

CAREGIVER SUPPORT DURING THE ACUTE, POST-STROKE PERIOD

by

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Abstract

Suffering a significant stroke can result in the individual becoming significantly dependent on family members for care and support, and this dependency can have a considerable impact on the caregivers' own health and wellbeing. The purpose of this report is to specifically assess caregiver needs during the acute post-stroke period and to hypothesize potential recommendations for practice. A literature review was conducted to explore the experience for the caregiver during this time and to identify specific strategies. Analysis of the literature resulted in three general themes: the role of education, having a specific stroke support contact, and screening caregivers for risk. A small survey study of seven participants was then conducted with caregivers on a stroke cohort unit and focused specifically on identifying what support caregivers require during the immediate, post-stroke time. Survey respondents were asked to rate various aspects of care and support and the three aspects that were deemed most significant were education, regular medical updates and the role of a specific stroke support contact. Specific strategies related to each of these areas are discussed. Integrating literature findings with caregivers' survey responses provides insight into caregivers' experiences, which may in turn guide new approaches and strategies that will improve care and support for caregivers on the stroke cohort unit. While this project provides much insight and proposes recommendations, further research is needed to define each area and to ensure changes and improvements are evidence-based.

CHAPTER I

INTRODUCTION

Stroke is a medical emergency that can have devastating effects on the patient's physical, mental and emotional wellbeing. The effects of stroke can result in the individual becoming significantly dependent on their loved ones for care (Heart and Stroke Foundation of Canada [HSF], 2015). This transition and loss has a considerable impact on caregivers, who must attempt to cope and adapt to their changing circumstances. As a result, caregivers often face poor health as well (Cameron et al., 2014; Grigorovich et al., 2015). The more significant the stroke a patient has had, the higher the level of caregiver burden experienced (Kruithof et al., 2016; Yeh & Bull, 2012). A significant stroke is defined here as one where the patient loses ability and function in one or more of the followings domains: speaking, word finding, swallowing, urinary continence, fecal continence, walking, memory, and problem solving.

Various factors, such as increased mental or physical dependence of the stroke victim, contribute to the escalating burden experienced by the caregiver (Kruithof et al., 2016). As well, caregiver stress and anxiety can impact the healing and coping of the stroke survivor, resulting in poorer patient outcomes (Gillespie & Campbell, 2011; Grant et al., 2013). For these reasons, it is paramount that interventions for the patient who has suffered a stroke focus on caregivers as well. Too often it seems the healthcare team is completely focused on the patient and their medical status. Team members put much energy into assessing, treating, and caring for the patient's body and forget the psychological and emotional aspects of the patient's care. The patient's caregivers are also overlooked and rarely considered as part of the patient's care. This all suggests there is a gap in our healthcare system that leads to the isolation of families. Involving families would provide the healthcare team with greater insight into the patient and

their overall health, and would also promote the health of both the patient and caregiver. Nurses must look at caring for the patient and family as one entity and embrace the family-centered care that is taught in nursing school as best practice (Ewart, Moore, Gibbs, & Crozier, 2014). Doing so would maximize potential for the patient and family's health as a whole.

Supporting caregivers may be most significant in the immediate acute, post-stroke period, as this is the time when caregivers feel most stressed and vulnerable (Cameron, Naglie, Silver, & Gignac, 2013). This period is defined as the time from onset of stroke symptoms to the time the patient has become medically stable and planning for discharge has commenced. If nurses are to strive for supportive care with families affected by stroke, the interventions put in place for caregivers must be informed by the literature so practice is evidence-based. Therefore, an examination of existing research is necessary in looking towards improving support for caregivers.

The purpose of this report is to describe findings from a literature review and a survey conducted with a small sample of caregivers that identify specific aspects of support that caregivers require after their loved one has suffered a stroke. Integrating literature findings with caregivers' survey responses provides clinical leaders with insight into caregivers' experiences, which may in turn guide new approaches and strategies that will improve care and support for caregivers.

Background

The origins of this work stemmed from my experience as a Clinical Nurse Educator and then as an Interim Patient Services Manager of two acute medical units in a large community hospital. The stroke cohort unit is located on one of these medical units where the interdisciplinary team has received increased training and experience caring for stroke patients.

The goal of the organization is to have all acute stroke patients cared for in this area where best practice recommendations related to stroke care are employed.

Over a two year period, this unit was highlighted as receiving many patient and family complaints, with caregivers often reaching out to Risk Management to share their concerns, and the leadership team came to notice that almost all of the families reaching out were those whose loved ones had suffered a significant stroke. The team speculated that there could be a relationship between a significant stroke and caregiver stress and difficulty coping. It appeared many families struggled to understand what was happening with their loved ones and nurses were unsure of how to intervene appropriately. The healthcare team appeared ill-prepared to provide the care and support caregivers deserved. Furthermore, all interdisciplinary team members on this unit were stretched thin for time and had to prioritize their work. There was no identified team member who specifically supported stroke patients and their families and, instead, the health care team often responded reactively to these families. Often it was only when complaints and concerns were brought forward that individual team members would spend a bit more time with these families because they had now vocalized their worries to senior administration and become a priority for the unit. This process was backwards with families needing to first escalate their concerns and complain before they received the attention they required. Furthermore, staff wondered if families who did not have the confidence or language skills to present their concerns also suffered but never received the support they required. It seemed clear that caregivers' needs were not being met on this unit and further exploration of both caregivers' wants and of interventions that could better support these families was necessary.

Purpose

The purpose of this project was to more closely and critically assess what aspects of support caregivers need during the acute, post-stroke period. This analysis will lead the way for interventions that are based on both recent research and the perspectives of caregivers from this stroke cohort unit. The hope is that these findings will guide the team on this unit to create an approach that better supports caregivers of stroke victims. Finally, this report forms the groundwork for a future project that could study the effect of the new approach as envisioned through this project. The approach to assessing caregiver needs during the acute post-stroke period was twofold:

- a) A review of the literature related to caregiver experiences during the acute, post-stroke period and interventions that better support these caregivers, so that evidence-based research informs a future approach;
- b) A survey of caregivers on this stroke cohort unit to specifically assess their stated needs and viewpoints during the acute, post-stroke period.

The goal was to bridge together findings from the literature with those from caregivers' survey results in order to propose recommendations for improved care and support for both patients and caregivers affected by stroke.

CHAPTER II**LITERATURE REVIEW**

The first step of this project entailed a literature search using three specific databases: CINAHL, MEDLINE, and PubMed. The key search terms used were stroke, family, caregiver, support, acute, and coping. These terms were entered in various combinations using Boolean searches. The search was restricted to literature from within the last 10 years. From the resulting

lists of over 100 articles, I chose works that appeared to focus on the acute care experience and reviewed these abstracts. I further narrowed the list by focusing on primary sources and systematic reviews, and selecting only the literature that focused on or included the early post-stroke phase when the patient is still acute or just past the acute phase and planning for disposition from hospital. Finally, I read through the remaining 24 articles and assessed them for quality by critically analyzing specific aspects, such as the purpose and objective of each study and how well it was supported by study background, the suitability of data methods used, and the appropriateness and generalizability of findings. The resulting seven articles represent literature with high scientific merit that focuses primarily on support of the caregiver during the acute, post-stroke phase.

Perspectives from the Literature

All seven studies focused on caregiver support during the acute stroke phase and were conducted primarily by Registered Nurses and other interdisciplinary team members who work closely with stroke patients and their families during the acute stroke phase. The studies all sought to learn about the experience of being the caregiver for an individual who has suffered a significant stroke, with a common primary outcome being to identify strategies to assist the acute healthcare team in better supporting caregivers during the immediate period following a stroke.

Analysis of the literature resulted in three general themes. The first is that of education needs and the type, amount, and delivery of such education for caregivers. The second theme relates to a specific stroke support contact for patient and caregivers and explores the purpose and function of this role. The third theme focuses on examining caregiver risk and the extent to which screening caregivers could help guide the health care team to better target their support.

Education needs. Much of the early research related to caregiver support during the acute post-stroke period focused on stroke education delivery (Cameron et al., 2013). More recent research has focused on different education approaches and the resulting impact of these. Researchers have come to see that general stroke education does not have nearly the impact of specific, individualized stroke education (Eames, Hoffmann, Worrall, Read, & Wong, 2013). Also, medical updates provided with clear explanations of meaning and the significance of these results for the caregiver is another education gap that has been noted and studied.

Eames et al. (2013) conducted a randomised controlled trial to compare two approaches to patient and caregiver stroke education. The study was conducted on acute stroke units at two tertiary hospital sites. The authors randomly selected a sample of patients and caregivers who met criteria, resulting in a total of 119 study participants. Eligible caregivers included those who were expected to act as the primary support for a stroke victim whose expected discharge destination was home. Patients and caregivers studied also had to have use of a telephone and be able to understand and speak English. The control group received the usual post-stroke assessment, treatment, and education delivered in a non-structured manner by all members of the interdisciplinary team via face-to-face sessions. The intervention group differed from the control group in that they received additional support such as a written stroke education manual, follow-up teaching of up to three sessions in which the manual was used as a guide, and a telephone number participants could use to call with questions or concerns both pre-discharge and for up to three months post-discharge.

While there was no statistically significant difference in stroke knowledge between the control group and the intervention group at three months post-discharge, the investigators did however find “significantly better self-efficacy... feeling informed... and satisfaction” in the

intervention group, when compared to the control group (Eames et al., 2013, p. 5). Although Eames et al. argued that it was the increased time spent on education that accounts for these significant results, it is possible that it was simply the increased individualized attention given to the intervention group that led to these improvements. Participants in the intervention group were given more one-on-one time, allowed to direct the education topics, and reassured with follow up phone calls where they could ask questions. Eames et al. did not consider whether this increased individual attention and time is what actually accounted for the significant improvements. The authors assumed it was the education approach even though no actual improvement in stroke knowledge was noted. Therefore, while this research did show that individually-tailored education support can improve self-efficacy, feeling informed, and satisfaction, it is unclear which exact variable led to these improved scores. A final limitation of this study was that they did not separate caregiver and patients' results. Therefore, these results may not be specifically generalizable to caregivers alone.

Danzl et al.'s (2016) well-conducted qualitative study aimed to explore patient and caregivers' experiences of education in the post-stroke period. The researchers' recruitment was directed at stroke survivors and caregivers with either one or both being eligible to volunteer. Danzl et al. led a qualitative descriptive study based on semi-structured interviews with 13 patients and 12 caregivers. This was a convenience sample of participants who responded to letters that had been mailed to individuals discharged from one of two medical centers following a stroke. Danzl et al. used the term "education" throughout the research, although some of their references to "education" might be more accurately described as "medical updates". For example, participants stated they needed regular communication informing them of what was occurring with their loved one, why it was occurring and what the next steps would be. Danzl et

al. refer to this as proactive education, but it might be better interpreted as participants' need to know what was happening specifically to the stroke patient and the significance of these events. This study also found that patients and caregivers appreciated education that explained the specific symptoms they were seeing, and had a need to be informed about what they could personally do to support the patients' recovery. This again highlights participants' need for *individualized* updates and education as applicable to the patient case. However, this was not addressed by Danzl et al., who concluded that *general* stroke information was necessary to support stroke patients and caregivers. Future research is likely needed to distinguish between benefits of general stroke education and benefits of individualized stroke education tailored to stroke survivor's type of stroke and associated impairments.

A limitation of Danzl et al.'s study may have been their decision to interview the patient and his or her caregiver together. While the authors explained that this was based on patients' preferences, it is possible that caregiver responses may have been different if they had been interviewed separately from their relative. With Danzl et al.'s approach, caregivers may have held back on some of their experiences or concerns because their relative was present.

Finally, Roy, Gasquoine, Caldwell, and Nash's (2015) large, well-structured mixed-methods study also focused on information delivery for both patients and caregivers after a stroke. This research study used purposive sampling that targeted participants with flyers posted at a stroke hospital and at local stroke support groups. The patient's stroke must have occurred within the last two years. A total of 19 caregivers participated in face-to-face interviews following questions from the authors' survey. Roy et al.'s study identified that delivering information at the right time and specific to the individual patient and caregiver's needs is a priority. Participants in the study voiced that the health care team constantly appeared too busy to

take time to seek caregivers' concerns and to provide information. Instead, participants felt that different health care team members would "dump" information on the caregivers in such a way that made it difficult for caregivers to understand and to retain the information. Roy et al.'s research findings echo many of Danzl et al.'s (2016). It is evident from these rich studies that an education gap exists, and from the findings it might appear that a tailored education approach is necessary to improve support for caregivers and increase their confidence.

A specific stroke support contact. A newly studied approach to caregiver support after a stroke is that of one identified stroke support contact for the patient/family unit. This continuous support may be exemplified via reassurances and the addressing of emotional needs, in addition to previously discussed medical and education components. Also, studies show that it may be best if this reassurance, as well as the delivery of education and medical updates, comes from one individual only (Cameron et al., 2013; Danzl et al., 2016).

Cameron et al. (2013) conducted a qualitative study to explore a deeper understanding of caregiver needs over the trajectory of the stroke survivor's post-stroke care. Participants were recruited from an inpatient rehabilitation center and from two community programs serving stroke clients' needs. A total of 24 participants, all of whom were caregivers having gone through these experiences between one month and one year prior, participated in one-on-one interviews either face-to-face or by telephone. Cameron et al. (2013) used Framework Analysis to analyze their data. This qualitative method appears appropriate for Cameron et al.'s (2013) research since their work was shaped by pre-existing ideas that could then be used to inform practice rather than theory (Ward, Furber, Tierney, & Swallow, 2013). This study found that it was during the diagnosis and immediate stabilization or treatment period following diagnosis that caregivers identified the highest levels of stress. During this period, caregivers reported not

feeling “cared for” (Cameron et al., 2013, p. 318) by the healthcare team. Caregivers identified emotional support as being of primary importance in the immediate post-stroke period (Cameron et al., 2013). This emotional support was described as “ongoing reassurance... fears [and]... worries addressed...” (Cameron et al., 2013, p. 318). Specifically, Cameron et al. found that caregivers preferred to have one healthcare team member compile updates from each interdisciplinary team member and then share this information with them. Caregivers reported feeling overwhelmed and unable to ask questions when multiple team members provided information.

Building on this work, Cameron et al. (2014) conducted a small randomized control trial comparing two support approaches for caregivers. Caregiver outcomes were assessed at one, three and six months post-stroke, examining caregiver variables such as depression symptoms, psychological wellbeing, mastery and others. Although Cameron et al.’s (2014) response rate was low at 35%, with only 31 participants consenting to participate in the end, their interventions were based on a thorough review of the literature. It would, however, be useful to note reasons for low response rate. If a specific subgroup of this target population was refusing to complete the survey, then this category of respondents may be underrepresented, thereby decreasing generalizability (Polit & Beck, 2012).

Similar to Eames et al.’s (2013) findings, Cameron et al. (2014) found that caregivers who worked specifically with one dedicated health care team member, and who also were able to direct their session and learning, exhibited less depression and fewer symptoms of burden, even though there was no change in their stroke knowledge. When compared with other stroke caregivers, those with a dedicated stroke support clinician showed statistically significant improvement in perceived support and in mastery (Cameron et al., 2014).

Duthie, Roy and Niven (2015) used thematic interpretive analysis to explore the experience of stroke in a case study of three family members during the first few months after their relative's stroke. Duthie et al.'s small sample size of three participants from one family allowed for detailed exploration of the caregiver experience. An interesting finding from this research was that caregiver self-care in the immediate post-stroke phase may differ depending on the amount of pre-stroke knowledge the caregiver has about stroke and expected outcomes. For example, the interviewed family members were all health care professionals familiar with stroke and the long term impact of stroke on a family. These individuals felt they offered one another one-on-one stroke support because they arrived to their situation with the knowledge and experience that is usually missing for other families. This family was able to focus on self-care right from the start, advocating for themselves and other members of their team. These participants compared themselves with another caregiver on the same unit who did not have any pre-stroke knowledge or any obvious direct stroke support clinician to provide this education. The unaware caregiver felt it was her "duty" to sit at her loved one's bedside each and every day. The interviewed family members encouraged this other caregiver to take time away for herself and informed the caregiver of what was to come post-discharge. The interviewed family members felt this other caregiver, who did not arrive with prior knowledge, was not provided with the necessary information outlining the realities of the situation.

Although Duthie et al.'s (2015) study was based on just one family unit, this research followed the participants over a longer period of time and used a phenomenological approach appropriately to explore these perspectives. Duthie et al.'s work may contribute to better understanding of why caregivers who receive tailored, one-on-one stroke education and support show better outcomes for caregiver burden and depressive symptoms even though no change in

stroke knowledge is seen. The study suggests that these individually-tailored one-on-one education and support sessions empower caregivers to better prepare and plan ahead, a need that has been identified by caregivers in other research (Roy et al. 2015).

Danzl et al.'s (2016) qualitative descriptive research also suggested that a specific contact for patients and caregivers would offer improved support. Participants voiced the need for one "navigator" (Danzl et al., 2016, p. 20) to coordinate the education and support offered to stroke survivors and their caregivers. Danzl et al.'s research echoed others in that multiple team members offering education and information increased confusion and stress for patients and caregivers. Furthermore, Danzl et al. highlighted the importance of having a team member present to actively listen to concerns and to support the family through the care continuum. As Danzl et al. stated, "A contact person... [is] desired" (p. 16). Further to this, findings from Roy et al.'s (2015) study highlighted the importance of providing social and emotional support to caregivers throughout the acute care experience, and that doing so paves the way for long-term caregiver success.

Screening caregivers for risk. When looking to support caregivers after a stroke, it is also important to recognize that each caregiver and each stroke experience is individual. Not all caregivers require the same amount and type of support. Therefore, assessment of pre-stroke factors that may place the caregiver at an increased risk for impaired coping is important. Further to this, assessment of the individual caregiver's status post-stroke is a crucial step when efforts are focused on support.

Certain factors are known to be associated with an increased risk for caregiver stress and burden. Kruithof et al.'s (2016) study looked at this, using a prospective cohort study design to examine 183 caregivers. Results showed that the factors that placed a caregiver at higher risk for

stress and burden included: a younger age of the patient and/or the caregiver, a spousal relationship, and poorer functional state of the stroke survivor. Patient-specific factors that proved to correlate directly with caregiver burden included stroke severity and symptoms of depression. Caregivers who experienced less satisfaction in their relationship prior to the stroke also showed increased burden and anxiety. Furthermore, when patients experienced increased anxiety, caregivers in turn reported increased burden and anxiety. Kruithof et al. found that caregivers who experienced this burden in the immediate post-stroke phase most often continued to feel this way one year post-stroke, a finding that aligned with previous research.

Grigorovich et al.'s (2015) longitudinal cohort study examined 399 caregiver/patient dyads during one hour one-on-one telephone interviews. Researchers assessed caregivers' restriction from participating in normal activities, caregivers' level of mastery, and self-rated depression. The study was completed in the acute care setting. Grigorovich et al. drew many of the same findings as Kruithof et al.'s (2016). Firstly, Grigorovich et al. concluded that the patient's post-stroke status, particularly their stroke severity as exhibited by extent of physical and cognitive deficits, was a strong predictor of impaired caregiver coping. The greater the stroke severity, the more likely the caregiver would experience greater restriction from participating in meaningful activities. Similar to Kruithof et al., Grigorovich et al. found that the younger the caregiver, the greater the risk for poor caregiver outcomes. Other factors highlighted as strong predictors for caregiver burden included the caregiver being employed and greater depressive symptoms. While Kruithof et al. found depressive symptoms in patients as a risk factor for caregiver burden, Grigorovich et al., did not. Instead, they found caregiver depressive symptoms to be statistically significant, stating it placed the caregiver at a higher risk for

experiencing increased caregiver burden. Finally, Danzl et al. (2016) also acknowledged the role of depression in impacting outcomes for both stroke survivors and caregivers.

One aspect that is not teased out in the literature is the significance of these symptoms of depression. For example, it was unclear whether these caregivers experienced depressive symptoms even before their loved ones had a stroke. Knowing this would guide the healthcare team to know whether it would be useful to assess for any caregiver depression pre-stroke when screening caregivers for risk of burden. Also, it was unclear if depressive symptoms led caregivers to participate less in meaningful activities or if the act of participating less in meaningful activities was what led to depressive symptoms. Therefore, more research is needed in this area to guide risk assessments and caregiver interventions.

Cameron et al. (2014), like Kruithof et al. (2016), also highlighted that the extent of stroke severity contributed to increased caregiver burden. For example, the more significant the stroke survivor's physical and cognitive impairments, the more caregivers reported increased burden and depressive symptoms. Therefore, using a functional assessment tool to assess the patient's functional and cognitive abilities could help the team to identify caregiver risk level.

Summary

There were many overlapping findings throughout the literature reviewed as well as gaps that highlighted potential areas for further research. In relation to the theme of education support, it appears that individualized education specific to the patient and caregiver's immediate needs results in more positive feelings and increased confidence for the caregiver (Danzl et al., 2016; Eames et al., 2013). Furthermore, it appears that caregiver outcomes are more positive when education is provided regularly and is related to the patient's current medical status (Eames et al., 2013; Roy et al., 2015). While it is clear that specific variables lead to improved outcomes for

caregivers, each study utilized multiple strategies within one intervention group. Therefore, further research is needed to clarify the effectiveness of each individual approach.

In relation to the theme of a specific stroke contact, much of the literature found that caregivers prefer to have information delivered, and support received, primarily from one team member instead of many (Cameron et al., 2014; Danzl et al., 2016; Duthie et al., 2015; Roy et al., 2015). Additionally, individually-tailored education and regular contact from a supportive team member results in significantly improved symptoms of depression and perceived support (Cameron et al., 2014; Danzl et al., 2016; Eames et al., 2013). The discussions related to the specific stroke contact role did not identify whether certain disciplines, such as social work or nursing, with a specific skill set would best serve the caregiver's needs when providing this one-on-one support. It is unclear whether the amount of support offered would differ depending on role and/or skill set and further research is needed.

In relation to the theme of screening caregivers for risk, many factors, such as greater functional dependence of the stroke patient and decreased satisfaction with relationship pre-stroke, were associated with increased burden and depressive symptoms in caregivers (Danzl et al., 2016; Grigorovich et al., 2015; Kruithof et al., 2016). However, there exists no tool for specifically addressing risk level in caregivers of stroke victims. It is hoped that future research will look to adapt caregiver risk screens for this specific population.

CHAPTER III

SURVEY STUDY

The literature review presented in the previous chapter suggests that there is a discrepancy between current research and what is currently offered on the stroke cohort unit at this site. This recent research has challenged conventional methods of support and exposed a

need for improvement in our approach. Therefore, I conducted a small survey study with caregivers on a stroke cohort unit to gather primary data about this subject matter and to discover whether the findings of the literature review are applicable in this practice setting and target population. I developed a questionnaire for caregivers that assessed what specific strategies they felt were needed in the immediate post-stroke acute period to better support them and, in turn, their relatives. This survey study was approved by the University of British Columbia's Behavioural Research Ethics Board (# H15-02848).

Sampling Strategy

The population I sought to learn more about was caregivers of stroke survivors. My specific target population was caregivers of stroke survivors who had been involved in the stroke survivor's care during the immediate, acute post-stroke phase. I studied this target population from within the geographical boundaries of a stroke cohort unit.

Criteria. To be included in this study, participants needed to be a caregiver, which was defined as a family member or friend who had been involved in the patient's care during the acute stroke phase, supporting the patient and collaborating with the health care team, and who was not paid for this assistance. Criteria for inclusion also included this being the first significant stroke the patient had suffered. Finally, the patient must have had a need for support in at least one functional domain, whether it was physiotherapy support, occupational therapy support, speech language pathologist support, or dietician support. All caregivers of stroke patients on the hospital unit during the five weeks of survey administration time, who fit the above criteria, were offered the opportunity to complete a survey after the patient was past the acute phase of their stroke journey, was deemed medically stable, and for whom discharge planning had commenced.

Caregivers were excluded if this was not the patient's first significant stroke or if the patient remained functionally un-impacted when compared with baseline, pre-stroke functional status. These patients, and therefore caregivers, were excluded because the patient had not suffered a functional loss. Also, these patients tended to be discharged from hospital within 48 hours. Finally, caregivers of stroke victims who became palliative were also excluded from this study.

Recruitment. I carried out a convenience sampling method using volunteer participants. At rounds each day, each patient's status and plan of care is discussed by the interdisciplinary team. Rounds are always led by the Patient Care Coordinator (PCC). The PCC approached caregivers who met study criteria, and followed a recruitment script to invite their participation (see Appendix A). The PCC gave the caregiver the written explanation and the survey, and asked the caregiver to take their time reviewing the material. See Appendix B for survey instructions given to eligible participants. The PCC also let the caregiver know the survey could be completed at their earliest convenience, if they chose to complete it. Consent was implied with survey completion.

I scheduled five weeks for survey administration time as this worked best when outlining my entire project timeline. To increase response rate, I asked the PCC to track who had been given a survey so that they could remind the caregiver about the survey one time after the initial discussion had taken place. Over the study period of five weeks, a total of seven caregivers were provided the questionnaire and all seven completed and submitted the questionnaire.

Survey Design

I employed a cross-sectional descriptive study design to describe and explore factors that caregivers feel will support them during the acute post-stroke phase. A descriptive approach

worked well for this topic because there was knowledge brought forward previously in the literature in relation to key outcomes and the survey provided the opportunity to explore the application of this knowledge to my practice area. This was a cross-sectional design because data was obtained from the caregiver at one point in time only. My data collection method was a self-administered paper survey.

To ensure the questionnaire was as respondent-friendly as possible, it consisted of only 10 questions and I included clear instructions in order to decrease measurement error (Andres, 2012). I also used large font and simple language, and likert scales with only five points to make the survey more user-friendly. Since my survey was a pen-and-paper questionnaire, I used colour at the end to highlight for the respondent where they were to submit completed questionnaires. Finally, I avoided marathon questions and double-barrelled questions which run the risk of confusing the participant and therefore skewing results (Andres, 2012).

The survey began by asking demographic questions about the caregiver completing the survey with the intent of exploring whether specific relationships between patient and caregiver or particular age of caregiver seemed to draw similar or different responses at all. The survey asked participants about their experience with medical updates, education, comfort approaching health care team, and the caregiver's needs assessment during the first weeks after the stroke. The survey then asked participants how important they thought each of those things, along with planning for discharge and explanation of the patient's care, was for the caregiver during those first few weeks. Finally, the survey outright asked participants if they felt having a specific stroke support contact would have aided their experience at all. To increase the richness of the data, the survey also allowed space for open-ended comments with each question. See Appendix C for questionnaire given to eligible participants.

Analysis plan. My study goal was to explore and describe, and this was reflected in my analysis method. I retrieved all of the closed-ended/Likert scale questions and answers and plotted results into an excel spreadsheet to facilitate analysis. Examining frequencies of responses received, I looked for trends and how varied responses were for each individual question. For the survey's open-ended questions and comments, I transcribed this data into a separate word document. I then highlighted common statements that appeared to build on the closed-ended responses. These phrases were then organized under specific themes that arose during this analysis.

Results

A total of seven questionnaires were provided to caregivers and all seven were completed and returned. Of these, five respondents were female and two were male. All respondents were at least 30 years of age and older. Three respondents were children of the stroke victim, one was a grandchild, one was a parent and two were husbands, wives or partners.

As shown in Table 1, when asked how much time, during the immediate post-stroke period, was spent providing the caregiver with medical updates, the majority of respondents answered "some" time or less. Only one respondent felt "much" time was given to update caregivers. One caregiver added that doctors were rarely available for caregivers to speak with.

Table 1

Time Spent Providing Regular Medical Updates

A great deal	0%
Much	14%
Somewhat	43%
A little	14%
Not much	29%

When caregivers rated how important receiving this information should be, they all answered “extremely” or “very” important.

As shown in Table 2, when asked how much time, during the immediate post-stroke period, was spent providing education, all caregivers rated this as even less than the amount that was spent providing medical updates.

Table 2

Time Spent Providing Education

A great deal	0%
Much	0%
Somewhat	29%
A little	14%
Not much	57%

When asked how important they thought education should be during this period, most respondents answered “extremely” or “very” important. Only one respondent rated education as of lower importance.

When rating importance of three other aspects of the patient’s care during the immediate post-stroke acute period, caregivers rated “planning for discharge” as “moderately” important, “explanation of care being done with loved one” as “moderately” to “very” important, and “having someone on team available to listen and care” as “very” to “extremely” important. Overall, caregivers rated “medical updates” and “having someone on the team available to listen and care” as more important than all other areas.

Interestingly, when asked how comfortable each caregiver felt asking the team questions, most respondents, as shown in Table 3, felt quite comfortable. Only one respondent said they felt “uncomfortable”.

Table 3

Caregiver Comfort Asking Healthcare Team Questions

Very comfortable	14%
Comfortable	43%
Moderately comfortable	14%
Uncomfortable	14%
Very uncomfortable	0%

Caregivers were asked how often a team member asked them what they needed. Most caregivers answered “never” or rarely”. Only one caregiver answered “sometimes”. One respondent commented that only when this caregiver escalated concerns to the Charge Nurse did the family’s concerns get heard. Furthermore, when asked how often the caregiver felt they knew who to go to with questions or concerns, all respondents answered “rarely” or “sometimes”. Another respondent added, “I stopped bothering with doctors, [I] went straight to [the] Charge Nurse.”

Finally, caregivers were asked outright how helpful it may have been to have one single team member identified as the caregiver’s specific contact. As shown in Table 4, this question received a unanimous response. This was the only question to receive complete agreement by all respondents.

Table 4

Helpfulness of Having One Specific Team Member as Primary Contact

Extremely helpful	100%
Very helpful	0%
Somewhat helpful	0%
Not very helpful	0%
Not at all helpful	0%

The final question on the survey was open-ended and allowed caregivers to suggest ways caregivers could be better supported during this acute, post-stroke period. Five out of seven caregivers provided detailed written responses to this question. Two particular concerns emerged from this data. The first is that of consistency. Caregivers described weekly “switching doctors”, nurses “constantly changing”, and “so many faces”, stating these factors added to their stress and burden. Caregivers voiced that they felt unsure of how to proceed and there was no particular person they could approach. Two families mentioned how once they escalated their concerns to the Charge Nurses and continued communicating with these individuals instead, things improved. Many respondents mentioned one specific contact, using phrases such as “provide [a] main contact for updates”, “[have] a consistent person”, and “somebody families can talk to”. One respondent was even more specific, recommending a “paid staff member to act as a liaison and main point of contact between medical staff and families”. This clear theme of one consistent individual was a voiced priority for almost all of the respondents.

A second concern emerging from respondents’ narrative responses related to the idea of chaos and calmness. Caregivers’ responses highlighted “chaos” getting in the way of caregivers feeling supported by the healthcare team. The chaos discouraged caregivers from approaching the team with questions and concerns. Many respondents mentioned that the healthcare team was “extremely busy”. Respondents asked that team members “listen” and “be more gentle and patient”. The chaos of the acute hospital environment appears to increase caregivers’ stress and burden.

Limitations

Limitations of this pilot study begin with the small sample size. Due to the project timeline, only seven caregivers were eligible to complete the survey. While the findings offer

some insight into the experience of caregivers on this specific stroke cohort unit, the sample size may be too small to generalize to the larger population. Furthermore, having previously worked on this unit, some of the participants may have recognized my name on the cover page and, despite the questionnaire being completed anonymously, may have not been completely open with their responses. Finally, the survey did not ask caregivers about the severity of stroke suffered by the stroke victim. My results, then, cannot comment at all on the potential relationship between stroke severity and extent of caregiver burden or need for support.

CHAPTER IV

DISCUSSION AND RECOMMENDATIONS

On the basis of the review of recent research, and the survey conducted on the unit, certain key findings are noticeable. In what follows, I propose recommendations based on these learnings as they relate to the need for caregiver education, support and screening.

Meeting Educational Needs

The literature review revealed that caregivers experienced improved confidence and satisfaction when more time was spent on education (Eames et al., 2013). Caregivers who completed the survey likewise rated education as a very important need, although they felt that there was insufficient time devoted to this kind of support. Findings from the qualitative data further explained that caregivers felt they would benefit from not feeling rushed. Survey participants requested that the healthcare team slow down and that environmental chaos be better controlled. Respondents described the unit as “extremely busy” and asked that team members “be more gentle and patient”. The research discussing follow up phone calls, with its devoted time to the caregiver and focused attention, was also a theme supported by respondents in the survey. Finally, there was much reference in the research to “education” that appeared to more

closely resemble medical updates. In both study results and caregiver survey responses, it was clear that caregivers needed to know what was occurring with their relative, what this meant, and what could then be done going forward (Danzl et al., 2016; Roy et al., 2015). From the survey it appeared that participants needed this information because it helped them to direct their next steps. Survey respondents also mentioned sitting and waiting because they were unsure of what to do. Such sentiments support the literature that found caregivers needed to be informed about what they could do that would be most helpful to their relative (Danzl et al., 2016).

Learnings from the literature and survey responses suggest that regular meetings with the patient/family would help ensure that they receive timely education and medical updates. The meetings would also allow for questions and discussion, instead of the quick, “busy” in and out approach that is currently occurring, as evidenced by survey responses. Findings from the literature review suggested that the education delivery method should step away from being too general and, instead consider the patient’s type of stroke, resulting stroke deficits, and patient-specific plan going forward (Eames et al., 2013; Roy et al., 2015). A form that guides the healthcare team to approach education in this manner may be useful.

Coordinating Support

Survey responses were clear that participants felt strongly about the importance of medical updates, suggesting that a coordinated approach was critical for patients and caregivers to receive the necessary information from the medical and entire interdisciplinary team so that regular and accurate medical updates are provided. Some of the literature highlighted that caregivers required reassurance, emotional acknowledgement, medical updates and education delivery that was communicated by one healthcare team member only (Cameron et al., 2013; Cameron et al., 2014). This emerging model of one “navigator” (Danzl et al., 2016, p. 20) who

can provide one-on-one support that assesses caregivers' priorities was directly addressed in the caregiver survey. The results were unanimous that surveyed caregivers felt such an approach could better support them. As survey respondents stated, having one contact would "bridge the gap between family and medical doctors/staff". , Previous research has shown that having multiple team members provide information creates chaos and confusion for the caregiver (Danzl et al., 2016). This sentiment was a main theme of survey respondents, with many commenting on the "busy" nature of the unit and of the healthcare team. This resulted in caregivers feeling even more stressed, lost and angry.

All seven of the survey respondents answered "extremely helpful" when asked how useful a designated stroke support clinician role would be. Having a specific stroke contact role for families could provide daily emotional support, provide regular medical updates, facilitate communication and care planning in the face of rotating doctors and nurses, and provide education that is specific to that patient's stroke type and stroke severity. As we have learned from the literature and from survey results, all this could significantly decrease caregivers' stress and burden.

In the current healthcare system, with its minimal resources and persistent financial constraints, funding for a new role to support the patient/family unit may not be forthcoming. Another option may be to rotate responsibility for such a role amongst interdisciplinary team members, who would in effect "take turns" serving as an individual stroke support contact for a family. Different team members, such as the PCC, physiotherapist, occupational therapist, dietitian, and Clinical Nurse Educator could each take on a small caseload of families. Each healthcare team member would follow a specific approach that could be developed based in part on the findings of this report. Of course, further research may be necessary to work out the

feasibility and details, such as the need for the support contact to have a medical background (as was suggested by one survey respondent).

Strategies for Screening

Although stroke patients and their families do experience more significant risk for stress and burden than other patient groups, one might predict that a specific “contact” role would help all patients and families admitted to hospital. These gaps and needs that affect the stroke population likely affect others to some degree as well. Learnings from our stroke population about new approaches for family support can likely be applied to other areas as well.

Assessing caregiver status, patient/caregiver relationship pre-stroke, and stroke severity post-stroke all significantly affect caregiver coping post-stroke (Cameron et al., 2014; Kruithof et al., 2016). The gap is determining how to assess this and, as we work towards implementing a new approach on the unit, it will be necessary to examine the literature for potential tools. One tool currently used in the region that would address the question of stroke severity is the alpha FIM tool. This tool assesses the patient’s current functional and cognitive status, helping to estimate the patient’s potential for recovery of losses and potential discharge options (Clark, Stillman, Linn, & Granger, 2000). This tool could be used with every stroke family to address risk for caregiver burden and also to help guide education that is tailored to individual patient status.

Assessing the caregiver’s status post-stroke is perhaps even more of a priority as this would guide the team’s approach and determine priority levels for supportive interventions. Kruithof et al. (2016) found that caregivers who experienced this burden in the immediate post-stroke phase most often continued to feel this way one year post-stroke. This reinforces the importance of screening patients and caregivers to make both them and the health care team

aware of the risks so that potential strategies can be introduced. While Kruithof et al. used the Caregiver Strain Index (CSI) to measure partner burden, the literature also suggested using the more recent version, updated in 2003 by Onega, called the Modified Caregiver Strain Index (MCSI). Both tools have caregivers run through 13 statement but the MCSI allows points for a “sometimes” response, where the original CSI only offered “yes” and “no” responses (Onega, 2003). Using such a tool in the post-stroke phase will guide the team, patient and caregivers about short and long-term risk for burden. Three articles found that depressive symptoms in either patients or caregivers contributed to increased caregiver burden (Duthie et al., 2015; Grigorovich et al., 2015; Kruithof et al., 2016). However, the studies varied in how they found these factors contributed and more research is needed to clarify the impact of this component on caregiver coping. A more thorough examination of the research is necessary before incorporating patient and caregiver depression screens into practice.

The literature review suggested that some pre-stroke factors affected caregivers’ post-stroke status. For example, being a husband, wife or partner of the stroke victim was correlated with higher levels of caregiver burden and strain post-stroke (Kruithof et al., 2016). When examining survey results, there did not appear to be any specific associations between variables when looking at relationship status to the stroke victim, although findings were likely limited due to the small sample size. Also, asking more targeted questions in the survey might have helped assess for any differences based on relationship status. The extent of stroke severity was also shown to significantly impact caregiver coping (Grigorovich et al., 2015). Again, survey respondents were not asked about the extent of their relative’s stroke severity and perhaps doing so would have provided additional insight.

Conclusions and Next Steps

Evidence from the literature and themes from the survey of caregivers from a stroke cohort unit have been integrated to lay the groundwork for improvements in the support of caregivers of stroke patients in the acute post-stroke period. Other hospital sites in the region have focused on providing general stroke education for caregivers. Findings from this project suggest a new approach that views the patient and family as the care unit and promotes individualized care and support for caregivers. It is inspirational to see practice moving in this direction and literature supporting such approaches. The literature findings were further supported by the caregivers on the stroke cohort unit who completed the survey. Together, these findings have informed specific recommendations for practice that we eagerly look to explore on this stroke cohort unit.

For example, the stroke cohort unit meets weekly to discuss current and new stroke initiatives. At this venue, learnings will be shared and discussions can begin regarding practical strategies for improvement based on project findings. Due to limitations of the small survey study, potential changes must first be grounded in current research and then trialled. Many gaps in the literature and limitations of the pilot survey study were identified. Further research into education approaches, responsibilities of the stroke contact role, and specific criteria for an accurate stroke caregiver risk screen are needed. This means advocating for and participating in further research that builds on this literature review and pilot study. Engaging in a more extensive analysis of the literature will lead the way for improvements that are evidence-based. As the discipline who spends the most time with patients and their caregivers, nurses must stand as leaders and advocates for stroke patients and caregivers. As we strive to continually improve,

pilot projects such as this one bring us one step closer to meeting the needs of the patients and caregivers we care for.

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Appendix A

RECRUITMENT SCRIPT FOR PATIENT CARE CO-ORDINATOR

Your loved one has had a stroke and now that we are beginning to plan for discharge, we want to learn more about how this experience has been for you. Our goal is to find out how best to support caregivers of stroke patients. Specifically, we want to hear what resources caregivers feel they need within the first weeks after a stroke when their loved one is still quite ill.

This survey takes about 15-20 minutes to complete and it is anonymous. You are not required to complete the survey, and it will have no effect on the care you and your loved one receives.

This survey is being conducted by Silvia Nobrega, RN as part of the requirement for her Masters of Science in Nursing final project. Results of the survey will be used to improve programs and practices for future caregivers and their loved ones.

Appendix B

Caregiver Support during the Acute Post-Stroke Period

You are being invited to complete a survey because your loved one has had a stroke and we want to learn more about how this experience has been for you. Our goal is to find out how best to support caregivers of stroke patients. Specifically, we want to hear what resources caregivers feel they need within the first weeks after a stroke when their loved one is still quite ill.

This survey is being conducted by Silvia Nobrega, RN as part of the requirement for her Masters of Science in Nursing final project. Results of the survey will be used to improve programs and practices for future caregivers and their loved ones.

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A few important things to know before beginning the survey:

- All information you supply is strictly anonymous and cannot be traced back to you or your loved one.
- Completing the survey is voluntary and you have the right to refuse to participate at any time. You also have the right to refuse to answer any of the questions in the survey.
- Should you choose to complete the survey, completion of this survey indicates your consent to participate.
- The survey has 10 questions and takes about 15-20 minutes to complete
- Please read instructions at the start of each section carefully.

- Please leave the completed survey in the labelled Survey Box, located on the table just across from patient room 369.
- If you have any questions or concerns about this survey or its purpose, please contact the Patient Care Coordinator (PCC) at 604-278-9711, local 4747.
- If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Appendix C

Caregiver Support during the Acute Post-Stroke Period

The first section of this survey asks about your personal information.

Please checkmark ✓ one box that best applies to you.

1. a) What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other

b) What is your age?

- ☐ Less than 30 years old
- ☐ 30 years – 39 years old
- ☐ 40 years – 49 years old
- ☐ 50 years – 59 years
- ☐ 60 years – 69 years
- ☐ 70 years – 79 years
- ☐ 80 years or older

2. What is your relationship with the stroke patient? He/she is your...

- ☐ Friend
- ☐ Husband/Wife/Partner
- ☐ Mother/Father
- ☐ Grandparent
- ☐ Son/Daughter
- ☐ Other: _____

**Note: For the remainder of this survey, "loved one" will be used to refer to your family member/friend who has suffered a stroke and is being cared for in hospital.*

The next set of questions asks about your current experience in hospital, since the day your loved one was admitted for stroke.

Please checkmark ✓ the box that best applies to you.

3. In the first weeks after your loved one had a stroke, how much time was spent by the team giving you regular medical updates about your loved one?

- ☐ A great deal
- ☐ Much
- ☐ Somewhat
- ☐ A little
- ☐ Not much

Comments:

4. In the first weeks after your loved one had a stroke, how much education did you receive from the team about stroke?

- ☐ A great deal
- ☐ Much
- ☐ Somewhat
- ☐ A little
- ☐ Not much

Comments:

5. Please provide one answer for each statement below.

How important do you think each of the following is during the first weeks after your loved one has had a stroke?

	Extremely	Very	Moderately	Slightly	Not at all
Receiving regular medical updates.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receiving education about stroke.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Planning for discharge.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation of the care being done with your loved one.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having someone on the team available to listen and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

6. How comfortable did you feel asking questions to the health care team members?

- ☐ Very comfortable
- ☐ Comfortable
- ☐ Moderately comfortable
- ☐ Uncomfortable
- ☐ Very uncomfortable

Comments:

7. How often did a team member ask you what **YOU** needed?

- ☐ Always
- ☐ Very often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

Comments:

8. How often did you feel you knew who to go to with any questions or concerns?

- ☐ Always
- ☐ Very often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

Comments:

9. How helpful would it have been to have **ONE** single team member identified as **YOUR** specific contact for any questions related to your loved one?

- ☐ Extremely helpful
- ☐ Very helpful
- ☐ Somewhat helpful
- ☐ Not very helpful
- ☐ Not at all helpful

Comments:

10. What are some ways we can better support caregivers of stroke victims?

End of survey.

Please leave the completed survey in the labelled Survey Box, located on the table just across from patient room 369.

Thank you for sharing your experiences.

*Your responses will help us to identify better ways to support
caregivers of stroke victims.*