke as a paradigm case. *Journal of Clinical Nursing*, *6*, 425-434.
- Canam, C., & Acorn, S. (1999). Quality of life for family caregivers of people with chronic health problems. *Rehabilitation Nursing*, *24*, 192-196.
- Dennis, M., O'Rourke, S., Slattery, J., Staniforth, T., & Warlow, C. (1997). Evaluation of a stroke family care worker: Results of a randomized controlled trial. *BMJ*, *314*, 1071-1076.
- Dilorio, C., Hockenberry-Eaton, M., Maibach, E., & Rivero, T. (1994). Focus groups: An interview method for nursing research. *Journal of Neuroscience Nursing*, *26*, 175-180.
- Evans, R.L., Matlock, A.L., Bishop, D.S., Stranahan, S., & Pederson, C. (1988). Family intervention after stroke: does counseling or education help? *Stroke*, *19*, 1243-1249.
- Forster, A., Smith, J., Young, J., Knapp, P., House, A., & Wright, J. (2006). Information provision for stroke patients and their caregivers. *Cochrane Database of Systematic Reviews*, *4*.

- Forster, A., & Young, J. (1996). Specialist nurse support for patients with stroke in the community: A randomized controlled trial. *BMJ*, **312**, 1642-1646.
- Grant, J.S. (1999). Social problem-solving partnerships with family caregivers. *Rehabilitation Nursing*, **24**, 254-260.
- Grant, J.S., Elliott, T.R., Weaver, M., Bartolucci, A.A., & Giger, J.N. (2002). Telephone intervention with family caregivers of stroke survivors after rehabilitation. *Stroke*, **33**, 2060-2065.
- Greshman, G.E., Duncan, P.W., Stason, W.B., Adams, H.P., Adelamn, A.M., & Alexander, D.N. (1995). **Post-stroke rehabilitation. Clinical practice guideline, No. 16.** Rockville, MD: US Department of Health and Human Services. Public Health Service, Agency for Health Care Policy and Research.
- Han, B., & Haley, W.E. (1999). Family caregiving for patients with stroke. Review and analysis. *Stroke*, **30**, 1478-1485.
- Jones, A.L., Charlesworth, J.F., & Hendra, T.J. (2000). Patient mood and carer strain during stroke rehabilitation in the community following early hospital discharge. *Disability & Rehabilitation*, **22**, 490-494.
- Kalra, L., Evans, A., Perez, I., Melbourn, A., Patel, A., Knapp, M., et al. (2004). Training carers of stroke patients: Randomized controlled trial. *BMJ*, **328**, 1099-1101.
- King, R.B., Hartke, R.J., & Denby, F. (2007). Problem-solving early intervention: A pilot study of stroke caregivers. *Rehabilitation Nursing*, **32**, 68-76.
- Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *BMJ*, **311**, 299-302.
- Korner-Bitensky, N., Tarasuk, J., Nelles, J., & Michallet, B. (1998). The impact of interventions with families post-stroke: a review. *Topics in Stroke Rehabilitation*, **5**, 69-85.
- Kwakkel, G., Wagenaar, R.C., Kollen, B.J., & Lankhorst, G.J. (1996). Predicting disability in stroke—a critical review of the literature. *Age & Ageing*, **25**, 479-489.
- Larson, J., Franzen-Dahlin, A., Billing, E., Arbin, M., Murray, V., & Wredling, R. (2005). The impact of a nurse-led support and education programme for spouses of stroke patients: A randomized controlled trial. *Journal of Clinical Nursing*, **14**, 995-1003.
- Lincoln, N.B., Francis, V.M., Lilley, S.A., Sharma, J.C., & Summerfield, M. (2003). Evaluation of a stroke family support organizer: A randomized controlled trial. *Stroke*, **34**, 116-121.
- Low, J.T., Payne, S., & Roderick, P. (1999). The impact of stroke on informal carers: A literature review. *Social Science & Medicine*, **49**, 711-725.
- Mackenzie, A., Perry, L., Lockhart, E., Cottee, M., Cloud, G., & Mann, H. (2007). Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. *Disability & Rehabilitation*, **29**, 111-121.
- Mant, J., Carter, J., Wade, D.T., & Winner, S. (1998). The impact of an information pack on patients with stroke and their carers: A randomized controlled trial. *Clinical Rehabilitation*, **12**, 465-476.
- Mant, J., Carter, J., Wade, D.T., & Winner, S. (2000). Family support for stroke: A randomized controlled trial. *Lancet*, **356**, 808-813.
- Mayo, N.E., Wood-Dauphinee, S., Cote, R., Durcan, L., & Carlton, J. (2002). Activity, participation, and quality of life six months post-stroke. *Archives of Physical Medicine & Rehabilitation*, **83**, 1035-1042.
- Nieboer, A.P., Schulz, R., Matthews, K.A., Scheier, M.F., Ormel, J., & Lindenberg, S.M. (1998). Spousal caregivers' activity restriction and depression: a model for changes over time. *Social Science & Medicine*, **47**, 1361-1371.
- Patel, A., Knapp, M., Evans, A., Perez, I., & Kalra, L. (2004). Training care givers of stroke patients: Economic evaluation. *BMJ*, **328**, 1102-1104.
- Robinson, L., Francis, J., James, P., Tindle, N., Greenwell, K., & Rodgers, H. (2005). Caring for carers of people with stroke: Developing a complex intervention following the medical research council framework. *Clinical Rehabilitation*, **19**, 560-571.
- Rodgers, H., Atkinson, C., Bond, S., Suddes, M., Dobson, R., & Curless, R. (1999). Randomized controlled trial of a comprehensive stroke education program for patients and caregivers. *Stroke*, **30**, 2585-2591.
- Rodgers, H., Bond, S., & Curless, R. (2001). Inadequacies in the provision of information to stroke patients and their families. *Age & Ageing*, **30**, 129-133.
- Rodgers, H., Francis, J. J., Brittain, K., & Robinson, A. L. (2007). Who cares? – Caring for the carers of stroke patients. *Disability & Rehabilitation*, **29**, 425-427.
- Rosamond, W., Flegal, K., Friday, G., Furie, K., Go, A., Greenlund, K., et al. (2007). Heart disease and stroke statistics – 2007 update: A report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation*, **115**, e69-171.
- Rudd, A.G., Wolfe, C.D., Tilling, K., & Beech, R. (1997). Randomized controlled trial to evaluate early discharge scheme for patients with stroke. *BMJ*, **315**, 1039-1044.
- Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research*, **13**, 905-923.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: the caregiver health effects study. *JAMA*, **282**, 2215-2219.
- Schure, L.M., van den Heuvel, E.T., Stewart, R.E., Sanderman, R., de Witte, L.P., & Meyboom-de Jong, B. (2006). Beyond stroke: description and evaluation of an effective intervention to support family caregivers of stroke patients. *Patient Education & Counseling*, **62**, 46-55.
- Smith, J., Forster, A., & Young, J. (2004). A randomized trial to evaluate an education programme for patients and carers after stroke. *Clinical Rehabilitation*, **18**, 726-736.
- Tilling, K., Coshall, C., McKeivitt, C., Daneski, K., & Wolfe, C. (2005). A family support organizer for stroke patients and their carers: A randomized controlled trial. *Cerebrovascular Diseases*, **20**, 85-91.
- van den Heuvel, E.T., de Witte, L.P., Nooyen-Haazen, I., Sanderman, R., & Meyboom-de Jong, B. (2000). Short-term effects of a group support program and an individual support program for caregivers of stroke patients. *Patient Education and Counseling*, **40**, 109-120.
- van den Heuvel, E.T., de Witte, L.P., Stewart, R.E., Schure, L.M., Sanderman, R., & Meyboom-de Jong, B. (2002). Long-term effects of a group support program and an individual support program for informal caregivers of stroke patients: Which caregivers benefit the most? *Patient Education & Counseling*, **47**, 291-299.
- Visser-Meily, A., Post, M., Gorter, J. W., Berlekom, S.B.V., Van Den Bos, T., & Lindeman, E. (2006). Rehabilitation of stroke patients needs a family-centred approach. *Disability & Rehabilitation*, **28**, 1557-1561.
- Visser-Meily, A., van Heugten, C., Post, M., Schepers, V., & Lindeman, E. (2005). Intervention studies for caregivers of stroke survivors: A critical review. *Patient Education & Counseling*, **56**, 257-267.