

Changes in Activities of Wives Caring for Their Husbands Following Stroke

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ABSTRACT

Purpose: The purpose of this study was to explore the perspectives of caregivers of persons with stroke with respect to their own physical activity.

Methods: A qualitative, descriptive approach was used to study 10 caregivers of persons with stroke, recruited from a stroke exercise class in a large urban rehabilitation facility. Caregivers participated in individual, semi-structured interviews that were audiotaped, transcribed verbatim, and analysed using a constant comparative method. An inductive, iterative approach was applied to determine the codes and themes.

Results: Four main themes were identified: change in role, change in activity, barriers to activity and health, and change in meaning of activity. Barriers to activity included guilt, time, and energy. Participants revealed that activity became more therapeutic after stroke and that participants preferred purposeful, functional, and partnered activities.

Conclusions: These findings emphasize the importance of the husband–wife dyad and of movement toward a family-centred care approach. Education should be provided to caregivers regarding their role, barriers, and health-promoting activities. Future research should focus on determining appropriate physical-activity programmes for caregivers as well as on evaluating implementation of partnered exercise programmes for caregivers and persons with stroke.

Key Words: activity, caregiver, partnered activities, physical activity, qualitative research, stroke

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RÉSUMÉ

Objectif : L'objectif de cette étude consistait à analyser la perspective des soignant(e)s de personnes ayant subi un accident vasculaire cérébral (AVC) face à leur propre degré d'activité physique.

Méthode : Une approche qualitative descriptive a été retenue pour l'étude des habitudes en matière d'activité physique de dix soignantes de personnes ayant subi un AVC ; ces personnes ont été recrutées dans une classe d'exercices de réadaptation suivant un AVC, offerte dans un centre de réadaptation d'un grand centre urbain. Chaque soignante a pris part à des entrevues individuelles semi-structurées, enregistrées sur bande audio et dont les propos ont été ensuite transcrits puis analysés suivant une méthode comparative constante. Une approche itérative inductive a été utilisée pour en préciser les codes et les thèmes.

Résultats : Quatre grands thèmes ont été identifiés : changement de rôle, changement dans les activités, obstacles à l'activité et à la santé et changement dans la signification rattachée à l'activité. Parmi les obstacles à la pratique de l'activité physique, on a relevé la culpabilité, le manque de temps et le manque d'énergie. Les participantes ont révélé que l'activité devenait plus thérapeutique et qu'elles préféraient des activités à but précis, fonctionnelles et pratiquées en compagnie d'un partenaire.

Conclusions : Ces constatations soulignent l'importance de la dyade mari et femme et de la tendance vers une approche thérapeutique plus centrée sur la famille. Il serait important d'éduquer les soignant(e)s quant à leur rôle, aux obstacles auxquels ils pourraient être confrontés et aux activités de promotion de la santé. La recherche devrait se pencher sur la création de programmes d'activité physique adaptés à ces personnes ; la mise en place de programmes d'exercices avec partenaire à l'intention des soignant(e)s et des personnes ayant subi un AVC devrait aussi être évaluée.

Mots clés : accident vasculaire cérébral, activité, activité physique, activités en partenariat, recherche qualitative, soignant(e)s

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INTRODUCTION

Stroke is the leading cause of disability in older adults in Canada, where approximately 300,000 people are currently living with the sequelae of stroke and 40,000 to 50,000 strokes occur each year.^{1,2} While medical advances in stroke management have improved survival rates,³ the growing number of people now living with stroke has led to an increased number of caregivers providing assistance to persons with stroke living at home. These caregivers are usually family members, primarily spouses.⁴ Inadequate and limited community resources such as home care and outpatient services create challenges for these caregivers in their new role.⁵

People living with stroke typically experience a decrease in physical function, depression, and diminished quality of life, which in turn may limit their capacity to participate fully in activities of daily living (ADL).^{4,6-8} The resulting higher demand for assistance may affect caregivers' own health, and they may experience caregiver burden.⁹⁻¹³ To date, studies that have described the experiences of caregivers of persons with chronic conditions such as stroke have focused predominantly on caregiver burden and psychosocial issues.^{4,6,9,10,14-17} There is little research focusing on the caregivers' experiences of maintaining their own health through participation in physical activity and how such activity has changed upon becoming a primary caregiver. The purpose of this study was to explore the meaning of physical activity for caregivers of persons with stroke and their experiences with maintaining their own physical activity following the stroke.

BACKGROUND AND LITERATURE REVIEW

As noted above, the literature on caregiving to date has focused mostly on the psychosocial issues associated with being a caregiver, such as depression, anxiety, social isolation, exhaustion, and feeling overwhelmed.^{4,6,9,10,14-18} These psychosocial issues are related to the cognitive and disability level of the person with stroke, the personal coping strategies of the caregiver, and the relationship between the caregiver and the person with stroke.¹⁷ Primary caregivers of persons with stroke are more likely than the general population to have poor psychosocial health.¹⁷ In comparison to caregivers of persons with chronic degenerative neurological diseases, caregivers of persons with stroke experience a higher level of emotional, psychological, and physical distress.¹⁶ Caregivers also feel an added responsibility to provide optimal care because of the relationship they have with the person with stroke.¹⁹ The physical and emotional demands involved in providing care have been reported to strain family relationships.¹⁹

There is little literature on how caregivers of persons with stroke balance the demands of caregiving with their

own health and wellness needs. It is likely that psychosocial issues, combined with the time constraints and physical demands imposed by becoming a caregiver, reduce the time spent on health-promoting activities. This can predispose caregivers to health problems associated with a sedentary lifestyle, such as risk of coronary heart disease and exacerbation of pre-existing health conditions.^{11,12} For example, a study by Schulz et al. demonstrated that elderly caregivers who experience mental or emotional strain have a higher risk of mortality than non-caregivers.⁹ These authors also found that caregivers with existing health conditions had a greater mortality risk. However, Schulz et al.'s study did not address the caregiver's participation in health-promoting activities and did not focus specifically on caregivers of persons with stroke. Satariano et al. suggested that if caregivers had access to resources that promoted positive health-related behaviour, caregiving might not lead to negative health practices.²⁰

To date, there is limited evidence on the daily physical activity of caregivers of persons with stroke, although caregivers are reported to experience decreased leisure time and a disruption in social activities that is likely to reduce physical activity.¹¹ Caregivers may not have the time, energy, or desire to engage in physical activity. However, a decrease in recreational activities in caregivers may coincide with an increased level of overall daily physical activity, as the caregiver may be responsible for physically assisting the person with stroke in completing ADL such as showering, dressing, and transfers.¹⁰ The studies cited here did not specifically evaluate what caregivers meant by "physical activity" or their preferences with respect to physical activity.

It is well documented in the current literature that a decrease in the caregiver's physical health results in increased depressive symptoms, which may further compromise caregivers' physical well-being^{4,9} and may subsequently affect their ability to provide care for persons with stroke.²¹ Further understanding of how the role of providing care for a person with stroke affects physical activity is important in addressing the health care needs of the caregiver.

As mentioned above, there is a large body of research on caregivers of persons with stroke. Qualitative studies have explored the experiences of caregivers of persons with stroke and identified areas where caregivers expressed concern, such as support, information, role change, training, dealing with emotions, living with physical limitations, participation in physical activity, and balancing all of these responsibilities.²²⁻²⁴ However, there is a lack of information on caregivers' thoughts about physical activity and how their own physical activities have changed as a result of their new role. The present study explores the perceptions and experiences of caregivers of persons with stroke with respect to their own health and their participation in physical activity, in

order to understand (1) the ways in which caring for a person with stroke affects the caregivers' own physical activity and (2) their preferences, needs, and interests in physical activity.

METHODS

A qualitative, descriptive approach was used to explore the experiences of primary caregivers of persons with stroke, particularly with respect to their perceptions of and participation in activity.²⁵ This approach allowed for an in-depth understanding of the perspective of a primary caregiver and focused on the individual needs of the participant, in congruence with the client-centred model of care.²⁵

We used symbolic interactionism as a broad theoretical framework for this project. Symbolic interactionism is a social psychological theory with three basic premises.^{26,27} First, people assign meanings to the people, objects, and events in their lives and act on the basis of these subjective perceptions of the world. Second, meanings develop through interaction with others. Finally, people establish and modify meanings through a continuous process of interpretation. According to this theoretical perspective, an inquirer can understand human action only by understanding how the people being studied define the situation, what they take into account, and how they interpret this information. In the present study, caregivers of people with stroke renegotiate the meaning of activity when their social world changes with the advent of the stroke. New meanings of activity come about through interactions with the spouse in his new, altered state as the spouses' roles evolve and opportunities for activity change.

The study received ethics approval from the rehabilitation facility's ethics board. Informed consent was received from all study participants.

Participants

The study population consisted of current primary caregivers of persons living with stroke. Individuals were eligible for inclusion if they were live-in primary caregivers of persons with stroke and were able to participate in a one hour-long interview in English. Paid caregivers were excluded. A convenience sampling approach was used to identify potential participants whose spouses were past or present attendees of a stroke exercise class at an urban rehabilitation centre.²⁵ Participants were recruited between April and June 2008 through information provided at the stroke exercise class, posted flyers, and telephone contact with the researchers. In addition, a list of past participants in the stroke exercise classes was obtained through the class leader, and participants were contacted directly by telephone to maximize study enrolment.

Participants' anonymity was assured, as only the researchers had access to the class list. Participants were assigned identification numbers to protect their identities in the transcripts, and identifying information such as names was omitted from the transcripts.

Data Collection

Two student researchers conducted semi-structured individual, in-depth, face-to-face or telephone interviews, following qualitative interview training from the senior author. The semi-structured interviews lasted approximately 1 hour and consisted of approximately seven open-ended questions aimed at eliciting information about participants' experiences in their own words (see Table 1). The interview questions were meant to guide the interview; interviewers varied the wording and order of the questions based on the participant's response in order to facilitate an uninterrupted flow. Prompts were used for clarification or elaboration. Demographic information was collected at the end of the interview. Ten interviews with primary caregivers were conducted; six were face-to-face interviews, and four were telephone interviews. All interviews were audiotaped and transcribed verbatim by a professional transcription service. After the transcripts were received, they were checked for accuracy by comparing each transcript with the corresponding audiotape.

Member checking was performed with a sub-group of participants to verify the accuracy of the content and intended meanings.²⁵ Three participants were randomly chosen to review a preliminary analysis of the data. A one-page outline of the key findings of the study was mailed to these three participants and followed up with a telephone interview. All three participants confirmed the results of the study as reflecting their experiences.

Table 1 Interview Questions

<i>Questions</i>
1. What was your life like before you became a caregiver, and how was that changed?
2. Can you describe a typical day for you?
3. What makes it easier or harder for you to care for your spouse/yourself?
4. What sorts of things are you struggling with?
5. What kinds of activities were you doing before/after?
6. What sorts of activities would you like to do, and what's stopping you from doing them?
7. Is there anything that we did not cover that you would like to talk about?
<i>Possible Prompts</i>
1. Can you tell me more about that?
2. Can you give me an example?
3. How does this make you feel?

Data Analysis

Data analysis occurred concurrently with data collection. Once each interview was completed, the interviewers dictated field notes on their impressions of the interview and any preliminary analytical thoughts that could be further explored. A reflective journal was used to document the researchers' ongoing thoughts, feelings, and decision-making throughout the data collection and analysis processes.²⁵ Student researchers and faculty supervisors met frequently to discuss the unfolding data collection and analysis.

Following transcription of the interviews, interview content was categorized and coded using a constant comparative method.^{25,28} An inductive, iterative approach was used to determine codes and themes that arose from the data, rather than using a predetermined set of codes. Each of the five student researchers first coded two transcripts and then reviewed the codes together with faculty supervisors. Consensus on the naming and definition of codes was achieved through discussion in order to develop a coding scheme. The remaining data sets were then reviewed by all the students and coded into discrete themes and concepts that allowed for a comparison of similarities and differences. The coding scheme used was as follows: (1) life pre-stroke; (2) current life; (3) hobbies; (4) barriers; (5) supports; (6) perceptions of health status and caregiving role; (7) physical activity; and (8) future life. Codes were compared and contrasted both within individual interviews and across all interviews to identify four main themes: (1) change in role; (2) change in activity; (3) barriers to activity and health; and (4) change in meaning of activity.

To facilitate the emergence of themes, quantifying terms were used when referring to the number of caregivers who shared similar experiences. The term "majority" was applied when 8–10 caregivers shared a thought or experience; "most" was applied when referring to 5–7 caregivers; "some" was applied when referring to 3–4 caregivers; and "few" was applied when referring to 1–2 caregivers who shared a thought or experience.

RESULTS

The 10 participants were the wives and primary caregivers of men who had experienced a stroke. The participants' ages ranged from 45 to 73 years; however, the majority were young-old (in the 60–70 age range). The women had spent, on average, between 2 and 5 years as caregivers, with the exception of one participant who had 12 years of caregiving experience. Four also identified themselves as primary caregivers for other family members, such as parents, young children, or adult children with special needs. Five participants continued working after becoming caregivers. Caregivers reported

being "in good health," but a few stated that they had health problems. The persons with stroke varied in their health status and functional level, as determined through data analysis. A few were physically high functioning and required little assistance from their spouses. The majority of husbands were ambulatory, with or without the use of gait aids, but still required some assistance from their wives to complete ADL.

Most participants reported that their lives changed and became quite different once they became caregivers. One described the day her husband had a stroke as "that fateful day" (Participant 4). These changes were especially related to their roles and their physical activities.

Change in Role: From Wife to Caregiver, "Princess" to "Maid"

All participants talked about undergoing changes in their roles and responsibilities after their husbands' strokes. Concerns about finances, hobbies, barriers, and their own physical health and wellness emerged. The participants' roles were significantly changed, as they had to undertake the responsibility of being a primary caregiver. When describing her new role, one participant stated, "I used to be a princess but now I'm a maid" (Participant 4). Most caregivers were required to take on additional chores that had previously their husbands' responsibilities, such as mowing the lawn, driving, and home repairs:

Certainly the chore part of it has been difficult for me, and so I find that every day there's a little something like if you have to change a lightbulb or something needs painting or just things that I wouldn't normally be involved in doing. (Participant 2)

Being a caregiver was described as "a full-time job," "very demanding," "very stressful," having "increased responsibility and more physical demands" with "decreased personal time," and feeling "burnt out." Most of the participants mentioned the need to have "free time" and to "escape," something they felt they needed to incorporate into their caregiving routines in order to alleviate stress. Some common factors identified as making caregiving more difficult were increased responsibilities, degree of spouse's impairment level, additional caregiving roles for other family members, financial stress, and limited support.

Loss of independence was reported by caregivers who spent the majority of their time with their husbands; one said she felt "tied to" her husband. The added dependence of spouses on their caregivers decreased participants' independence: caregivers are responsible for taking their spouses to their various appointments and for ensuring medication adherence. Their lives have consequently become more organized and routine driven:

So it's like every day, Monday to Fridays, my schedule is very tight. I have to get the same train, everything must be on time. Because we live far ... so I have to come downtown, so every day I have the same schedule. I can't miss it, I can't like mess it up. (Participant 10)

Change in Activity: From “We” and “Recreational” to “Him” and “Therapeutic”

The majority of participants experienced a change in physical activity level once they became caregivers. Those who had been active experienced a decrease in their recreational activity; a few participants who were not previously active experienced an increase in physical activity when they became caregivers as they helped their spouses with walking or other therapeutic exercises. However, most participants described themselves as having been more “active,” “busy,” and “independent” prior to becoming caregivers. They also described their pre-stroke lives as more “straightforward” and filled with leisure activities shared with their husbands:

We would go to outings, we would visit friends, we would, we had actually quite a nice life in that we could both be independent, we could go to whatever we like, nothing very spectacular but we did occasionally take trips. (Participant 5)

Activities pre-stroke were things they did together with their spouses and were recreational, such as travel, social outings, and golfing. For example, the majority of participants talked about travel as a hobby prior to their husbands' strokes. However, all revealed that their current travel has changed as a result of their spouses' physical limitations or for financial reasons:

We actually travelled a lot but now that he has the stroke and whatever, just getting insurance to go across the border is too expensive. (Participant 8)

After the spouse's stroke, participants tended to describe their activity as being more of a rehabilitative nature, with a focus on “him” as opposed to “we.” For most, physical activity had become therapeutic, purposeful, and focused on the person with stroke. Rather than sharing recreational activities with their spouses, participants now tended to take on the responsibility of physically assisting their spouses in their exercises and ADL. Participants who reported continuing their previous activities now described these activities as more purposeful:

I only go biking if it's a destination I have to go [to] pick up a prescription or something. It's not pleasure biking like what we used to do. (Participant 1)

For most caregivers, activity level was maintained by incorporating it into instrumental ADL, such as grocery shopping and other errands:

We'll go to the grocery store not too far away from me. He will walk, sometimes I say, “Okay, I'm going to walk a step up, you keep on coming,” and I'll go to the store, buy what I want, meet him like half the way back and we'll walk back together. There's a lot of little things you can do. (Participant 9)

Barriers to Activity and Health: No Time or Energy for Herself

Participants identified physical activity as a key component of their own health status, as well as “watching their diet,” checking “blood pressure, cholesterol,” emotional and mental well-being, morbidities, and amount of sleep. They were aware of the importance of their own health and how it would affect their ability to provide care. Participants who neglected their own health were aware of their actions:

You just don't have any independence to do anything like that, and I'd like to get back into taking better care of me, because you get so busy taking care of the patient ... that you sometimes neglect yourself. (Participant 2)

Most of these participants cited fatigue and lack of time as reasons for neglecting their own health. The majority reported time constraints since becoming caregivers, as a result of increased household chores and responsibilities. This was identified as a barrier to engaging in activities that they were previously involved in, or that they would like to do. Although a lack of “free time” was identified as a barrier to participation in activity, some participants mentioned that even if they had the time, they would not have the energy:

You don't really have the time to do that, and then when you do have a break most of the time you're so worn out and exhausted you don't, the last thing you think about is going to exercise. So you have to take your time whenever you can, and I could probably get up earlier in the mornings and maybe exercise or do something, but at the same time, if you haven't had 8 hours' sleep that little extra half-hour is important as well, and that you get settled in and, you know, you got three hours maybe you can sleep. (Participant 2)

Another barrier identified by most participants was that their involvement in physical activity was limited by their own health status. One participant stated,

I used to do aquafit. I don't do it anymore because actually I do have pretty serious health problems now. (Participant 5)

Most participants mentioned that their spouses' abilities and health status contributed to a change in their physical activity participation. The majority mentioned their husbands' impairments and how they have had to change their lifestyle in order to accommodate these

impairments. Most described participating in physical activity together as difficult, because their husbands need their assistance to do the exercises. Other caregivers have accepted their husbands' physical limitations and have had to modify the way in which they approach activities in order to accommodate them:

He's fine going out on his own after dinner, or I might join him and walk at his pace and we just sort of walk along. (Participant 6)

Change in Meaning of Activity: Not the Same Without Him

In addition to noting their spouses' impairments, some participants described feeling less compelled to participate in activity independently because they do not like to do these activities alone. Prior to the stroke, companionship made the activity meaningful; with the impact of the stroke, they felt they had "lost the man [they] married" (Participant 1). This loss of a partner or companion was described as a reason for stopping previous activities, and contributed to lack of enjoyment and loneliness:

So things like that we used to go together, but I had to go alone, which wasn't too nice because I don't like to go out alone, but now I have to. (Participant 9)

Furthermore, some participants reported feeling guilty about engaging in activities without their spouses. Caregivers were reluctant to participate in activities that they had previously shared with their spouses, because they felt guilty that their husbands were no longer able to participate:

You feel wrong doing it, because he can't do it, and you know he's thinking about you out there doing it and wanting to be there. (Participant 1)

Participants were divided on how they managed their feelings of guilt. Many opted to avoid such activities altogether, while others saw this as their only "break" from their spouses. Guilt appeared to be a barrier to participating in health-promoting activities such as exercise, social outings, and activities independent of their husbands.

Supports and coping strategies were essential aids in the role change associated with becoming a caregiver, as well as in caregivers' participation in physical activity. The majority of participants' husbands were able to provide some support to their caregivers by completing some aspects of their own care, such as independently showering/bathing, dressing, taking medication, washing dishes, and making simple meals. This independence allowed participants to have a "break" from caregiving; a few of the caregivers were able to maintain full- or part-time employment:

I'm fortunate now that my husband is such that I can leave him for a few hours at a time and he's okay. (Participant 2)

With this type of encouragement from their spouses, there is an interruption in the "constant care" the participants are providing, as they have independent, non-caregiving activities taking place outside the home. A couple of the participants also said they felt fortunate that their husband was such a "good patient," alleviating some of the caregiving duties they were responsible for. Participants also identified an optimistic attitude, family support, and external supports as facilitators in coping with the changes.

With respect to the future, the majority of participants reported wanting to be more active and healthy, either wanted through involvement in a structured exercise programme or by returning to their previous physical activity levels. Three common preferences for physical activity were reported by the majority of participants. They preferred activities that are more leisurely paced, such as walking; participants also favoured doing outdoor activities and going to facilities rather than doing exercises at home. In addition, the majority of participants preferred doing physical activity with their spouses.

DISCUSSION

Becoming a caregiver for a person with stroke is associated with numerous life changes. The caregivers in our study revealed that the first such change to occur was a role change from wife to caregiver. Participants found that this role change brought additional responsibilities and duties, many of which they had not previously carried out. Meeting these increased demands is seen to come at the expense of caregivers' free time and independence. These findings are supported by a study by Pierce et al., in which the authors sought to understand the experience of caregivers for persons with stroke.¹⁸ Pierce et al. found that caregivers felt overwhelmed and inadequate when taking on their new roles.¹⁸ Similarly, the participants in our study revealed that caregiving is highly stressful and that they felt the need to escape from these stresses in an effort to prevent burnout and regain some free time.

Some participants reported having more organized daily schedules following their husband's stroke, which is supported by Pierce et al.'s claim that caregivers are trying to achieve a new "normal" by developing a set daily routine. The "Timing It Right" framework, developed by Cameron and Gignac, highlights five phases representing family caregivers' changing experiences and corresponding support needs across the care continuum: (1) event/diagnosis; (2) stabilization; (3) preparation; (4) implementation; and (5) adaptation.²⁹ Stages 4 and 5 are most relevant to this study, as they relate to

return to the home environment. During implementation (stage 4), caregivers are often focused on providing physical care as they attempt to develop routines. They begin to experience the personal consequences of providing care but are often too involved in actual caregiving to attend support groups. After this period of adjustment, as they settle into a caregiving routine, caregivers' focus shifts to community reintegration and helping stroke survivors resume participation in valued activities and interests.²⁹ As the person with stroke becomes more integrated into the community and independent, he or she requires less care from the caregiver,²⁹ which allows the caregiver to return either to her or his pre-stroke activity level or to a modified level of activity. Some of the participants in our study were in the process of finding this new "normal," whereas others had already achieved it and had adapted to their role change. Thus, it appears that regaining this sense of normalcy is important in alleviating the stressors of caregiving and helping caregivers cope with their change in roles.

The caregivers' activity also changed alongside this change in role. Prior to caregiving, activity was described as being recreational and as shared with their husbands. In contrast, post-stroke activity is therapeutic and focused on their husbands. Even though some of the caregivers recognized that this change has negatively affected their own participation in activities, they continued to prioritize their husbands' need for therapeutic activities. As a result, caregivers' health and well-being was often being neglected. The implementation phase of Cameron and Gignac's framework supports our findings that caregivers neglected their own health and that they were aware of their actions.²⁹ The implementation phase is characterized as the period when caregivers become aware of the consequences of caregiving, such as the inability to pursue their own activities and interests because of lack of time.²⁹ As there is limited information in the literature on the activity levels of caregivers of persons with stroke, the change in activity from partnered pre-stroke recreational activities to post-stroke therapeutic activities focused on their husbands is novel information.

Most caregivers in our study reported that their reasons for neglecting their own health were lack of time and lack of energy. These are common barriers cited in the literature to explain caregivers' inability to participate in previously enjoyed hobbies, interests, and health-promoting behaviours.^{25,28} A recent study focused specifically on caregivers of persons with stroke found that the physical demands of caregiving led to decreased leisure time and, consequently, to physical exhaustion at the end of the day.³⁰

In addition to a lack of time and energy to pursue activity, the caregivers in our study identified a change in the meaning of activity: namely, activities were more meaningful when they could be shared with their husbands. The husbands' functional limitations prevented

them from participating in joint activity, and the resulting loss of companionship, combined with some caregivers' dislike for solitary activity, was a barrier to participating in activity. Furthermore, some caregivers felt guilty when participating independently in activities that they had enjoyed with their husbands prior to the stroke. Coombs, who also reported guilt, found that feelings of guilt were associated with leaving husbands alone at home for any amount of time,³⁰ and was specifically tied to an obligation to remain constantly by their husbands' side. Further research on the prevalence of feelings of guilt and their role as a barrier to participating in physical activity is needed. These feelings can be better managed by supporting caregivers and by providing adequate education.

The present study increases our understanding of the experiences and perspectives of caregivers. A qualitative approach provided insight into the health needs of caregivers. Since physiotherapists often interact with families of persons with stroke, they may have a role in facilitating health-promoting activities for caregivers. The research findings allow us to make some recommendations for physiotherapists involved in stroke rehabilitation. Physiotherapists need to consider the husband-wife dyad and involve caregivers throughout the continuum of their spouses' recovery in order to deliver effective services. In addition, potential barriers to the caregiver's ability to provide care should be identified early and addressed by implementing coping strategies in order to improve quality of life for both the person with stroke and his or her primary caregiver. Caregivers may benefit from education about their new role and how it may affect their marital relationship. More importantly, we recommend that the caregiver's health be considered and discussed. Physiotherapists should play a more active role in helping caregivers to manage their problems so that they can be successful at providing care not only for the person with stroke but also for themselves. To deal with more complex issues, an inter-professional approach may be most appropriate. Counselling or family meetings may help address issues and barriers that caregivers may experience in adapting to the changes associated with caring for a spouse after stroke. This recommendation is in agreement with the findings of a study by Pierce et al., which found that in order for life to return to "normal," behavioural and interpersonal issues must be addressed.¹⁸

While caregivers often have adequate support during the acute phase, there is a tendency for community resources and support systems to decrease over time.³¹ Thus, advice and management strategies regarding expectations and coping strategies must be initiated prior to discharge, in order to minimize the barriers encountered at home. Effective education and training have been shown to ease the burden and emotional distress of the caregiver, as well as to increase their quality of

life and psychological well-being.²⁹ Discussions about the caregiver's health and about health-promoting activities would be ideal, since our findings suggest that caregivers are aware of the importance of their own health yet still neglect it because of barriers such as guilt, fatigue, and lack of time. Caregivers should be advised early on about the importance of maintaining their own health, as poor health may affect the quality of care they are able to deliver to their spouse.²¹

Healthcare professionals have traditionally treated adult patients as a single entity. The implementation of a family-centred approach would allow the needs of both the caregiver and the person with stroke to be met concurrently.³² Goal setting and decision making should involve the whole family, and supports should be provided to address the needs of the caregiver in coping with their change in role. Another recommendation is that when exercise programmes for the caregiver are suggested or initiated, the activity should be meaningful. Our findings suggest that meaningful activity is activity that is purposeful, functional, and can be done with the caregiver's partner.

Several limitations of this study should be mentioned. Study participants were all recruited from one urban rehabilitation facility offering specialized services for stroke; participants were recruited from an existing stroke exercise programme in which their partners with stroke were receiving additional rehabilitation that may not be readily available to every person with stroke. Further, participants may already have had an interest in physical activity. All participants were female, and most were in the young-old age range. This proportion is reflective of many caregivers of persons with stroke,¹ and therefore provides a practical representation of the perspectives of caregivers; however, further research would require a more diverse sample of participants in both urban and rural facilities, with a variety of background, health status, and involvement in physical activity.

Future research should address the perspectives of other family caregivers of persons with stroke, such as husbands and adult children of varying ages. Additionally, future research geared toward further understanding of the perspectives and interests of the person with stroke in partnered physical activity would be of interest, and could lead to pilot partnered exercise programmes for future research.

CONCLUSION

Caregivers experience many changes with respect to their roles and activities. The meaning of their activities has changed from recreational to more therapeutic, with a focus on their spouse. In spite of this, most caregivers acknowledge the importance of physical activity to their health and well-being and express interest in incorporat-

ing more activity into their daily lives. Their preference is for activities that are meaningful and purposeful; in addition, participants prefer engaging in physical activity together with their spouses. However, caregivers experience barriers to activity and consequently neglect their health. Feelings of guilt have been identified as a major barrier to participation in activity. Ongoing support and education for the caregivers can help overcome these potential barriers. Our findings suggest that caregivers need to be involved in all aspects of their spouses' recovery and that early identification and management of caregiver barriers is vital to achieve optimal health and well-being for both the caregiver and her or his spouse.

KEY MESSAGES

What Is Already Known on This Subject

Caregivers of people living with stroke face psychosocial and physical health challenges because of the burden of caring for the person with stroke. Caregivers are predisposed to health problems associated with a sedentary lifestyle, as the time constraints and physical demands of caregiving reduce the time they are able to spend on health-promoting activities.

What This Study Adds

Caregivers are aware of the importance of their own health, yet still neglect it as a result of barriers such as feelings of guilt, fatigue, and lack of time. Prior to the stroke, physical activity was shared and recreational; after the stroke it becomes therapeutic and focused on the person with stroke. Physiotherapists need to adopt a family-centred approach that recognizes persons with stroke and their spouses as dyads and considers partnered activity for patients and caregivers.

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