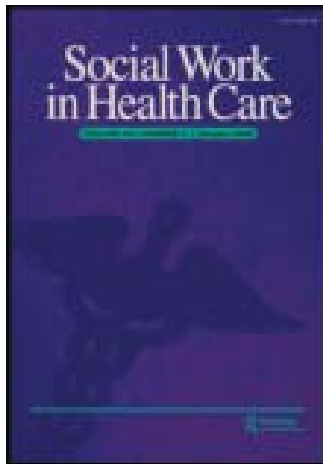


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“We Don't Have a Back-Up Plan”: An Exploration of Family Contingency Planning for Emergencies Following Stroke

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“We Don’t Have a Back-Up Plan”: An Exploration of Family Contingency Planning for Emergencies Following Stroke

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Little research has explored emergency preparedness among families coping with stroke. In this longitudinal qualitative study, we explored contingency caregiving planning by interviewing (N = 18) family caregivers providing care for a stroke survivor at home during the first 6 months post-discharge from the hospital. Emergent themes showed most families did not have a concrete “back-up plan” for a crisis or disaster situation involving the primary caregiver being unable to provide care. Furthermore, they

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assumed formal respite services or long-term care would be available should the need arise. Despite increased awareness over time, most caregivers had not devised contingency plans at 6 months.

KEYWORDS *caregiving, aging, crisis management, pandemic, disaster preparedness, respite*

INTRODUCTION

When an individual experiences a stroke, there are rippling effects through the family, particularly when the impact of the stroke leaves him/her with functional limitations related to communication, cognition, emotions, motor control, or mobility. Strokes occur suddenly, they can threaten a family's usual way of doing things, and are accompanied by uncertainty about recovery (O'Sullivan, 2009). These attributes of a traumatic event are all encompassed in existing definitions of "crisis" (McConnell & Drennan, 2006), and in the case of stroke, the crisis occurs at the level of the family unit, and can be a significant life adjustment for family caregivers (Cameron & Gignac, 2008).

Boin (2004) emphasizes that "a crisis brings uncertainty with regard to the specific nature of the threat, peoples' responses, the dynamics of the situation, possible solutions, and future consequences" (p. 171). Whether at the family or community level, a crisis requires people and systems to cope with the challenges that are presented. When people have adequate and appropriate resources, they can usually cope (Hobfoll, 2001). However, the point at which the demands of a situation outweigh the available resources is referred to as the disaster threshold (St. John, Berry, & Shropshire, 2009), or the point at which a crisis becomes a disaster. When this point is reached, the family unit or community must reach out for additional formal or informal supports.

For many stroke survivors and their families, daily functioning requires adjusting to challenges that arise from living with an acquired disability. This can be an onerous process, particularly when social and physical resources are limited (Cameron & Gignac, 2008), but what if there is a secondary crisis in the family and the primary caregiver becomes unable to provide care? This type of situation can arise from illness or injury, or as a result of a community crisis or disaster (e.g., earthquake, flood, outbreak of pandemic influenza).

Caregivers fulfill important roles by providing various forms of assistance for stroke survivors, and this contribution supports the societal movement toward more community care, as a solution for limited beds and human resources in health care facilities (Lowry, 2010; Teasell, Meyere, Foley, Salter, & Willems, 2009). But dependence on this informal sector of the health care system is a fragile approach, because when caregivers

become unable to provide care, the health and social service sectors lose capacity and must find other ways to address the functional needs of stroke survivors.

During a community crisis or disaster, high risk populations, such as the elderly or chronically ill, are more susceptible to the devastating impacts because of their dependence on others for basic necessities (O'Sullivan, 2009). Families coping with the impacts of stroke are particularly at risk during the early months following discharge from a health care facility, as they adjust to new roles, learn about available resources in the community, and re-organize their daily living routines to accommodate declines in functional capacity caused by the stroke (Byrne, Orange, & Ward-Griffin, 2011; Coombs, 2007; Draper & Brocklehurst, 2007; Grant, Glandon, Elliott, Newman Giger, & Weaver, 2004; Ostwald, Bernal, Cron, & Godwin, 2009; Palmer & Glass, 2003; Teasell et al., 2009). The addition of a secondary crisis at the level of the family unit or more widespread in the community represents a scenario where resources could be quickly outstripped and families would need to quickly identify formal and informal supports to assist.

In the aftermath of Hurricane Katrina in the United States, mortality was predominantly among seniors with disabilities, due to inadequate preparation and challenges encountered during evacuation (Aldrich & Benson, 2008; Uscher-Pines et al., 2009). In many cases, caregivers and care recipients were separated, exacerbating the difficulties experienced by people with complex medical needs or other functional needs for personal care (Campbell, 2007/2008; Uscher-Pines et al., 2009). The Federal Emergency Management Agency (FEMA) and the Administration on Aging (AOA) stress the importance of a personal plan to ensure families can be self-sufficient for at least 72 hours during a community disaster (Public Health Agency of Canada, 2008; Thobaben, 2011). Family preparedness is viewed as a reliable indicator of resilience in times of a disaster (Eisenman et al., 2009), unfortunately many households with residents who have functional limitations do not take action toward being prepared (Eisenman et al., 2009; Uscher-Pines et al., 2009). Contingency caregiving plans are a particularly important consideration in preparation for pandemic influenza, when it is expected that 4.5 to 10.5 million in Canada could be ill at the height of the outbreak (Public Health Agency of Canada, 2006).

While research on the burden of care and health impacts experienced by family caregivers has proliferated in recent decades (Keefe, Legare, & Carriere, 2007), little research has focused on strategies family caregivers employ to promote resilience during secondary crises or disasters at the family or community levels. In particular, there is a paucity of literature on caregiving contingency plans and disaster preparedness following a stroke. This study is part of a larger longitudinal research project focused on the experiences of family caregivers providing care at home for a stroke survivor during the first 6 months post-discharge from hospital or

rehabilitation center, with particular emphasis on adjustments to lifestyle, sources of stress, support needs, and the roles that caregivers assume in the care trajectory. This article presents one component of the study that explores preparedness among family caregivers to determine (a) what type of contingency plans they had in place if the primary caregiver was unable to provide care, and (b) what type of preparedness activities the families engaged in, to promote resilience during secondary crises or disasters.

METHODS

This study, conducted in two communities in the Canadian province of Ontario, employed a qualitative, longitudinal exploratory design. Primary caregivers living with a stroke survivor (>55 years of age) were recruited by social workers at the point of patient discharge in three stroke rehabilitation units and via flyers posted in the community. Additional inclusion criteria for the caregivers in this study were (a) being over 18 years of age and (b) the ability to understand and participate in an interview conducted in English.

For each family unit, three semi-structured interviews were conducted with the primary family caregiver, (at months 1, 3, and 6 after the stroke survivor was discharged home from hospital or a rehabilitation facility). Each interview was approximately one hour in duration and was conducted at the caregiver's home or at an office on campus, by the first and second authors. The interviews were audio recorded with permission and participant names were replaced with codes to ensure confidentiality. Each participant signed an informed consent form and the data collection procedures and design were approved by the university research ethics committee.

All interviews were transcribed verbatim, and checked for accuracy by a different member of the research team. The transcripts were read in their entirety to explore similarities and differences over time for each caregiver and across participants. After reading each transcript we went back to look for meaningful segments and preliminary themes using conventional, undirected content analysis (Hsieh & Shannon, 2005). Transcribing and identification of preliminary themes were ongoing as data collection progressed over 18 months. The research team who were immersed in the data and identified preliminary emergent themes consisted of an associate professor and graduate student who both have experience doing qualitative content analysis, and an undergraduate research assistant. The emergent themes were finalized once the full dataset was analyzed in its entirety, and longitudinal comparisons were possible. Longitudinal theme analysis was conducted across the three interviews for each participant (or if they did not complete all interviews, we compared the interviews they did complete). As well, for each time point we compared and contrasted the themes that emerged across all participants who completed interviews at that time point.

The fourth member of the research team, a full professor with experience in qualitative content analysis, reviewed the coding reports and participated in subsequent discussions to revise and finalize the themes and develop the model presented in Figure 1. All members of the research team agreed saturation had been reached.

RESULTS

The dataset for this study consisted of interview transcripts from ($n = 18$) primary caregivers, between the ages of 49 and 81 years, providing post-stroke care for a family member at home. All the primary caregivers lived with the care recipient. Of the 18 participants enrolled in the study, ($n = 13$) caregivers completed all three interviews, and ($n = 5$) caregivers did not complete all the interviews for reasons such as the death of the care recipient, the care recipient being admitted to hospital, and overwhelming stress from caregiving responsibilities. Among the five caregivers who did not complete all the interviews, ($n = 2$) completed the first two interviews at the 1- and 3-month time points, and ($n = 3$) completed the first interview at month 1. All interviews conducted were included in the analysis. Demographic characteristics for the participating caregivers are presented in Table 1.

Six themes emerged from the data at months 1, 3, and 6 in the longitudinal design. The overarching theme was the absence of any contingency caregiving plan at all three time points in the study, despite increased awareness of the need. The caregivers assumed their adult children would step in to provide care or that the stroke survivor could go into a health care facility for respite. Many caregivers hoped they would not get sick, but several put power of attorney in place as a precaution, and in general they felt the families would be able to "get by" on their own for 72 hours if there

TABLE 1 Participant Demographics

Mean age	67.9 years $SD = 10$ Range = 49–81 years
Ethnicity (Caucasian)	$n = 18$
Sex (Female; Male)	($n = 13$; $n = 5$)
Geographic location (Urban; Rural)	($n = 11$; $n = 7$)
Household Income	
<\$45,000	$n = 6$
\$45,000–60,000	$n = 5$
\$61,000–80,000	$n = 4$
>\$80,000	$n = 3$

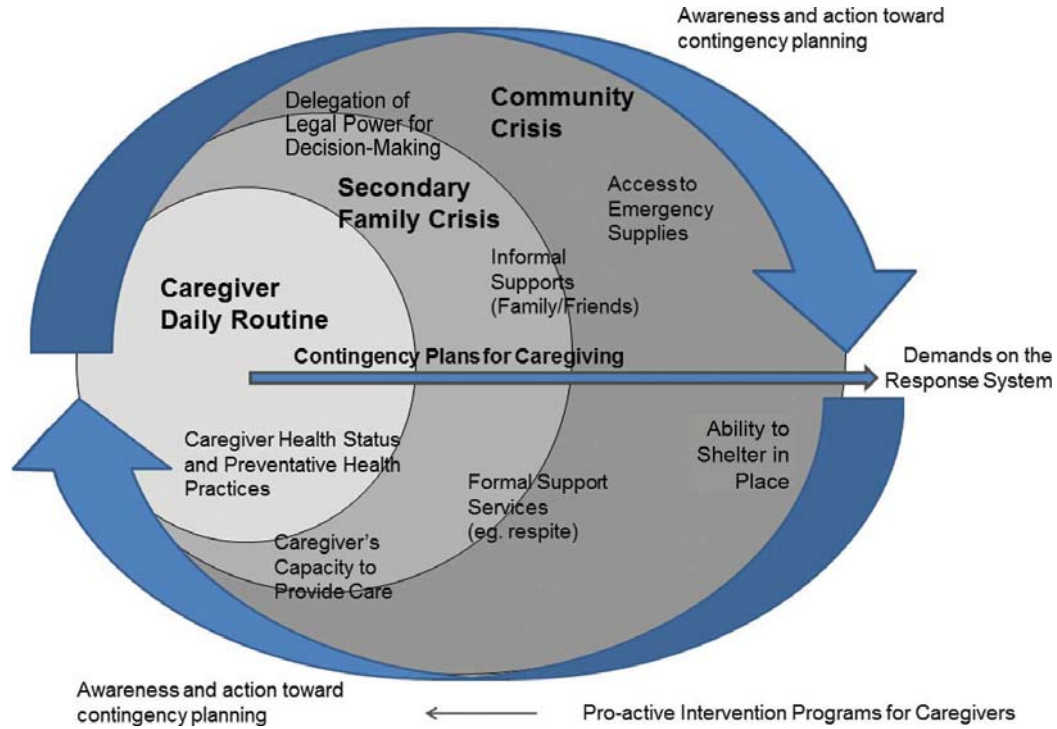


FIGURE 1 Potential action levers for intervention to enhance family and community response capacity (color figure available online).

was a community crisis or disaster, however they did not have adequate supplies of medication. The emergent themes are summarized in Table 2 and informed the development of the model (see Figure 1) presented at the end of this results section which provides an overview of how awareness is needed across the continuum as families cope with the crisis of stroke, and should anticipate their needs and options for contingency planning for the possibility of a secondary crisis or disaster at the family or community level. It also depicts how a family's ability to cope with a secondary crisis has implications for formal support systems, such as respite services and other health care facilities.

Theme 1: We Don't Have a Back-Up Plan

The overarching theme for this study was the absence of a "family back-up plan" should a secondary crisis result in the primary caregiver being unable to provide care. During the first month, most caregivers were overwhelmed by the challenges associated with the provision of care for the stroke survivor and they had not considered the need for a back-up plan. This pattern prevailed, and most families had not established contingency plans after 3 and 6 months:

TABLE 2 Longitudinal Themes for Preparedness

Theme	1 month	3 months	6 months
We don't have a back-up plan	Contingency planning was not on their radar; They had not thought of it	Contingency planning was on their radar only because of being asked about it at the first interview; Most had not thought about devising a back-up plan and several who had thought about it were overwhelmed with the idea	Most families still had no back-up plan, despite increased awareness from being asked about it at months 1 and 3; the three caregivers who did take action had brief discussions with adult children, but no formalized planning
Family and friends would have to step in	Caregivers assumed they could rely on family and friends if they were unavailable to provide care, but it had not been discussed	Caregivers continue to assume family would have to step in to provide care, but only three of the primary caregivers had spoken to their adult children about it	Caregivers realized the burden of care would be too high for other family members and they revised their view to assume formal care would be required as back-up
The back-up would have to be residential or long-term care	Caregivers assumed that respite services, nursing homes, and hospitals will be available as back-up in a crisis or disaster	Many experience difficulties with respite services, but continued to assume respite, nursing homes, and hospitals will be available during a community crisis or disaster	Same as month 3
Increased awareness doesn't necessarily lead to action	The question about having a back-up plan was surprising and many caregivers did not want to think about it; most assumed other families coping with stroke did not have contingency plans either	Awareness about contingency planning increased from the first interview; caregivers recognized the importance of their roles, but for most caregivers, this did not lead to action; The repeated question	Increased awareness from discussing whether they had a back-up plan for caregiving at the 1-month and 3-month interviews did not lead to action for most of the caregivers; the three caregivers

(Continued)

TABLE 2 (Continued)

Theme	1 month	3 months	6 months
Avoid getting sick and arrange for power of attorney	Most of the caregivers planned to get immunized and were trying to eat well and rest as strategies to avoid illness	Most caregivers continued to worry about their own health, particularly given their realization of the long-term reality of the situation; several caregivers considered revising their own power of attorney	Most caregivers continued to attend to their own health to avoid getting sick; several people did their power of attorney to ensure someone could make appropriate decisions on their behalf if they were unable
We could get by for 72 hours during an emergency, but wouldn't have enough meds	Most caregivers believed they could sustain themselves and continue providing care for 72 hours while sheltering in place during a community crisis or disaster; they had basic supplies, but could not stockpile medications due to prescription and insurance regulations	Same as month 1	Same as months 1 and 3

I don't have any other strategy at the present time. I don't know. I haven't given that a lot of thought. (P5, 3 months)

One participant alluded to the social norms of caregiving and suggested that most caregivers do not think about a contingency plan so soon in the process of adjusting to the crisis imposed by the stroke:

I'm like most people, we're not really set up you know. I mean maybe we are better off than most people. I don't know. . . . (P5, 1 month)

No, because this was a total shock and we kind of pulled things together very quickly. [We don't have a] back up plan. This wasn't supposed to happen. (P19, 3 months)

Over the 6-month timeframe, the caregivers realized the need for contingency planning, but were simply overwhelmed with the coping required of them to manage the impacts of the stroke:

I can't predict everything. I can't plan for something I can't predict. (P3, 6 months)

The idea of anticipating additional another crisis was overwhelming to think about and despite their awareness of the possibility, many of the caregivers avoided the stress of thinking about it or engaging in planning, and they consciously or unconsciously decided to focus on their current challenges.

Theme 2: Family and Friends Would Have to Step in

When asked about a contingency caregiving plan, several caregivers brainstormed on the spot during the interview and tried to provide what they assumed would be their plan. At the initial interview, a common assumption among most caregivers was that they could rely on family and friends to provide care if they were unavailable to do so, but this assumption had not been discussed openly in the social support network:

No, not really. If something happened to me, I guess my sister would have to go back home [where her adult children live]. (P10, 1 month)

Over the course of the study, three caregivers spoke to their daughters about contingency plans, but most of the caregivers did not follow up by discussing or making a concrete plan:

We would have to have a family discussion I guess, as to what to do . . . I am fortunately in good health. (P16, 3 months)

. . . There's no problem with family support in that sense . . . [my daughter and son] would suddenly realise it's time. Favours are being called in, guys. And they would be there to help I'm sure. (P3, 3 months)

After 6 months, however, there was a distinct change in the manner in which they described potential solutions, as most participants came to realize that relying on other family members to support the care recipient was an inadequate solution due to the level of care required. Several of the caregivers had been disappointed in the amount of social support they received from family members they thought they would be able to rely on. Others had already experienced secondary crises, such as a back injury for one caregiver, medical complications for several care recipients due to falls or additional complexities from the stroke, and inadequate respite services which resulted in one family removing the care recipient from a facility mid-way through the scheduled respite period. Several caregivers stated that family would serve as an appropriate short-term solution but that arrangements would need to be made for respite or long-term care facilities:

My son certainly couldn't, he has a 7 and a 9 year old. . . . My daughter she is very good, but she is across town . . . but I guess if it was an emergency [she] would. . . . If it's long term . . . I'd have to bring in somebody you know. (P16, 6 months)

Theme 3: The Back-Up Would Have To Be Residential or Long-Term Care

Many of the caregivers stated they would have to rely on respite services, nursing homes, and hospitals as back-up should the caregiver be unable to provide care. At the initial interview, participants assumed these publicly funded services would be available:

Our back up plan? I don't have one. . . . My sister wouldn't look after her and my mom wouldn't go there anyway so we'd have to rely on the [respite] services. (P11, 1 month)

If something happened to me . . . he would have to go into a retirement facility until he got well enough to handle it. (P3, 1 month)

At 3 and 6 months, participants continued to assume that they could rely on these facilities and services should their family resources be outstripped. Some had experienced difficulty already with securing and maintaining

respite services for their loved ones in non-urgent situations, but still held the assumption that this service would become available if they could not provide care. The overarching emotion associated with the discussion about respite care. The overarching emotion associated with the discussion about respite facilities as a contingency plan was resignation. The caregivers were reluctant to think about the possibility of a secondary crisis and when they realized the options were limited, they resigned to assume that formal services would be there to help. Most of the families were considering placement in care facilities as a last option, either for respite or long-term care, but in their absence and with limited options, they assumed the facilities would come available should the care recipient be in need.

Theme 4: Increased Awareness Doesn't Necessarily Lead to Action

Many participants showed surprise when asked at the initial interview (1 month) if they had a back-up plan if they were unable to provide care for the stroke survivor. Many did not express a willingness to think about it:

It's in the back of my mind you know. Health can take a turn at any time. I'm afraid we haven't thought of it . . . I just don't want to go there. (P19, 1 month)

At the time of the second interview (3 months), an apparent increase in awareness of the need for contingency caregiving plans was observed as caregivers recognized the importance of their supportive roles. Despite the observed changes in awareness, with the exception of three participants, the awareness did not lead to action: "I guess because we really don't know if something were to happen to me" (P17, 3 months).

One caregiver stated that she had discussed the issue of a back-up plan with her daughter, but not her husband, who was the care recipient:

. . . no, that would upset him. (P12, 3 months)

I do worry if anything happens to me . . . what the heck would he do you know? . . . I must have a plan B. I don't know how I am going to do that. (P13, 3 months)

At the final interview (6 months), awareness of the need to establish a contingency plan for caregiving was present among all participating caregivers, but the changes in awareness had not led to concrete action. Participants expressed their understanding of its importance from previous discussions, but as two participants summarized:

Right now we're just focusing on today. . . . (P15, 6 months)

You asked me this before and I thought I just wished I had discussed this. . . . I guess I don't really have one. (P6, 6 months)

Most of the caregivers in this study participated in all three interviews, so they were exposed to the question at months 1 and 3, yet only a few had taken action by month 6, to form a contingency caregiving plan. The greatest form of action (reported by three caregivers) was conversations about contingency plans with their adult children. While most did not create a plan after being exposed to this type of trigger, it did appear to prompt consideration, if not action. When asked what her biggest concerns were at the 6-month time point, the following response was given by participant 4, one of three caregivers who had spoken to their adult children about what they might do if the caregiver could not provide care. Despite this participant's apprehensions however, no further contingency plans had been made: [My biggest worry at this time?]

. . . worrying about if something happened. If I get sick. (P4, 6 months)

Theme 5: Avoid Getting Sick and Arrange for Power of Attorney

While participants did not express concrete back-up plans, they did recognize the importance of good health as a strategy to mitigate a possible health crisis or disaster. At the initial interview, most caregivers expressed their belief that in order to avoid the need for a contingency plan it would be most efficient to assume healthy nutritional habits, receive seasonal influenza vaccinations, and to avoid illness altogether:

My only plan is not to get sick. (P17, 1 month)

We would have to just hope for the best. . . . I am just hoping it won't happen. (P1, 1 month)

Concern for their health continued to distress the caregivers at 3 months. In particular, given their realization of the long-term reality of the situation, several caregivers stated they were thinking of revising their power of attorney because the stroke survivor would be incapable of making certain decisions autonomously. One caregiver who had a complex medical condition himself was concerned about his wife's ability to make decisions on his behalf. His increasing awareness that her cognitive ability was unlikely to improve prompted him to reflect on his own caregiving options, should his medical status decline and he be faced with a secondary crisis related to his health.

At the final interview at 6 months, the majority of the caregivers continued to engage in preventive health behaviors to avoid illness, such as proper nutrition and ensuring they protected their own sleep. By this time point, several participants mentioned they had revised their power of attorney to ensure someone could make appropriate decisions on their behalf if they were unable to do so.

Theme 6: We Could Get by for 72 Hours During a Disaster, but Wouldn't Have Enough Meds

When asked about their preparedness for community crises or disasters, most caregivers framed their response in terms of coping with extended power outages or an ice storm, which are two types of community disasters that have occurred in the area. At the initial interview they expressed confidence in sustaining themselves and the ability to care for the stroke survivor for 72 hours while sheltering in place during a community crisis or disaster; most had essential supplies of water, food, candles, and batteries, and they stated their gas fireplaces would be an asset in a power outage. The majority of participants were unable to stockpile medications however, due to prescription and insurance regulations that impede this type of preparedness. This issue was a concern for many of them as it would quickly turn a crisis into a disaster for the family if the situation was prolonged and the stroke survivor or caregiver was in need of medication.

The rural families in this study ($n = 7$) reported having a more extensive list of supplies in comparison to urban participants, as well as having generators. Many of them described it as their way of preparing for normal living in the country, because you have to be self-sustaining when adverse weather or other types of events occur. They talked about how the rural areas are often last to receive services, so it is understood among families who live outside the city that you need to be prepared. One caregiver stated:

We would just do what we always do. (P3, 1 month)

Yeah, we probably would be okay. We have enough food in the house.
(P5, 1 month)

Personal preparedness, with respect to having essential supplies or contingency plans, was discussed at each interview, yet most caregivers had not considered the possibility of needing to shelter in place or the need to evacuate during a community disaster. As one participant exclaimed:

I never think about not being able to get out or someone not getting to us. That never kind of crosses my mind. But it has crossed my mind—what if something happens to me. (P3, 3 months)

Model

The resulting model (presented in Figure 1) illustrates the emergent themes and potential action levers that could be targeted in interventions designed to enhance family and community response capacity, depending on the level of crisis or disaster. Support mechanisms can be infused to enhance coping with the daily routine of caregiving for a stroke survivor, as well as managing a secondary family crisis where the caregiver is not readily able to provide care, whether occurring at the level of the family unit or the community where there are extensive demands on formal systems and families may be required to shelter in place or evacuate.

Across all of these contexts, awareness is an important factor to consider, particularly how it can be used to prompt active contingency planning. Daily functioning, coping during a family crisis, and coping during a community crisis all draw on the same resources, but to a different extent depending on the demands of a situation. In this study, preventive health strategies were the primary strategies caregivers used to cope with the “*new normal*”, which was their daily routine providing care for the stroke survivor. For all of the participants, a secondary crisis would require them to rely on another caregiver, or formal services such as respite. Legal delegation of decision-making power, such as updating their power of attorney, was used as a preparedness strategy by several caregivers to enhance coping capacity should their circumstances change and they be unable to provide care or make decisions on their own behalf. In a larger scale crisis involving the community, if able, the caregivers would still assume a role providing care for the stroke survivor, although depending on the nature of the event, they may need to rely on formal services, available supplies, and family supports.

The arrow radiating from left to right depicts how families are not likely to have a contingency caregiving plan across the crisis continuum. The arrow surrounding the diagram emphasizes the need to raise awareness of the need to develop a contingency caregiving plan, particularly one that does not solely involve reliance on formal services. Embedded in this diagram is the need for system interventions to address gaps in the availability of respite services for families coping with stroke. The demand for these types of services should not be underestimated during a community level crisis which can quickly turn to a disaster scenario when health and social services respite resources are outstripped. This theme was particularly salient in that most families would need to draw on formal health and social services as their back-up plan.

DISCUSSION

During the first year after returning home following stroke, families face numerous challenges, including fatigue, lack of time, and information

overload (Coombs, 2007; Draper & Brocklehurst, 2007; Grant et al., 2004; King & Semik, 2006; Palmer & Glass, 2003; Silva-Smith, 2007). The caregivers in this study, particularly at the 6-month time point, described it as adjusting to the "*new normal*." They recognized the important role they were fulfilling in the provision of care for the stroke survivor; however, it was too daunting for most caregivers to think about what they might do if they were to become sick, injured, or worse. They expressed that it was too worrisome to think about the possibility that the stroke survivor might be left without an obvious replacement caregiver who could step in to provide care over the long term. This finding is consistent with a recent study by Byrne et al. (2011), which reported that older caregivers worry about their declining health and the possibility they may not be able to sustain care for their spouse.

The results from the current study suggest that despite the critical need for care for most stroke survivors, preparedness planning is not a priority for families coping with acquired disability from stroke within the first 6 months at home following discharge. Instead, the caregivers were focused on their daily responsibilities and unanticipated roles in providing post-stroke care at home, which supports previous research suggesting caregivers are often overwhelmed following the transition home (Grant et al., 2004; King & Semik, 2006). In general, awareness was not sufficient to elicit actual planning and to ensure there was a concrete back-up. More research is required to understand the transfer from intent to behavioral action enactment.

In everyday care for a stroke survivor, family caregivers often shoulder the majority of the caregiving burden alone and report minimal assistance from other relatives (Almborg, Ulander, Thulin, & Berg, 2009; Coombs, 2007; Hartke & King, 2002; Lovat, Mayes, McConnell, & Clemson, 2010). This may explain in part why the caregivers in this study did not discuss a contingency plan within their limited social support networks. After 3 months, many participants realized that the support they could rely on from family and friends would be minimal because of geographical distance and in some cases, unwillingness on the part of some family members to assist. For most caregivers, it was due to feelings of guilt about asking their adult children to assist, knowing how many other responsibilities they were already juggling between home and work. The caregivers who did believe they could count on family to step in during a family or community disaster, knew the form of this help would be acute and another solution would be required; typically the alternative was formal respite services or long-term care. However, in considering this it is important to acknowledge the lack of ethnic and socioeconomic diversity among the participants in this study. All the participants in this study self-identified as Caucasian, and this may have impacted the results, as cultural factors may influence individual experiences of caregiving, families' expectations for formalized support, and prioritization of contingency planning (Bakas et al., 2009; Mackenzie et al., 2007).

In their discussions about contingency planning, some participants in our study compared themselves to other caregivers, expressing their belief of a social norm that most families do not have a contingency plan. This type of comparison with peers may be a coping strategy (O'Connell & Baker, 2004) to rationalize their own lack of action in developing a back-up plan. Given these recommendations, and in light of the findings from our study, it is critical that post-stroke programming include awareness strategies to ensure caregivers consider the need for contingency planning and have resources and instrumental support to develop appropriate back-up plans.

Most caregivers in this study held an expectation that emergency respite services would be available in the event they were unable to provide care. This is an alarming and overwhelming finding, as current health care systems in Canada typically do not have the resources to support this particular expectation, as they are already strained beyond capacity (Lowry, 2010; Menon, Bitensky, & Straus, 2010; Teasell et al., 2009). Previous studies focused on nursing homes affected by Hurricane Katrina or Rita demonstrated the dire consequences of overcrowding, insufficient human resources, and lack of disaster preparedness for the needs of high risk populations (Uscher-Pines et al., 2009).

Present inadequacies of the health care system in Ontario, shortcomings of services available for stroke survivors, and limited resources for this high risk population have all been acknowledged recently by the Champlain Community Care Access Centre (CCAC), in their latest strategy to improve future home health care delivery in the province (Community Care Access Centre, 2011). The CCAC has reformulated their plans to encompass consideration of patients with various functional limitations, which includes provision of more home care and other support for clients and their families. However, families are encouraged to be self-sufficient, which puts the responsibility on the family to anticipate and plan for scenarios where they are unable to provide needed care or receive assistance from formal services. An apparent gap in the CCAC strategy is the lack of a contingency strategy for a large-scale community disaster. Given the limited capacity of current health and social systems to accommodate individual stroke patients on daily or emergency bases, it is imperative that formal support systems take into consideration the support needs and expectations of families coping with stroke, to ensure demands for respite and other types of support do not come as a surprise when demands outstrip the available resources in a community disaster.

Awareness is often described as an important element in building family and community resilience (Chandra et al., 2011; Uscher-Pines et al., 2009; O'Sullivan et al., in press), yet in this study despite the repeated prompt of being questioned about their back-up plan at each interview, participants did not form a contingency plan. The increased awareness did not lead participants to take action, which supports findings from a

previous study that suggest passive information has limited influence on the behavior of stroke caregivers (Bakas et al., 2009), and highlights an important gap in designing intervention programs to support planning or behavior change among families coping with stroke. It is important to recognize, however, that the protocol for this study did not include member checking after identification of emergent themes. It is possible that confirmation of this trend by the participants would have provided more depth leading to understanding of why increased awareness did not lead to action. Over time, in the current study, there were a few caregivers who acted on the awareness which was triggered by being asked about their contingency planning during the interview. These caregivers mentioned that they had talked about the need for contingency planning with their daughters; however, beyond preliminary discussions, they had not taken further action toward being prepared in the event of a secondary crisis.

An important observation from this study is that lack of action was most noticeable among caregivers who were providing complex personal care for the stroke survivor. While we did not specifically ask about the type and level of disability of the care recipient, all the caregivers made reference to the level of personal care they were providing. Extant literature has shown that greater challenges are experienced by caregivers when the care recipient requires more complex care (Campbell, Gilvar, Sinclair, Sternberg, & Kailes, 2009; Hartke & King, 2002; Eisenman, 2009). It is plausible that the additional responsibilities and activities that stem from providing more complex care make planning more cumbersome, yet this is contrary to what we expected, assuming that the motivation to ensure back-up plans were in place would be great and lead to preventive action, given the fragility of the care recipient and the heightened risk he/she has with respect to being affected by a secondary crisis at the family or community level. This issue warrants further consideration, as it has implications for support services that can be targeted toward caregivers who are required to provide more personal care. Future research could assess the saliency of this indicator and whether caregivers and families benefit from guidance and instrumental support in planning for future crises and disasters.

The Canadian federal government promotes awareness among families to encourage them to prepare to sustain themselves for a minimum period of 72 hours in any community crisis or disaster. The emphasis has been on the need to build self-efficacy among high risk populations through the development of their own initiatives to address communication, medical, and transportation needs (Public Health Agency of Canada, 2008). Extant literature also suggests various resources are available for caregivers to use in crisis and disaster preparedness planning, including suggestions of making lists of essential contacts and medical documentation. However, the main focus in all of these initiatives includes the development of a personal contingency plan among high risk populations (CCAC, 2011;

PHAC, 2006, 2008; Thobaben, 2011). The findings from our current study suggest program planners should not assume contingency plans are a priority for caregivers, given their primary focus on coping with the daily demands posed by the stroke. Quite simply, most families in this situation are not focused on the possibility of a secondary crisis, as many of their resources are being invested in coping with the impacts of the stroke.

The caregivers in this study believed they could sufficiently sustain themselves for the first 72 hours of a public emergency. Their responses were most often in the context of extended power outages or an ice storm, which are the types of community crises and disasters that have occurred in this area in recent years. This perceived self-sufficiency is not often reported in the literature with high risk populations, who are less likely to have surplus supplies (Campbell et al., 2009; Eisenman, 2009); however, it is important to recognize that many of the caregivers in this study reported a high annual household income (>\$60,000), which would provide them with the financial resources to stock extra supplies or go to a hotel if necessary. However, they did emphasize the issue of electricity for oxygen equipment as a potentially major problem and they suggested that not having enough medication would be a challenge due to limitations imposed by prescription and insurance regulations, which prevents them from ordering a surplus to have on hand. This issue has been reported in previous studies (Eisenman et al., 2009) and is cause for concern because a sudden interruption in a stroke survivor's medical regimen can lead to severe and potentially fatal deterioration in health, creating additional demands on the health care system (Aldrich & Benson, 2008).

IMPLICATIONS FOR PRACTICE/RESEARCH

Given the results of this study, it is apparent that interventions are needed to assist stroke survivors and caregivers, but awareness through passive communication campaigns alone is not enough. Bakas and colleagues (2009) stressed that education with the opportunity to apply problem solving for evolving needs such as the Telephone and Skill Building Kit (TASK) program, is more successful than providing caregivers with passive information alone. Interventions that promote the empowerment of stroke caregivers could be useful in preparing them to cope with future crises and disasters at both the family and community levels. Existing frameworks that outline key functional needs of caregivers across the stroke care trajectory (Byrne et al., 2011; Cameron & Gignac, 2008) could assist planners with anticipating the needs of families coping with stroke. The model developed in this study builds on existing frameworks by showing how secondary crises can cross levels of the family unit and community. It also depicts how regardless of the type of event, families rely on different formal and informal supports

to cope, particularly when the caregiver is unable to provide care for the stroke survivor. It can be used to identify action levers which can be used as targets for intervention to promote contingency planning among families coping with stroke, and emphasizes the need for awareness across the crisis spectrum to promote action within families and formal support organizations. Engaging health and social service professionals who have knowledge of the needs of caregivers and stroke survivors is an important strategy to ensure macro level contingency plans are in place for potential increases in the demand for respite services.

Social workers providing support for families coping with stroke should consider planting the seed for contingency planning over time, to raise awareness about the importance of having a "back-up plan." One strategy could be to provide a planning tool kit based on functional needs assessment and resource mapping to guide families in the planning process.

Future studies could also consider the behavioral effects of being exposed to information (triggers) on disaster preparedness among caregivers and whether increased awareness over an extended period of time can change the caregivers' stage of readiness to act. Last, but not least, future research could explore barriers to disaster preparedness among families coping with stroke, particularly those which affect their willingness to form contingency plans.

CONCLUSION

Families providing daily care for a family member recovering from stroke are at high risk of finding themselves unprepared during a crisis or disaster, particularly in a situation where the primary caregiver is unable to provide care. For many of these families, developing contingency caregiving plans is a low priority, given the everyday distress of coping with the impact of stroke. Post-stroke support programs should consider the need to inform caregivers about contingency planning and provide instrumental support to assist with the development of realistic back-up plans. At the macro level, formal support services should anticipate high demands for respite care in community crises or disasters and consider the needs of this particular population in future policy development.

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