

Post Stroke Survivors' Experiences of the First Four Weeks During the Transition Directly Home From the Hospital

Author: Teresa Connolly

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PSSs' Experiences of the First Four Weeks During the Transition Home

Boston College

William F. Connell School of Nursing

**POST STROKE SURVIVORS' EXPERIENCES OF THE FIRST FOUR WEEKS
DURING THE TRANSITION DIRECTLY HOME FROM THE HOSPITAL**

Doctoral Dissertation

by

TERESA CHARLOTTE CONNOLLY

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PSSs' Experiences of the First Four Weeks During the Transition Home

Abstract**Post Stroke Survivors' Experiences of the First Four Weeks During the Transition Directly Home From the Hospital.**

Teresa Connolly

Dissertation Chair: Ellen Mahoney RN, DNS

Purpose: The purpose of this qualitative descriptive study was to investigate the experiences of post stroke survivors (PSSs) during transition from hospital discharge home during the first four weeks.

Background: PSSs describe the transition from hospital to home as an important time in recovery and stress various physical and cognitive concerns early within the recovery period. Research to date fails to adequately reflect PSSs' experiences early after discharge home. This gap in research limits the ability to create interventions for PSSs during this critical time period.

Methods/analysis: Semi-structured telephone interviews were conducted with 31 participants, recruited from a large metropolitan hospital in the northeastern United States. The use of in-vivo codes lead to the development of themes that described PSSs' experiences during the four week transitional period. Credibility and transferability of findings were strengthened through memoing, field notes, reflexivity of analysis, member checking, and peer review throughout the analysis process by qualitative experts.

Results: The five major themes were: (a) the shock of a stroke interrupting a normal day, (b) transition to an unfamiliar home, (c) experiencing a life riddled with uncertainty, (d) a journey to a new sense of self, and (e) adjusting to a new sense of self. Throughout their journey all PSSs had to cope with uncertainty and adjust to a new sense of self. PSSs that experienced less uncertainty were able to return to their prior daily routine, knew how to

prevent another stroke, had a helpful support system, and had frequent follow-up and communication with health care professionals.

Conclusion:

All PSSs are at risk for complications regardless of stroke severity. To address PSSs complex needs, nurses can provide care beyond symptom management by fostering a dynamic intentional relationship to support recovery. The framework resulting from this study can provide the platform for advanced neuroscience nurses to engage with PSSs to improve their recovery and adjustment to a new sense of self as they transition from hospital to home.

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Chapter 1

Introduction to the Problem and Research Aims

Introduction

Each year approximately 795,000 people in the United States experience a stroke and of those nearly half experience a transition directly home from the hospital (Casper, Nwaise, Croft, & Nilasena, 2008; Go et al., 2013; Mayo et al., 2000). Post stroke survivors (PSSs) in the community complain of physical experiences such as fatigue or difficulty communicating, psychological experiences such as anxiety or stress, or cognitive experiences such as inability to focus on multiple tasks at once (Erikson, Park, & Tham, 2010; Green & King, 2009; Reed, Harrington, Duggan, & Wood, 2010; Schmid et al., 2009; van Veenendaal, Grinspun, & Adriaanse, 1996). In addition, many PSSs complain of poor health status for years after a stroke secondary to psychological experiences such as depression or anxiety (Sturm et al., 2004). However, the pattern of PSSs' transitional experiences has not been described. Complaints of PSSs are prevalent within the first few weeks of experiencing a stroke and continue for years after a stroke (Burton, 2000; Dhamoon et al., 2010) however, the unique transitional experiences of PSSs during the first four weeks after discharge home are unknown. Understanding the experiences after discharge is warranted as the issues PSSs face can be subtle and difficult to detect by both health care providers and PSSs, but lead to profound difficulties in functioning within the community once discharged home (Carlsson, Moller, & Blomstrand, 2004). This suggests that understanding and identifying PSSs' experiences within the first four weeks after discharge home from hospital could improve

long term outcomes by identifying the focus for early intervention. Specifically, evidence suggests that PSSs experience physical and psychological issues early in the stroke recovery that increase after being discharged home (Burton, 2000; Rochette, Desrosiers, Bravo, St-Cyr-Tribble, & Bourget, 2007). This evidence points to the importance of understanding both the physical and psychological experiences of PSSs early within recovery, such as being discharged home.

As research continues to describe experiences faced by PSSs, interventions and national guidelines have been implemented in an attempt to address these issues (American Heart Association, 2010; Redfern, McKevitt, & Wolfe, 2006). These guidelines have focused primarily on health care professional goals for PSSs, but do not address the actual needs of PSSs (Gallacher et al., 2013; Salter, Hellings, Foley, & Teasell, 2008). The guidelines lack attention to subtle changes that can occur during times of transition for PSSs' during the first four weeks after discharge home. For example, researchers have found that PSSs' interventions are ineffective at solving PSSs' complaints because they do not address both the physical and psychological needs of PSSs (Redfern et al., 2006). However, when both physical and psychological interventions were tested in randomized controlled trials for PSSs, the success of the intervention was more likely (Allen et al., 2009; Joubert et al., 2008). This evidence suggests that implementing both physical and psychological interventions are warranted to increase the likelihood of success for PSS interventions. Yet, without adequate knowledge of the subtle changes that PSSs' experience after discharge home,

interventions may lack the grounding in PSSs actual early transitional needs and thus not be effective, relevant, and time specific.

The frequency of follow-up visits is most intense during the first month after leaving the hospital, researchers need to explore the transitional experiences that can lead to the development of knowledge for future interventions. Past qualitative research on PSSs' experiences provide little understanding of the subtle changes that can occur during the first four weeks after discharge home from the hospital since interviews of PSSs' experiences in previous studies started at one month or later (Lawrence, 2010; Murray, Ashworth, Forster, & Young, 2003). Prior qualitative research is also unable to provide how experiencing a stroke is integrated into a PSSs' health. According to Newman (2008), what occurs at one particular point in time can have a lasting effect on someone's health course. This suggests that identifying transitional PSSs' experiences within the first four weeks can alter how nursing could aid the transitional care of PSSs. Whittemore and Grey (2002) suggest that the exploratory or descriptive phase of research is necessary to establish both the pertinent content and timing for interventions. Descriptive research, such as conducted here, provides a foundation for interventions to be targeted based on the surrounding context of PSSs' experiences (Ory, Lee Smith, Mier, & Wernicke, 2010). As suggested by Naylor et al. (2011), early intervention during transitions can improve health outcomes. This suggests that if interventions were guided by specific knowledge of the transitional period of PSSs during the first few weeks after being discharged, the lasting complaints PSSs described might be ameliorated or mitigated. The current state of the science is unable to support PSSs' interventions in the

first four weeks of transition home. Thus, research was needed to fill the gap of identifying the transitional needs of PSSs during the first four weeks after discharge home from the hospital.

Purpose

The purpose of this research was to identify the transitional experiences of PSSs during the first four weeks after discharge home directly from the hospital. Using an exploratory qualitative descriptive approach, the study interviewed PSSs who were discharged directly home from a large metropolitan hospital in New England.

Background

Epidemiology of stroke

According to the American Heart Association/Stroke Association, a stroke is a prevalent, reoccurring, concern that has been defined as “an infarction of the central nervous system” (Easton et al., 2009, p. 2282). Each year the American Heart Association, Centers for Disease Control and Prevention, the National Institute of Health, and other governmental agencies provide a statistical update about risk factors associated with stroke. According to the recent update by Go et al. (2013), stroke is the fourth leading cause of death and the leading cause of serious long-term disability in the United States. Each year about 795,000 people experience a stroke with about 185,000 being recurrent strokes. Approximately 87% of strokes are ischemic while another 13% are hemorrhagic. Post stroke care differs between these two types of strokes. For example, blood thinners are often administered during the recovery for ischemic strokes (Hickey, 2009). The number of PSSs is probably underestimated in the United States, because

many people can experience silent attacks and/or do not seek medical attention. Current research predicts there will be 3.4 million people who will experience their first stroke by 2030 and close to 10% may experience a second stroke within a year (Go et al., 2013). The 30 day risk for reoccurrence of a second stroke is 3-10% with the 5 year reoccurrence of a stroke being 25-40%. Some researchers have suggested that more than 60% of strokes are mild (M. R. Jones et al., 2000; Sturm et al., 2004) and Go et al. (2013) found that among Medicare PSSs about 45% return directly home. However, the exact number of PSSs across all ages who are discharged home is not reported, but research appears to imply that many, and perhaps a growing number of PSSs are discharged back into the community. All these statistics point to a growing population with detrimental risks due to experiencing a stroke.

Experiences after a stroke

Post stroke survivors describe a variety of physical, psychological, cognitive, and social experiences that impede their ability to function in the community. Some physical experiences are fatigue, difficulty communicating, and physical limitations such as not being able to drive (Eilertsen, Ormstad, & Kirkevold, 2013; Flinn & Stube, 2010; Northcott & Hilari, 2011). Psychological experiences are depression, fear of another stroke, or a change in relationship between family and friends (Bendz, 2003; Dhamoon et al., 2010; Jones & Morris, 2013; Reed et al., 2010; Wood, Connelly, & Maly, 2010). Cognitive experiences refer to the inability to focus on tasks such as working or listening to a conversation (Carlsson, Moller, & Blomstrand, 2009; Pallesen, 2013; Rochette et al., 2007). Stroke severity does not predict a PSS's functional abilities, nor does it reflect the

physical, psychological, cognitive or social experiences (Danzl et al., 2013; Sturm et al., 2004). As described by Carlsson, Moller, and Blomstrand (2004), mild stroke survivors experience fatigue and cognitive impairments. These experiences were often overlooked by health care professionals, but yet had a profound impact on the PSS population. Ellis, Focht, & Grubaugh (2013) and Carlsson et al.(2004) describe how hidden impairments prevented many PSSs from feeling capable of functioning every day. Yet, all of these studies have PSSs reflecting back on the PSS experience after they are weeks to years post stroke. This leads to question of what is the specific PSS transitional experiences starting after being discharged directly home from the hospital.

Despite the importance of going home as a key transition for PSSs, little information is available describing the experiences of PSSs during the first four weeks after being discharged home from the hospital. A recent meta-synthesis (Salter et al., 2008) contributes to a growing body of knowledge about PSSs' experiences, however it lacks a comprehensive understanding of PSSs' during the first four weeks after discharge. Going home for PSSs is a marker for achieving a new sense of normality, moving in the right direction, or a sign of recovery (Jones, Mandy, & Partridge, 2008). This meta-synthesis described the experience of living with a stroke by using five themes: 1) change transition and transformation; 2) loss; 3) uncertainty; 4) social isolation and; 5) adaptation and reconciliation. Change in transition describes the sudden onset of stroke and the inability to return to the pre-stroke self. Loss describes both the loss of physical functioning as well as sadness and mourning. Uncertainty describes the questions PSSs have about the future like preventing another stroke. Social isolation describes the

feeling of loss or change of relationships due to physical limitations or friends not understanding what a PSS is experiencing. Finally, adaptation and reconciliation describes the recovery progression as one that moves both forwards and backwards with periods of plateaus, but eventually leading to the acceptance of the new identity as a PSS. The meta-synthesis describes the PSS recovery process as both a physical and psychological recovery that begins immediately after a stroke. However, based on this recent meta-synthesis, studies describing PSSs experiences had an initial interview when entering the hospital, but the following interview was at least 1 month later after a stroke (Salter et al., 2008).

Conclusions to be drawn from the current state of the science are: 1) PSSs have physical, psychological, cognitive, and social experiences that hinder their ability to function in the community both in the short and longer terms; 2) PSSs' recovery processes begins the day of the stroke; 3) being discharged home is a key transition for PSSs; 4) current research on PSSs' experiences does not describe the specific experiences during the first four weeks after discharge home; and 5) PSS interventions require an understanding of the subtle experiences during the first four weeks after discharge directly home from the hospital to determine the content and timing of future interventions.

Transitions

Transitions are critical changes that can occur for an individual (Meleis, 2010). PSS's experience a variety of transitions after a stroke like the transition of being discharged home from the hospital. Naylor et al. (2011) highlighted the importance of

providing transitional care to vulnerable populations to improve patient care. Methods used to provide transitional care vary from the use of an advanced practice nurse (Brooten et al., 2002; Naylor et al., 2011), creating extended care pathways (Coleman, 2003), to the use of informational technology (Chumbler et al., 2010). Researchers have created models of transitional care that aid a variety of populations (Naylor et al., 2011). Populations that have been tested using transitional care interventions are the elderly with chronic illness (Naylor, 2000), patients with heart failure (Naylor et al., 2004), and very low birth weight infants (Brooten et al., 2002). Naylor et al. (2011) describes how transitional care interventions can improve long-term health outcomes, if interventions are customized to patients' needs. Researchers are just starting to understand the transitional needs of PSSs. For example, Roding, Lindstrom, Malm, and Ohman (2003) describe the fatigue and lack of health care professional support during the transition to rehabilitation. Green and King (2010) describe the adaption and coping throughout the first year from experiencing a stroke. Similar to Green and King, Burton (2000) interviewed subjects over a one year period to learn about the lived experience of PSSs' from the acute care hospital setting to home. In this study, Burton discovered that PSSs experience feelings of uncertainty about the future or loss of control due to the lack of support and proper care during transitions. All this research provides vital insight into understanding the variety of PSSs' transitional experiences. There is a gap regarding what the transitional experiences of PSSs are during the first 4 weeks after discharge home.

Post stroke survivor interventions

In an attempt to address the magnitude of PSS complications, the American Stroke Association created *Get with the Guidelines*, which is a tool that hospitals can use to enhance stroke patient outcomes for discharge home (American Heart Association, 2010). Despite the institution of these guidelines, the stroke population continues to describe symptoms that impede their ability to function within the community (Dhamoon et al., 2010; Eilertsen et al., 2013; Gallacher et al., 2013). Many interventions continue to focus on physical disabilities after stroke (Redfern et al., 2006), however physical disabilities are not always the concern for post stroke patients. The literature demonstrates that many post stroke patients are more concerned about experiencing another stroke (van Veenendaal et al., 1996; Yilmaz, Gumus, & Yilmaz, 2013), fatigue, and/or stress (Green & King, 2009; Pallesen, 2013). The current literature suggests that there are two likely explanations for minimal success produced by current stroke interventions. As suggested by O'Connell et al. (2001), recovery from a stroke involves both physical and psychological issues and sometimes the psychological complaints are more prevalent and debilitating than the physical complaints. In order to develop transitional interventions researchers need to understand the unique experiences of PSSs during the first four weeks allows for researchers to tailor content of interventions that is appropriate for PSSs.

Summary

In conclusion, the population of PSSs in the United States continues to grow and both physical and psychological experiences of PSSs alter their ability to function in the

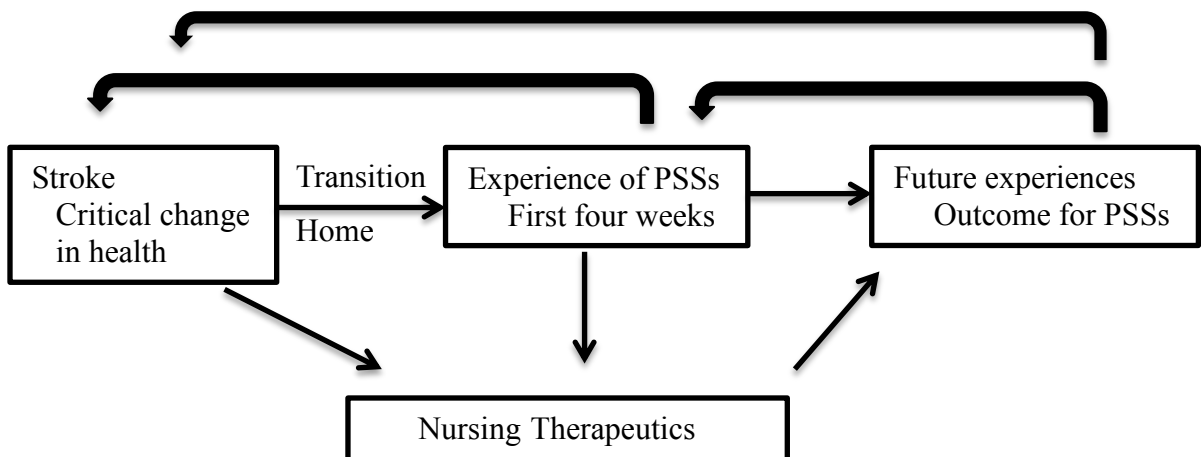
community. Since current interventions fail to address the unique experiences of PSSs during the first four weeks after discharge home, further research was needed to guide future transitional care of PSS interventions. As evidenced by other populations, understanding transitional experiences can improve long-term outcomes (Naylor et al., 2009).

Significance to nursing

As suggested by Meleis (2010) and Naylor et al. (2011), nurses have a unique position to optimize care to vulnerable populations. Chapter 1 has argued that PSSs are a vulnerable population, especially during transitions. Nurses have direct contact with PSSs before being discharged home from the hospital. However, upon discharge home PSSs may not have contact with any health care professional for weeks. As proposed by the Institute of Medicine (IOM) report on the *Future of Nursing* (2011) nurses are key leaders that can redesign care, for a variety of populations such as PSSs, but to achieve this goal nurses need to identify problems and areas for improvement. Nurses can then lead policy changes that can alter the care provided to PSSs. Since PSSs experience lasting complaints and little is known about what occurs during the first four weeks after discharge home from the hospital, nurses cannot develop interventions that adequately address experiences during this time. As suggested by Whittemore and Grey (2002), the foundation of a nursing clinical trial requires establishing the timing and content of an intervention. Furthermore, as proposed in 2011 by the National Institute of Nursing Research (NINR) nurses need to promote and improve the health of populations throughout a life span. Promoting health requires understanding the impact of

psychological, physiological, genomic environment, social, and cultural aspects of health. NINR proposed that nurses need to understand health as related to each person's unique experiences. A similar message is described by the American Nurses Association (2010) where the values and goals of the nursing profession are nurses need to be "concerned with the human experience and responses across the life span" (p.13). Specifically, nurses need to address issues within safety and quality of care, care coordination, and physiological and psychological processes throughout the life span. Currently, nurses need to further investigate PSSs' experiences during the first four weeks after discharge home to achieve the aims proposed by NINR, IOM, and American Nurses Association. Through improved understanding of PSSs experiences, nurse researchers can develop and test transitional interventions that may influence how nursing delivers care throughout the lifespan of PSSs. Figure 1 depicts the theoretical conceptualization of understanding the transitional experiences from hospital to home for PSSs unique to the nursing profession.

Figure 1: Theoretical conceptualization of transitional experiences for PSSs



As proposed by Naylor et al. (2011) nursing needs to encourage policy changes that incentivize transitional interventions. As suggested by the IOM, nurses are key leaders that can lead change (IOM, 2011). Through policy changes, nurses are able to effectively deliver the care needed to PSSs. To conclude, the nursing profession needs to be concerned with understanding the transitional experiences of PSSs that encompass PSSs needs to promote the health of PSSs throughout a lifespan. By understanding PSSs' experiences nurses can then alter both policy and practice of nursing care provided to PSSs.

Aims

The overall aim of this qualitative descriptive study was to investigate the experiences of PSSs during the transitional period from hospital discharge home during the first four weeks in order to identify the experiences and timing of issues. The understanding gleaned can be used to guide the development and testing of PSS early interventions, addressing a major gap in knowledge for practice.

Specific aims were:

1. Identify the needs, concerns, frustrations, and experiences of PSSs from the first 24 hours up to four weeks after discharge home from the hospital from the patient perspective.
2. Describe the experiences of four different cohorts of PSSs at 1, 2, 3, and 4 weeks after discharge home from the hospital.

3. Compare and contrast the similarities and differences in experiences between cohorts to identify both the unique and consistent themes along this 4-week transitional period.

Chapter 2

Review of the literature on post stroke survivors

Introduction

Chapter 2 is a review of the literature about the PSS recovery process, provides a current review of PSSs' experiences, and a review on post stroke interventions. The chapter will begin with a description of definitions followed by three reviews of literature. Each review of literature will describe the state of the science as well as highlight gaps in current knowledge about PSSs' experiences and post stroke interventions. The first review of literature provides an overview of understanding the PSS recovery process and supports the importance of understanding the physical and psychological aspects within PSS recovery and the transition home after experiencing a stroke. An argument will follow that little is known about PSSs' experiences during the first four weeks after discharge home from the hospital.

The second review of literature is on PSSs' experiences from 2008-2013. This review will highlight the physical, psychological and cognitive, health care professional and family experiences as well as the recovery process of PSSs. The review will also show how combining many of the previous listed experiences creates a unique PSS experience for each person. This review concludes that current literature does not describe the specific experiences of PSSs within the first four weeks after being discharged home from the hospital. Therefore, research is needed to adequately provide the foundation for future PSS interventions to addresses the physical and psychological needs of PSSs during the first four weeks after discharge home from the hospital.

The final review of literature is on post stroke interventions. This review will build from the previous two reviews to describe the inability for current interventions to link the patient problem to an outcome. Furthermore, the review will describe how post stroke interventions have the highest frequency of intervention implementation during the first month after discharge and both physical and psychological components are necessary for the success of PSS interventions. However, due to insufficient knowledge of PSSs' experiences during the first four weeks after discharge home from the hospital, post stroke interventions are unable to adequately address both the content and timing for future post stroke interventions.

The final section of Chapter 2 will be concluded with a section on limitations of the reviews, a description of transitions and transitional care, and final conclusions based on the literature review. Chapter 2 will conclude that there is inadequate information to address the content and timing of future post stroke interventions since little is known about PSSs' experiences during the first four weeks after discharge home from the hospital.

Definitions

According to the American Heart Association/Stroke Association, a stroke is “an infarction of the central nervous system” (Easton et al., 2009, p. 2282). This can be determined by either a computed tomography (CT) or magnetic resonance imaging (MRI) scan. This is a recent change in guidelines, which highlights that if a person no longer experiences physical or psychological symptoms they may still have a stroke if an infarction is visible on CT or MRI.

Transitions are critical changes people experience throughout life (Meleis, 2010). This study will be specifically looking at transitions from hospital to home.

Post stroke recovery process

Purpose, Aims, and Method

The aim of this literature review is to understand PSS recovery process after being discharged home from the hospital and to determine the current state of the science on post stroke recovery. Seminal studies of understanding PSSs' experiences date back more than twenty years (McKevitt, Redfern, Mold, & Wolfe, 2004). Prior to conducting a specific review of literature on PSSs' experiences it is prudent to understand the current knowledge about PSSs' recovery process. Inclusion criteria for the review were: (1) describes the post stroke experience from hospital to home, (2) qualitative research of any method, (3) a review article that analyzed at least two articles, (4) written in English, (5) published articles, and (6) written within the past ten years. Studies were excluded if: (1) the article only discussed the recovery process during the hospital course or rehabilitation course, (2) basic review of literature, (3) only focused on PSSs with hemorrhagic stroke (4) the article does not describe the PSS experience. Databases searched were Pubmed, PyschINFO, EMBASE, and Google scholar. Key terms used were stroke, cerebrovascular accident, qualitative research, review, or systematic review. Articles that were written within the past ten years were analyzed since stroke care has evolved extensively over the years, with new guidelines of care that could alter the PSS experience (American Heart Association, 2010). However, this restriction was not placed

on the articles within each review to allow for seminal PSS experience articles to be present within a review.

The findings presented for this review were determined by synthesizing the results of each review article. Each article was read for a general understanding then categories were created based on the findings within each article. Categories are a unit of information like an event, instance, or a happening (Creswell, 2007). Categories could also be phrases that go together (Denzin & Lincoln, 2005). Two categories emerged about the recovery process for PSSs, which were physical and psychological experiences and transitions.

Findings

A total of 1095 abstracts were retrieved. Each abstract was reviewed based on the inclusion and exclusion criteria. Articles were eliminated if they did not analyze two or more articles or if they were duplicates. The initial large number of abstracts retrieved is possible to databases searching for the word "review," but since a thorough search of the research was warranted limiting the search to only systematic review may have eliminated some articles. After reviewing each abstract, fourteen articles were retrieved for further analysis. Only eleven articles were included in the review, because the other three reviews did not meet inclusion criteria. The reviews were written from 2004-2013. Reviews retrieved literature from as far back as allowed by databases (Daniel, Wolfe, Busch, & McKevitt, 2009; Gallacher et al., 2013; Lamb, Buchanan, Godfrey, Harrison, & Oakley, 2008; Lawrence, 2010; McKevitt et al., 2004; Murray et al., 2003; Sarre et al., 2013) where other reviews were restricted to a specific time frame (Eilertsen et al., 2013;

Reed, Wood, Harrington, & Paterson, 2012; Salter et al., 2008; Satink et al., 2013).

Many of the reviews referenced and reviewed similar articles, however most articles were discussed in one review. However, since the aim of the review was to understand the recovery process post stroke, duplication of articles reviewed by different researchers would not alter the a description of the recovery process for post stroke survivors, so reviews were not eliminated if there was a duplication of articles discussed. Sample size within each review varied from 4-95 participants. In general, the reviewers searched a varied combination of Medline, Pubmed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), psychINFO, web of science, EMBASE, or other databases. Methods to conduct each review were also varied between studies. Some methods used instruments like the Joanna Briggs Institute Qualitative Assessment and Review Instrument or National critical skills program collaboration for qualitative methodologies while others used less formal analysis to report findings. Inclusion and exclusion criteria varied throughout each review based on the purpose, with the only group not represented in this review being people who experience stroke at less than 18 year of age. To conclude, this review of PSSs' experiences yielded a diverse and comprehensive review of PSSs' experiences.

Physical and psychological recovery of PSSs. All the authors concluded that recovering from stroke involves more than just physical recovery. Recovery also includes psychological, cognitive, social, and emotional recovery. For example, Lawrence (2010) describes how stroke causes physical, cognitive, and affective issues for PSSs. The importance of the recovery process involving more than just physical

recovery was evident when articles described how stroke recovery needs to be individualized and this would require health care professionals to listen to PSSs beyond just the physical issues (Eilertsen et al., 2013; Gallacher et al., 2013; Lamb et al., 2008; McKeivitt et al., 2004; Reed et al., 2012; Salter et al., 2008; Sarre et al., 2013; Satink et al., 2013). Furthermore, Murray, Ashworth, Forster, and Young (2003) specifically describe how recovery from stroke needs to go beyond traditional physical recovery. The importance of understanding PSSs' needs as more than just physical was also evident for Daniel, Wolfe, Busch, and McKeivitt (2009) who described returning to work as proxy for recovery.

The ability to achieve a positive post stroke recovery is related to the unique experiences of each PSS based on the interaction of physical, psychological, social, and cognitive experiences. However, researchers described how currently health care professionals are not meeting these unique recovery needs for PSSs (Daniel et al., 2009; Eilertsen et al., 2013; Gallacher et al., 2013; Lamb et al., 2008; Murray et al., 2003; Salter et al., 2008; Satink et al., 2013). Meeting the unique needs of PSSs can be difficult due to the interaction between each PSSs' experiences. For example, the intertwining of physical, psychological, social, and cognitive experiences of PSS recovery was described by Salter et al. (2008) who found the five major themes were not separate or distinct. Other reviews combined the social and emotional experiences of PSSs together stating people had depression and fatigue, which led to the inability to attend social functions (Murray et al., 2003). Another review described how PSS recovery process requires reconstructing life both physically and psychologically (Lamb et al., 2008). Satink et al.

(2013) described how health care providers only focus on biomedical recovery, but PSSs want their psychosocial needs met.

Transitions for post stroke survivors. The second category was transitions, which found that transitions are important aspects of the recovery process and returning home is a specific transition of importance for PSSs. Murray et al. (2003) concluded that transitions for PSSs were perceived as negative. Lawrence (2010) described three types of difficult transitions for PSSs, which were the transition to a rehabilitation unit from the hospital, discharged home from a unit, and returning to work. Specifically, returning home is extremely anticipated and for many PSSs signaled a return to normalcy. However, PSSs find that the transition home is poorly managed with difficulties with coordinating care (Gallacher et al., 2013). McKevitt, Redfern, Mold, and Wolf (2004) describe how early discharge home can lead to a more relevant recovery for PSSs, where PSSs are faced with challenges not seen within the structured health care settings. For example, the ability to make dinner and have a conversation with family is different once in the home setting.

Since returning home is described by PSSs as an important transition, each review was further analyzed for the timing of the interview when applicable. The analysis found that interviews can start during the hospitalization, but the majority of interviews start after one month post stroke. Of the eleven review articles, only seven listed the timing of each interview. Of the articles that did report the timing of the interviews, only three reported a study that performed interviews of PSSs at one and two weeks after discharge home (Eilertsen et al., 2013; Reed et al., 2012; Satink et al., 2013). The article that Reed

et al. (2012) referenced was a hermeneutic study that looked at the trajectory of the recovery process for PSSs over the first year and emphasized that the recovery process can be a gradual recovery overtime. This was a similar finding to the referenced article in Satink et al. (2013) which found stroke recovery is gradual and prolonged. The article that Eilertsen et al. (2013) referenced only focused on PSSs with a right hemisphere stroke. Another review had interviews starting at three months post stroke (Lawrence, 2010). Reed, Wood, Harrington, and Paterson (2012), Salter et al. (2008), Sarre et al. (2013), and Satink et al. (2013) had a few articles that interviewed PSSs at the hospital, but follow-up interviews were not until two months after stroke. In another review the earliest PSSs were interviewed was one month post stroke (Murray et al., 2003).

Summary of post stroke survivor recovery

Overall, this literature review provides the importance of physical and psychological aspects within PSS's recovery and the importance of the transitioning home after a stroke. This review also highlights multiple gaps in understanding the PSS recovery process during the first four weeks after discharge home. This review first concludes that PSS recovery can be categorized through physical, psychological, emotional, or cognitive experiences. Salter et al. (2008) describe how PSS recovery is determined by individual goals of recovery and health care professionals need to understand the diversity of the recovery process for PSSs. Murray et al. (2003) also describe the largest complaint of PSS recovery are the hidden dysfunctions. These findings implicate the need to understand the subtle differences in PSS recovery. Since the unique experience of each PSS is created through a combination of physical,

psychological, cognitive, and social aspects of recovery, further information is needed so health care professionals can understand the unique experiences of PSSs.

PSSs can experience a variety of transitions, with the transition home being a key part of the recovery process, yet interviews to understand this transitional process take place months after the transition. Due to the timing of interviews, little is known about the unique physical, psychological, cognitive and social experiences of PSSs within the first four weeks after transitioning home for a PSS's recovery process. Meleis (2010) would support the importance of understanding transitions for PSSs, since transitions can be critical changes for the recovery process for an individual. Newman (2008) would also suggest that what occurs at one particular point in time can have a lasting effect on someone's health course. Suggesting that for PSSs cannot return back to normal, but a new sense of normal is created based a PSSs' experiences. Lawrence (2010) describes the importance of returning home as key to PSS recovery this transition can be difficult for PSSs. Despite Reed, Wood, Harrington, and Paterson (2012) reporting one article that performed interviews at one, two, and four weeks post discharge, the study analyzed the trajectory of recovery for PSSs who went to a rehabilitation unit and then were discharged home, which is a different transitional pathway then described for this study. The PSS recovery process has unique and subtle changes, but after the transition home little is known about PSSs experiences until one month or later after experiencing a stroke.

Post stroke survivors' experiences: A review from 2008-2013

Purpose, Aims, and Method

The purpose of a current review of PSSs' experiences was to provide specific examples of experiences and determine at what time post stroke, PSS's were interviewed. A current review of PSSs' experiences was conducted from 2008-2013. The purpose of this review was to understand the unique experiences of PSSs and determine if current research described the PSSs' recovery process from the transition from hospital to home. Inclusion criteria for the review were: (1) discharged home after hospital, (2) qualitative study, (3) written in English, and (4) written between 2008-2013. Exclusion criteria was: (1) studies that focused on caregivers or family, (2) studies that focused on third world countries since these experiences would vary drastically from countries that have access to health care. Databases searched were Pubmed, infoPSYCH, EMBASE, and Google Scholar. Key terms used were stroke, cerebrovascular accident, and qualitative.

This search yielded a total of 578 articles to review. All the abstracts were reviewed based on the inclusion and exclusion criteria. Articles were eliminated if they provided a description of an intervention experience, were not qualitative research, were duplicate articles, or did not pertain to ischemic stroke patients. After this initial review 34 articles were retrieved for further analysis to determine if the articles were appropriate for analysis. Of these 34 articles four of the articles did not meet the inclusion criteria due to not describing the PSS experience. For this review 30 articles were included in the analysis. Please refer to Table 1 for a description of each article's purpose, year, sample size, and qualitative method. Sample size ranged was from 6-33 with cumulative total of

448 participants for the review. A variety of methods were used such as focus groups, in-depth interview with a thematic approach to analysis, phenomenology, and grounded theory. Some of the articles did not specify a specific qualitative method used beyond the type of interview. Due to the variety of methods and overall number of participants included in this review, this review appeared to have sufficient data to reach conclusions about PSSs' experiences from hospital to home.

Findings

The purpose of each article varied with some articles focusing on a specific experience like fatigue or depression while other articles focused on the experiences of stroke recovery for PSSs. Each article was analyzed and key phrases and terms were placed into one of six categories. Categories were created by analyzing the findings and clumping related units of information like events, instances, or phrases (Creswell, 2007; Denzin & Lincoln, 2005). The researcher then determined a word for the category that encompassed all the examples provided by the unit of information presented in each article. Some categories had sub categories. Sub categories were smaller reoccurring themes, seen within an existing category. The results of the analysis will be presented by the six categories with examples highlighted from the different research studies. The six categories were physical experiences, psychological/cognitive experiences, health care professional experiences, family experiences, recovery process experience, and a combination of experiences. After describing the PSS experience, there is an analysis of the frequency of interviews followed by the limitations of the study and overall summary of the findings.

Physical experiences. The majority of physical complaints for PSSs were fatigue, communication, and difficulty with traveling and many of these experiences are focused on within the first few months after experiencing a stroke. Physical experiences are related to bodily responses or activities for PSSs. Twenty-two of the 30 articles specifically described physical experiences of PSSs. Another five articles described a combination of physical experiences in relation to psychological experiences, which will be discussed in a later category. This left only three articles that did not describe any physical experience for PSSs (Jones & Morris, 2013; Schmitz & Finkelstein, 2010; White, Magin, & Pollack, 2009). Physical experiences were broken into three sub categories, which were fatigue, communication, and traveling. The most pronounced physical experience was fatigue. White, Gray et al. (2012) described how PSSs experience fatigue from the start of the stroke and continue for months after a stroke. Unique to fatigue was the ripple affect into other areas of recovery like the ability to concentrate, understand the bodily cues of another illness, work, or socialize (Anderson & Whitfield, 2013; Brunborg & Ytrehus, 2013; Flinn & Stube, 2010; Kirkevold, Christensen, Andersen, Johansen, & Harder, 2012; Klinke, Hafsteinsdóttir, Thorsteinsson, & Jónsdóttir, 2014; Pallesen, 2013; White, Gray, et al., 2012; Yilmaz et al., 2013; Young, Mills, Gibbons, & Thornton, 2013). The next sub category was communication. PSSs also experienced difficulties with aphasia or the ability to communicate (Dickson, Barbour, Brady, Clark, & Paton, 2008; Ellis et al., 2013; Erikson et al., 2010; Kouwenhoven, Kirkevold, Engedal, & Kim, 2012; Morris, Ferguson, & Worrall, 2013; Northcott & Hilari, 2011). Communication was placed within the

physical experiences because aphasia prevented a physical activity from occurring like talking or listening to others. Other physical experiences were physical limitations in writing or traveling, which could include being able to drive or go out to eat (Danzl et al., 2013; Northcott & Hilari, 2011; White, Miller, et al., 2012). Yilmaz, Gumus, and Yilmaz (2013) described the unique sexual difficulties women encountered after a stroke such as difficulty with sexual arousal. Furthermore, Eilertsen, Kirkevold, & Bjork (2010) found that PSSs specifically focused on physical changes during the first two months after experiencing a stroke.

Psychological and cognitive experiences. Psychological and cognitive experiences were broken into four subcategories relationships, uncertainty, self-image, and focus. Psychological experiences are related to an emotional state where as cognitive experiences are related to mental processes required obtaining information. Psychological and cognitive experiences were grouped together since emotion influences cognition and in many cases emotion and cognition are interrelated, so separating the two is impossible (Dolan, 2002; Pessoa, 2008). Only two articles did not specifically address psychological issues (Kirkevold et al., 2012; White et al., 2009). However, that is because both of these articles described the combination of both physical and psychological experiences of PSSs. The four sub categories (relationships, uncertainty, self-image, and focus) were created because these themes were reoccurring throughout the articles.

Relationships. Relationships are a key part of PSSs' experiences and when a PSS has a relationship with anyone it can lead to a positive psychological response.

Relationships were the most prevalent sub category in cognitive and psychological experiences for PSSs. Relationships encompassed any connection a PSS had with another person. This connection could be with a work colleague, health care professional, family member, or friend. PSSs describe changes in relationships with any or all of these people after a stroke (Anderson & Whitfield, 2013; Brunborg & Ytrehus, 2013; Danzl et al., 2013; Dickson et al., 2008; Klinke et al., 2014; Northcott & Hilari, 2011; Pallesen, 2013; Schmitz & Finkelstein, 2010; Williams & Murray, 2013; Young et al., 2013). Yilmaz et al. (2013) described how PSSs relationship with God changed as well. A change in relationship can lead to feelings of isolation, loss, dissatisfaction, belonging, and/or support (Anderson & Whitfield, 2013; Danzl et al., 2013; Eilertsen et al., 2010; Gilworth, Phil, Cert, Sansam, & Kent, 2009; Klinke et al., 2014; Kouwenhoven et al., 2012; Northcott & Hilari, 2011). For example, isolation and loss were described when there was a loss of a relationship where as belonging and support were described when there was a positive relationship. Erikson et al. (2010) describe the positive aspects of relationships as an inspiration and sense of belonging when engaging in relationships at work, home and friends. Anderson and Whitfield (2013) described how PSSs want to be treated as a person, not as a disabled person. Dickson et al. (2008) describe the positive response of PSSs when working with the speech therapist, because the relationship was beyond just therapy because the speech therapist would support a PSS throughout recovery.

Uncertainty. The next subcategory for psychological and cognitive experiences was uncertainty, which can be experienced any time through post stroke recovery,

especially through transitions. This subcategory revolves around the emotion of fear, questioning what is happening, vulnerability, or confusion. Uncertainty for some PSSs was related to discovering why they had a stroke (Yeung, Wong, & Mok, 2011). Fear for PSSs is prevalent early within the post stroke experience (Green & King, 2009; Salisbury, Wilkie, Bulley, & Shiels, 2010), however fear can also be prevalent throughout the recovery process (Jones et al., 2008; Klinke et al., 2014; Morris et al., 2013; Pallesen, 2013) and during transitions (Salisbury et al., 2010). Specifically, Williams and Murray (2013) described how PSSs thought the transition home was difficult and one PSS described this transition as “murder” (p. 43). As described by Green and King (2009), feelings of vulnerability or uncertainty can lead to problems with anxiety and depression.

Self-image. The next subcategory was perception of the self-image as either a positive emotion or negative emotion. Perceptions of self are due both to internal feelings and external perceptions. Self-image refers to when PSSs would talk about the post stroke experience by describing a characteristic of themselves. For example, Carlsson, Moller, and Blomstrand (2009) found PSSs experience both feelings of worthlessness and the need to succeed. Worthlessness was a negative self-image whereas the need to succeed was a positive self-image. The need to succeed was based on a PSS's capability to cope with and adapt to challenges (Brunborg & Ytrehus, 2013). Other examples of positive perceptions of self-image were hope, optimism, and embracement through the recovery process (Brunborg & Ytrehus, 2013; Danzl et al., 2013; Jones et al., 2008; White, Miller, et al., 2012). Examples of other negative perceptions of self-image

were embarrassment of a disability (Dickson et al., 2008; Jones & Morris, 2013; Klinke et al., 2014), feeling guilty since they needed more help from loved ones (Yeung et al., 2011), and loss of self-identity (Kouwenhoven et al., 2012; Pallesen, 2013; Yilmaz et al., 2013). Loss of self-identity was perceived as negative since PSSs described how they required help from caregivers for daily needs; the negative label was placed on them because they could not control their emotions, or the loss of pre stroke abilities (Jones et al., 2008; Kouwenhoven et al., 2012). The internal self-image was feelings about the recovery process that PSS's believe, like the ability to succeed in coping with a challenge (Carlsson et al., 2009). External feelings of self-image were created due to forces outside of a PSS's control that lead to altered self-image. For example, PSSs felt dissatisfaction because they felt a lack of help or support from health care professionals (Dickson et al., 2008). Pallesen (2013) described PSSs coping with changes in identity by either resigning to the situation or controlling the situation by trying to form a more positive self-image.

Focus. The ability to focus is a subtle and difficult to detect process for PSS recovery and is often discussed in conjunction with other PSSs' experiences such as relationships and fatigue. The final sub category of psychological and cognitive experiences is focus, which is the ability to attend to a task. After a stroke, PSSs described increased difficulty with the ability to focus on a conversation with multiple voices (Brunborg & Ytrehus, 2013; Carlsson et al., 2009; Ellis et al., 2013) or memory issues (Gilworth et al., 2009; Pallesen, 2013). As described by Carlsson et al. (2009) "despite appearing to recover from a stroke they still had to cope with persistent cognitive

and emotional dysfunctions” (p.776), which were often subtle differences. Lack of focus lead to issues like the inability to function at work or converse with friends and family. PSSs also described how increased fatigue would cause increased difficulty with focusing (White, Gray, et al., 2012), which would lead to further fatigue (Flinn & Stube, 2010).

Health care professional experiences. The next category of experiences for PSSs was health care professional experiences and the results were that PSSs required further information than provided by health care professionals, specifically when being discharged home. Health care professionals could be physicians, nurses, or therapists. Overall, people felt a lack of information and support was given throughout the recovery process by health care professionals. Seventeen out of the 30 articles described experiences of lack of information regarding the recovery process for PSSs. During the hospitalization people felt a lack of communication about potential experience such as fatigue (Flinn & Stube, 2010). During rehabilitation people felt a lack of support due to the disconnect between patient goals and therapists goals (Flinn & Stube, 2010; Jones et al., 2008; Salisbury et al., 2010; Schmitz & Finkelstein, 2010). Anderson and Whitfield (2013) found that PSSs felt that health care professionals prioritized goals based on physical issues, which may not reflect PSSs true goal. Once PSSs were home further information was desired, but none was received (Danzl et al., 2013; Williams & Murray, 2013; Yeung et al., 2011; Yilmaz et al., 2013). At discharge, PSSs were unclear about the next steps in their recovery and follow-up by health care professionals (Morris et al., 2013). Specifically White, Magin, and Pollack (2009) describe lack of communication with health care professionals during the transition home was a time that led to an

increased lack of knowledge. Lack of support early in PSS recovery lead to years of frustration (Brunborg & Ytrehus, 2013). Once home, PSSs had further questions like how to overcome barriers with transportation or driving (Northcott & Hilari, 2011; White, Miller, et al., 2012).

Family experiences. The next category of experiences for PSSs is family experiences. The review concluded that part of PSSs' experiences is based on the PSSs' perception of the families' experience. This is a separate category from relationships because this was when PSSs were describing the needs of family members, not the relationship they had with family members. Though needs and experiences of PSS caregivers were not specifically described in this review, PSSs acknowledged that family members needed support as well. Four articles have PSSs describing needs for their family. The articles described how PSSs stated that their families went through changes too (Erikson et al., 2010) and there is a need for working with family to understand a stroke (Carlsson et al., 2009). PSSs felt their family members did not understand their situation and how a stroke affected their life. For example, some PSSs thought their husbands wanted more sexual relations, but the PSS lacked the desire for sexual relations (Yilmaz et al., 2013). Other PSSs felt depressed, but did not seek help because they thought their husbands would not want them to be labeled (Danzl et al., 2013).

Recovery process. The next category of experiences for PSSs is the recovery process. Recovery is not a linear process and each stage can present new challenges that PSSs have to face, but going home appears as a key milestone in the recovery process. The recovery process is described as the progression to get back to normal. For some

PSSs achieving a new sense of normal requires getting speech back (Dickson et al., 2008; Williams & Murray, 2013) or gaining control of recovery and going back home (Anderson & Whitfield, 2013; Brunborg & Ytrehus, 2013; Jones et al., 2008; Pallesen, 2013). Part of the recovery experience was adjusting expectations, because the recovery process fluctuated between moving forward and backward (Wood et al., 2010). Carlsson et al. (2009) found that PSSs felt the need to accept the stroke to effectively cope with the experience. Both accepting and working with a fluctuating recovery was further emphasized by White and Miller et al. (2012) who describe how lifestyle change was core to promoting satisfaction, but there were ongoing challenges that PSSs faced. Green and King (2009) described how PSSs needed to come to terms with the recovery process and overtime learn to adapt to having a stroke. Part of the recovery process is going home, which signifies a move in the right direction (Jones et al., 2008).

Combination of experiences. A combination of PSS experiences provides the unique and individualized configuration of experiences that PSSs describe. A combination of PSS's experience can be an interaction of physical, psychological and cognitive, recovery, family, and health care professional experiences. Unique to this category is that findings are a description of the connection between experiences.

Twenty of the 30 articles described a combination of experiences. All combinations of experiences were created from the categories already discussed. Some of the combinations described how one experience led to another. For example, White et al. (2009) described how lack of confidence lead to further withdrawal in activities. This would be an example of how uncertainty can lead to issues with relationships. Another

example would be how fatigue affected both the mental and physical abilities (Kirkevold et al., 2012; Young et al., 2013). This is an example of how fatigue could affect other physical abilities like walking but fatigue can also affect mental abilities like focusing. Not all the experiences were caused by one specific experience. For example, Green and King (2009) describe how PSSs felt both physically and emotionally vulnerable. In this instance the feeling of uncertainty was created by the combination of both the physical and psychological experience. The complexity of combinations was evident by how functional changes led to frustration, less confidence, and isolation (Anderson & Whitfield, 2013; Schmitz & Finkelstein, 2010; Williams & Murray, 2013; Yilmaz et al., 2013; Young et al., 2013). Combinations of experiences were also composed of more than just physical and psychological experiences. For example, Carlsson et al. (2009) and Danzl et al. (2013) describe how the care provided at discharge by health care professionals affected the ability to cope for PSSs.

Frequency of interviews. The majority of interviews took place weeks to months post stroke. The time post stroke of interviews can be found on Table 2. Three studies did not define the interview times (Anderson & Whitfield, 2013; Morris et al., 2013; Yilmaz et al., 2013). Out of 30 studies, three performed interviews at pre-discharge (White, Gray, et al., 2012; White, Miller, et al., 2012; Wood et al., 2010). Another three studies did interviews between discharge home to before 1 month (Eilertsen et al., 2010; Wood et al., 2010; Yeung et al., 2011). These studies do provide insight into PSSs recovery; however these prior three studies focused on a different sample population than the proposed research study. Eilertsen et al. (2010) and Yeung et

al. (2011) interviewed only women recovering from a stroke while Wood et al. (2010) interviewed PSSs post rehabilitation stay who were returning home. Another four studies did interviews at one month (Eilertsen et al., 2010; Erikson et al., 2010; Green & King, 2009; Kouwenhoven et al., 2012; White et al., 2008). However, 19 out of 30 articles interviewed PSSs greater than 1 month post stroke (Brunborg & Ytrehus, 2013; Carlsson et al., 2009; Danzl et al., 2013; Dickson et al., 2008; Ellis et al., 2013; Flinn & Stube, 2010; Gilworth et al., 2009; Jones et al., 2008; Jones & Morris, 2013; Kirkeveld et al., 2012; Klinke et al., 2014; Morris et al., 2013; Northcott & Hilari, 2011; Pallesen, 2013; Salisbury et al., 2010; Schmitz & Finkelstein, 2010; White et al., 2008; White et al., 2009; Williams & Murray, 2013; Young et al., 2013).

Summary of post stroke survivors' experiences

This review highlights the physical, psychological and cognitive, health care professional, family, and the recovery process of experiences for PSSs, however gaps remain within the literature on understanding PSSs' experiences. First, the review describes the physical experiences after having a stroke and highlights that physical complaints are evident within the first few months and suggests that physical experiences such as fatigue can have a ripple effect into other experiences. PSSs describe a variety of experiences for years post stroke. However, PSSs also experience psychological and cognitive, health professional, and family experiences throughout the recovery process. These findings are supported by other researchers who also found that recovery after a stroke is more than just physical recovery (Eilertsen et al., 2013; Gallacher et al., 2013; Lamb et al., 2008; McKeivitt et al., 2004; Reed et al., 2012; Salter et al., 2008; Sarre et al.,

2013; Satink et al., 2013). Yet, the current literature is unable to provide an understanding the complexity of experiences for PSSs during the first four weeks after discharge home.

PSSs experiences are based on the contextual surroundings of recovery. For example, relationships appear as a frequent reoccurring theme of PSS recovery, yet the formation of a relationship is dependent on each specific PSS. Self-image is also described as important in the recovery process but self-image is determined both on individual views of the self and how the PSS perceives their image by others. These findings imply that the PSS recovery process is a reflection of how a person interacts with the surrounding world on a daily basis. The process of creating a positive relationship or a positive self-image is determined by the contextual surroundings of a PSS, whether it is the resources available or internal motivation. Furthermore, the combination of PSSs' experiences can lead to a unique experience for each PSS.

Despite uncertainty appearing at the onset of a stroke and increasing during transitions home, few of the studies interview PSSs frequently during the transition home after experiencing a stroke. As supported by Meleis (2010), transitions home are a vulnerable period for people, and this review supports that the transition home for PSSs is a vulnerable period for PSSs. Furthermore, since the recovery process after being discharged home for PSSs can fluctuate, the subtle changes in recovery can be difficult to detect. As supported by the Institute of Medicine report (2011) nurses are key leaders that can lead change to promote health throughout the lifespan, such as the first four weeks after discharge home for PSSs. The review highlights how only three studies

interviewed PSSs between discharge home and 1 month post stroke. This review found that the recovery process has periods of fluctuations and new challenges as well as subtle and difficult to detect changes. This suggests that small subtle fluctuations faced by PSSs during the transition home are minimally researched. Furthermore, due to a minimal understanding of the PSSs during the first four weeks of discharge home little is known about PSSs' experiences and the contextual surroundings of experiences.

Currently, PSS's describe a disconnect between PSSs' goals and the goals of health care professionals. Due to the lack of understanding of what occurs during the PSS recovery process from discharge home from the hospital, researchers are unable to adequately address the issues, needs, and concerns for PSSs. Hence further research is needed to understand the experiences of PSSs during the first four weeks after discharge directly home from the hospital to adequately provide a description and contextual surroundings of each experience.

Review of post stroke interventions

Purpose

The purpose of the review of post stroke interventions is to evaluate current post stroke interventions by analyzing the purpose, type of intervention, frequency of intervention, and results of randomized controlled trials (RCTs) for PSSs. This analysis will then determine whether or not current interventions address PSSs' needs and identify current gaps. First, the review will separate the purpose of the study into three categories: physical, psychological, and administrative outcomes. Then the interventions were categorized as either a physical intervention or a psychological intervention. Next,

the review will offer an evaluation of the timing of each intervention's implementation. Finally, the review will offer an analysis of the findings and describe possible reasons for either the success or shortcomings of an intervention.

Methods

For this review, four online databases were searched: Pubmed, EMBASE, CINAHL, and PsychINFO. Searches were restricted, as permitted by each database to: articles between the years 2006-2013, research articles, written in English, 18 years of age or older, human studies, and excluding drug trials. Key terms used to describe stroke were: stroke, hypoxia, brain ischemia, cerebrovascular accidents, and ischemic. Key terms to describe interventions were: therapy, interventions, and treatment. Key terms used to describe discharge were: hospital discharge, rehabilitation, or transition. Inclusion criteria for the current review were: (1) post stroke intervention; (2) published between 2006-2013; (3) post stroke adults ages 18 or older; (4) RCT. A post stroke intervention is defined as any RCT study that provided an intervention for PSSs that continued once the PSS was discharged from the hospital. This could include an intervention for PSSs to home or a rehabilitation unit. Studies between 2006-2013 were used since there was a prior review of complex post stroke interventions that reviewed articles from 1966-2005 (Redfern et al., 2006). Exclusion criteria for the review are: (1) RCT that did not offer an intervention post hospitalization; (2) all pediatric studies; (3) studies that focused solely on hemorrhagic stroke; (4) drug trials.

A total of 457 articles were found in the initial search. Abstracts of all 457 articles were reviewed based on the inclusion and exclusion criteria. The majority of articles

were eliminated because the intervention was not an RCT or described an intervention that was completed while participants were in the hospital. Another 31 articles required further assessment to determine if the article met the inclusion criteria. Of the 31 articles that required further assessment, this researcher was unable to retrieve three through Boston College's Library system for further review. Sixteen of the articles did not meet inclusion criteria after further evaluation. The final number of articles that met the review criteria was 15.

Findings

A brief description of the articles for this review is on Table 3, which depicts the sample size, purpose, and a basic description of the intervention. The first analysis of the review was to categorize the purpose, which is the focus of the study. The second step in the analysis was to categorize the type of intervention for each study. Categories were created for each group based on placing similar phrases together. For this review physical refers to bodily movement or manipulation such as encouraging movement through communication or walking, psychological refers to mental states, emotional states, or feelings, and administrative refers to organizational quality indicators.

Purpose of post stroke interventions. Current PSS interventions focus on a singular aspect of recovery, but up this point the literature has described the recovery process for PSSs as both physical and psychological components. Table 4 depicts the purpose of each interventional study and the category applied to the purpose. The purpose was separated into three categories, which were to alter physical improvement, psychological improvement, or administrative improvement. Only two studies aimed to

alter all three of these categories (Björkdahl & Bjorkdahl, 2006; Su Fee, Yee Sien, Eng Tan Lee, Tan Cheng Gaik, & Chew Jun Lin, 2009). Watkins et al. (2011) aimed to look at both psychological and administrative outcomes. The 12 other studies in this review focused on either physical improvement or psychological improvement. Besides the two studies whose purpose was to improve all three categories for PSSs, the other studies focused on a singular aspect of care to determine if the intervention was effective.

Type of post stroke interventions. Despite that 12 out of the nine RCTs focused on one aspect of care such as physical or psychological improvement, if the intervention created involved both a physical and psychological component; researchers might be adequately addressing the needs of PSSs. Two emerging categories were created, which were physical intervention and psychological intervention. Table 5 depicts the study and the category the intervention was placed in. Four studies have words such as tailored or comprehensive in the psychological category, which will be described later in the analysis.

The findings from this analysis suggest that current interventions focus mainly on physical interventions and are not adequately addressing the psychological needs of PSSs. Despite the focus of each study being variable, 14 out of the nine studies implemented a physical intervention (Allen et al., 2009; Askim et al., 2010; Askim, Morkved, & Indredavik, 2006; Batchelor, Hill, Mackintosh, Said, & Whitehead, 2012; Björkdahl & Bjorkdahl, 2006; Chaiyawat & Kulkantrakorn, 2012a, 2012b; Globas et al., 2012; Hegyi & Szigeti, 2012; Ihle-Hansen et al., 2012; Joubert et al., 2008; Su Fee et al., 2009; Torp et al., 2006; Ytterberg, Thorsen, Liljedahl, Holmqvist, & von Koch, 2010).

Watkins et al. (2011) was the study that implemented just a psychological intervention. Of the 14 studies that implemented a physical intervention, only two studies implemented both physical and psychological interventions (Allen et al., 2009; Joubert et al., 2008). Another four out of the 14 described part of the intervention by using terms such as individualized, comprehensive, or tailored care (Björkdahl & Bjorkdahl, 2006; Ihle-Hansen et al., 2012; Torp et al., 2006; Ytterberg et al., 2010). Individualized, comprehensive, and tailored are vague terms that could imply the use of some psychological intervention coupled with the physical intervention, however it was unclear what the psychological intervention might have been based on the study design and description.

Frequency of post stroke interventions. The next step in the analysis was to determine the frequency of the intervention to assess for the current timing of interventions for PSSs. The dose of the intervention refers to the type of intervention administered for the RCT, which was either physical, psychological or a combination of both. The findings demonstrate how PSS interventions are administered frequently during the first month after discharge from the hospital, with some lasting up to six months post stroke. Two articles, with the same study sample, implemented the intervention at discharge and continued monthly until six months (Chaiyawat & Kulkantrakorn, 2012a, 2012b). Two interventions were implemented at the discharge process at a rehabilitation unit (Hegyí & Szigei, 2012; Su Fee et al., 2009). Six of the studies had increased frequency of interventions during the first month, which consisted of a minimum of one dose of the intervention per week for four weeks after discharge

home (Allen et al., 2009; Askim et al., 2010; Askim et al., 2006; Björkdahl & Bjorkdahl, 2006; Torp et al., 2006; Ytterberg et al., 2010). One study provided a one day intervention for PSSs after the first two weeks of discharge (Batchelor et al., 2012). The frequency of interventions for Joubert et al. (2008) was 3 monthly interviews prior to each primary care provider appointment, which was determined by the primary care provider. Watkins et al. (2011) had four weekly sessions, however it was unclear when the sessions began post stroke. Three of the interventions continued past 1 month, but the frequency at which the intervention was provided lessened (Allen et al., 2009; Joubert et al., 2008; Ytterberg et al., 2010). Two interventions were not implemented until 3 or more months post stroke (Globas et al., 2012; Ihle-Hansen et al., 2012).

Results of post stroke interventions. The final part of the analysis was reviewing the results of each study to determine overall success of the interventions. This finding suggests that when researchers create an intervention, the psychological component can contribute to the success of an intervention. More importantly, using both physical and psychological interventions lead to an increase in success of the intervention. The outcomes measured and results of the studies are depicted in Table 6. Nine out of the 15 studies had statistically significant findings. Joubert et al. (2008) found that their intervention group was significantly less depressed. Askim, Morkved, and Indredavik (2006) found that walking speed was significantly different at one week, but not at 6, 26, or 52 weeks post stroke. Askim et al. (2010) found that motor assessment was significantly different at week 4 but not 12 or 26 weeks post stroke. Chaiyawat and Kulkantrakorn (2012a, 2012b), used a single sample to evaluate several

unique outcomes; they revealed several significant findings such as an increase with activities of daily living, increase in mobility, and decrease of depression when implementing an in-home rehabilitation program. Hegyi and Szigeti (2012) also found a change in mobility with acupuncture. Globas et al. (2012) found a variety of significant findings of surrounding improvements of cardiovascular fitness after the implementation of aerobic treadmill exercise. Watkins et al. (2011) found that motivational interviewing had a beneficial effect on mood at 12 months. Finally, Allen et al. (2009) found that stroke knowledge and lifestyle modification was significantly different between groups, with an increase in knowledge and lifestyle modification for the intervention group. Seven of the studies with significant findings focused on just a physical intervention or a psychological intervention (Askim et al., 2010; Askim et al., 2006; Chaiyawat & Kulkantrakorn, 2012a, 2012b; Globas et al., 2012; Hegyi & Szigeti, 2012; Watkins et al., 2011). Both Askim et al. (2010) and Askim et al. (2006) found significant findings but the intervention did not have sustained effects. Watkins et al. (2011) used only a psychological intervention while both Allen et al. (2009) and Joubert et al. (2008) focused on providing both a physical and psychological component to the intervention with each type of intervention clearly depicted in the description.

Summary of post stroke interventions

Despite some success of post stroke interventions, the interventions continue to lack an appropriate connection between the PSS's problem to an appropriate outcome as evidenced throughout this review. For example, the focus of 13 out of 15 interventions was either on physical recovery or psychological recovery. Yet, as already concluded,

PSSs experience an intertwining of physical and psychological recovery (Lamb et al., 2008; McKeivitt et al., 2004; Reed et al., 2012; Salter et al., 2008; Satink et al., 2013).

The inability of PSSs intervention to adequately reflect both of these experiences in the recovery process continues the disconnect of the goals of PSSs and health care professionals. Furthermore, researchers were unable to describe the methods involved with tailored care. This could imply researchers' lack of understanding the complexity of PSSs' experiences, which leads to the inability to offer an appropriate description of the method. Since interventions were administered most frequently during the first month, researchers need an adequate understanding of PSSs' experiences during this time to appropriately address how to tailor interventions for PSSs.

Significant findings of PSS interventions increased through a combination of both physical and psychological interventions, yet without an understanding of what occurs during the first four weeks after discharge home from the hospital researchers are unable to create interventions that adequately address the unique needs of PSSs. According to Redfern, McKeivitt, and Wolfe (2006), PSS interventions lack an appropriate framework, implying that researchers are unable to adequately address both the physical and psychological needs of PSSs. Due to an inappropriate foundation, studies in this review were unable to sustain significant findings (Askim et al., 2010; Askim et al., 2006) or did not obtain any significant findings (Batchelor et al., 2012; Björkdahl & Bjorkdahl, 2006; Ihle-Hansen et al., 2012; Su Fee et al., 2009; Torp et al., 2006; Ytterberg et al., 2010).

To conclude, this review found that when implementing both physical and psychological interventions there is an increased likelihood of significant findings.

However, the pertinent content and timing of interventions cannot be determined due to the current gap in knowledge in understanding PSSs' experiences during the first four weeks after discharge home.

Limitations of review of literature

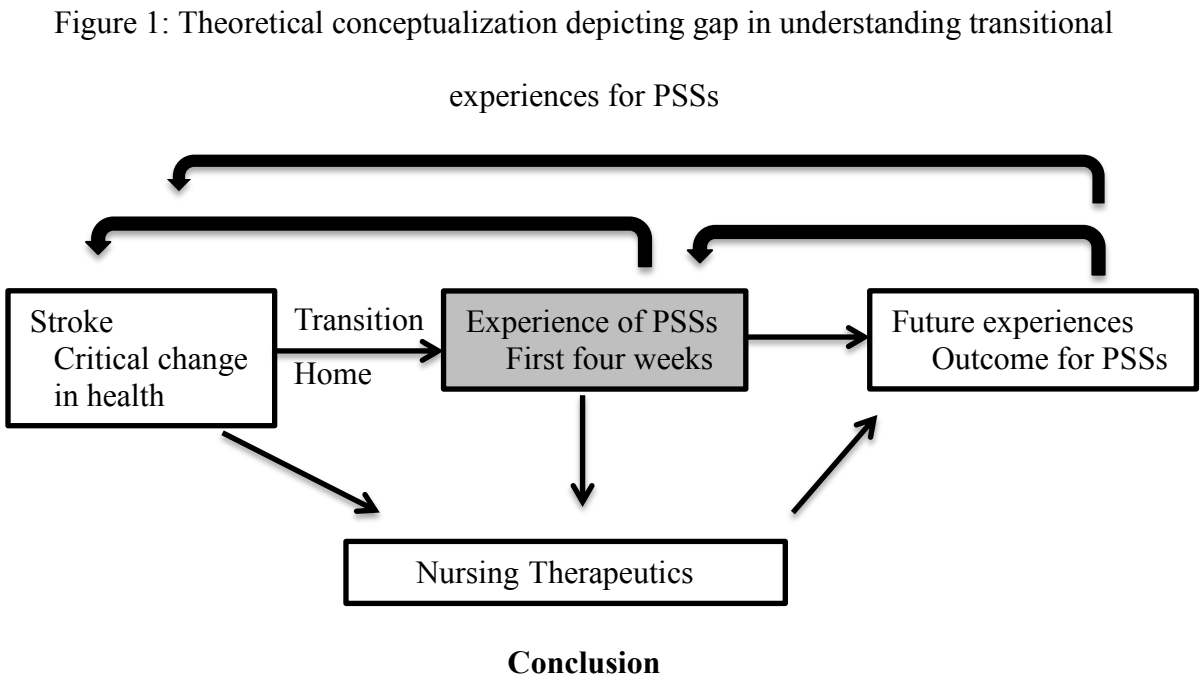
According to Whitemore and Knafl (2005), terminology or key words in database searches may only yield 50% of eligible studies. Each search was also limited in search terms and years selected. One limitation of the review is a lack of a specific framework to perform an analysis of each literature review. However, each review attempted to provide examples from all of the reviews to enhance the analysis. Another limitation is the findings were created through the analysis and conclusion of one researcher without verification or peer review of findings by another researcher. It is possible that the researcher's bias could alter the findings, however attempts were made to use specific examples from studies to prevent the author's bias from entering the findings. The final limitation of the literature review is the study design for post stroke interventions was limited to RCTs, therefore case studies, pilot studies, and preliminary analyses were excluded in the review, creating a selection bias and limiting the number of current interventions provided to the post stroke population. However, RCTs were deemed necessary to determine the effectiveness of current post stroke interventions.

Transitions and transitional care

This study builds on the theoretical and empirical work of Afaf Meleis (2010) and Mary Naylor (2004) who research transitional experiences. Though these researchers theory on transitions and model on transitional care are not directly influencing variables

or content for the proposed study, their research does support the importance of transitions for PSSs and created the initial foundation for my research. A brief summary of transitions and transitional care will be provided in this section to describe a basic understanding of transitions and transitional care. Meleis (2010) describes how nurses are key players who interact with a variety of people throughout transitions, such as changes in their health or ability to care for themselves. People can experience three types of role transitions throughout health and illness, which are developmental changes, situation changes, and health-illness transitions. Meleis describes how developmental changes could be both psychological and physiological. Situational changes are changing roles within a person's current interaction with other people, such as when a PSS transitions from being a caregiver to a care receiver. The final transition is health-illness transition, which is a role change due to an acute illness such as a stroke. Meleis describes how transitions due to changes in health and illness can lead to people being more vulnerable, which can in turn affect their health. PSSs can experience health-illness transitions due to the psychological and physiological changes occurring after a stroke, such as changes in self-image or inability to communicate. A variety of researchers have already highlighted the importance of providing transitional care to vulnerable populations to improve patient care (Naylor et al., 2011). Groups of vulnerable populations during transitions are older adults who are discharged home from the hospital and frequently can have multiple comorbidities that lead to poor patient outcomes (Naylor et al., 2004). Post stroke survivors fit within this vulnerable population since the majority are greater than 65 years of age, have associated comorbidities, and experience a transition from hospital

to home (Casper et al., 2008; Go et al., 2013). This framework is what led the need to understand the transitional experience of PSSs from hospital to home. Figure 1 depicts the information that is known about PSSs' experiences and highlights in gray the area that is currently unknown and how understanding PSSs' experiences during the transition from hospital to home can affect nursing interventions and future experiences.



Chapter 2 provides an overview of the recovery process for PSSs. The recovery process for PSSs have physical, psychological, social, and cognitive experiences that can impact their ability to function in the community. PSSs describe transitions in the recovery process can be difficult, especially the transition of returning home after a stroke. The current state of the science describes that PSS recovery involves more than just physical recovery, yet PSSs continue to describe that health care professionals are not

meeting their unique needs and PSSs continue to have issues affecting their ability to function within the community.

A further review of the literature found that content for post stroke transitional interventions from hospital to home during the first four weeks is inadequately established adding further justification for the proposed research. Researchers know that PSSs' experiences involve physical, psychological, social, and cognitive experiences. Specifically, experiences of PSSs are fatigue, difficulty communicating, difficulty traveling, altered relationships, uncertainty, change in self-image, and difficulty focusing. The unique recovery process of PSSs can be created through any combination of experiences. A current understanding of PSSs' experiences and the context surrounding an experience remain unknown during the first four weeks after discharge home from the hospital. Furthermore, PSSs describe recovery as a fluctuating process that can have subtle changes over time, yet little is known about the subtle changes that can occur during the first four weeks after discharge home.

Chapter 2 continues to emphasize the current gap in literature is understanding PSSs' experiences during the first four weeks after discharge home. Post stroke interventions have an increased frequency of the intervention during the first four weeks. However, without adequate knowledge of PSSs' experiences during this time researchers are unable to link a PSS's problem with an appropriate outcome. As PSSs continue to describe the transition to home as a key part of recovery and a time of uncertainty due to lack of support and information, nurses are obligated to further investigate how to improve patient care. To improve patient care research is needed that addresses both the

content and timing of PSSs' experiences to aid in the development of future post stroke interventions. Due to the overwhelming evidence provided by the literature review, further research is needed to understand PSSs during the transitional period from hospital discharge home during the first four weeks in order to understand the content and timing of experiences that can be used to guide the development of future PSS early interventions. To answer this gap the aims of the proposed qualitative descriptive study are:

1. Identify the needs, concerns, frustrations, and experiences of PSSs from the first 24 hours up to four weeks after discharge home from the hospital, from the patient perspective.
2. Describe the experiences of four different cohorts of PSSs at 1, 2, 3, and 4 weeks after discharge home from the hospital.
3. Compare and contrast the similarities and differences in experiences between cohorts to identify both the unique and consistent themes along this 4-week transitional period.

Chapter 3

Methods

Introduction

Chapter 3 describes the research method implemented for this study. The chapter begins with a brief introduction of the qualitative approach implemented for this study, which was a qualitative descriptive approach. The researcher conducted semi-structured telephone interviews with PSSs grouped into four cohorts based on their interview date relative to the day of discharge. Next is an explanation of the sampling plan, which includes the setting, sample size, enrollment and rationale for the cohort design of the study. An explanation on the interviewing procedure and rationale for implementing telephone interviews for this study is followed by an explanation and description of the data analysis plan. The data analysis section will describe three phases: preparation, exploration, data reduction, and reporting on how the study will achieve each aim which is described. Additionally, the data analysis section will provide a justification for the study's validity. The final sections of chapter 3 will focus on trustworthiness of qualitative data, ethical considerations for the study, and reflexivity of the researcher.

Qualitative Descriptive Approach

According to Margarete Sandelowski (2000), qualitative description allows a researcher to describe an experience based on the context of a participant's life. Furthermore, qualitative description can offer a summary of experiences based on a participant's point of view by using every day language. Qualitative description has been implemented by other stroke researchers as well (Danzl et al., 2013; Morris et al., 2013;

Pilkington, 1999), but not implemented during the first four weeks of discharge directly home from the hospital. Unlike other qualitative methods, the researcher is less interpretative with the data, but remains close to the description of the experiences as offered by participants. This does not mean qualitative description lacks interpretation completely, however the focus is to produce findings as data-near as possible (Sandelowski, 2010). Qualitative description is also a useful method to develop new interventions and refine current interventions among vulnerable populations (Sullivan Bolyai, Bova, & Harper, 2005). For example, one study planned a post stroke rehabilitation intervention based on the information received from the qualitative descriptive data (von Koch, Holmqvist, Wottrich, Tham, & de Pedro-Cuesta, 2000).

Qualitative description is derived from naturalistic inquiry, which draws observations from a participant's existing surroundings (Denzin & Lincoln, 2005). This means researchers enter the study without pre-existing variables to measure, manipulation of variables, or a priori commitment (Sandelowski, 2000). Sandelowski further describes the difference between qualitative description and quantitative description by quantitative description has pre-selected variables to describe a phenomenon and draw conclusions based on statistical tests. In contrast, qualitative description offers a comprehensive summary of a phenomenon. Qualitative description has not been developed by one person, which led to diversity in how researchers create a qualitative description study (Sandelowski, 2010). Sandelowski urged researchers to describe techniques implemented in a qualitative descriptive study that go beyond referencing Sandelowski's 2000 article. As suggested by Sandelowski (2010) Chapter 3

will describe this study's methods based on a variety of qualitative researchers. Through the implementation of the applied qualitative methods to this qualitative description, the individualized experiences of PSSs during the transition from hospital to home within the first four weeks of discharge will be better understood.

Sampling Plan

This section describes the sampling plan. The sampling plan includes a description of the setting and sample size describing both the inclusion and exclusion criteria. Next, the enrollment procedure for the study and a description of cohort sampling justification for the method and logistics for the process will be presented. An overview of the research procedure can be found in Appendix A.

Setting

The recruitment for this study was in a large metropolitan hospital in New England from two inpatient general medical and surgical neurological units. These two units provide care to the majority of stroke patients that are admitted to the hospital. According to M. Mott (personal communication, July 25, 2012) the hospital admits about 500 people with ischemic strokes to the hospital each year. Specifically, in the month of May 2012 the hospital had 72 people admitted for an ischemic stroke, which may be a slightly higher number than other months. Of those admitted, it is anticipated that approximately half would be discharged home (Casper et al., 2008). Currently, no data exists on the number of PSSs discharged home from the hospital, so numbers of PSSs who were discharged home from the hospital were estimated through communication with the chief of neurology and the inpatient nurse practitioner for the stroke service.

Sample size

Participant selection was based on a purposive sampling of participants from two neurological units. Purposive sampling allows a researcher to select specific individuals for a study that are experiencing a phenomenon of interest (Creswell, 2007). Purposive sampling was implemented for this study to select PSSs who experienced an ischemic stroke and were discharged home. For example, if after 5 interviews the majority of participants were Caucasian males ages 50-60 years, future sampling focused on other individuals differing in gender, ethnic, and age status. Purposive sampling, unlike other sampling approaches, can lead to a sampling bias that is not reflective of the population. However, since this study aimed to understand the PSS experience, it would lead to a bias in results if specific genders, ethnic groups, or ages were not representative in the study sample.

Currently, there is not an exact number of participants to ensure an adequate sample size for qualitative description designs, however a sample size of 20-50 is considered a moderate sample size for qualitative description (Sullivan Bolyai et al., 2005). However, this study implemented the use of cohorts, a quantitative sampling method. The adaptation of this method to qualitative research had not been researched. Due to limited information on sample size, for this study the minimum number of participants was 10 per cohort, but up to 15 participants were included within each cohort for an overall projected total of 40-60 participants. This minimum sample size was determined based on a prior descriptive qualitative study with the stroke population that

reached data saturation of PSS experiences after a sample size of 10 (Pilkington, 1999) and to support a moderate sample size as suggested by Sullivan-Bolyai et al. (2005).

Data saturation and recruitment

The original sampling plan was for a minimum of 10 participants enrolled in each cohort, and recruiting for the study continued until data saturation had been reached. Data saturation occurs when no new information is gathered from the data (Denzin & Lincoln, 2005). Data saturation was determined by analyzing data, while continuing to recruit and conduct interviews, until no new categories emerge during the data analysis of the interviews.

According to Guest, Bunce, and Johnson (2006) when attempting to determine if data saturation can be achieved in some cases 6-12 interviews is most likely sufficient and provides at least 94-97% of codes for the study. These researchers also found that after about 12 interviews, only minor changes or additions to existing codes emerged. They concluded that to determine if a 6-12 range of participants is appropriate for a study, researchers need to look at factors such as homogeneity of the group and the degree of structure to the interview. The more homogenous the group with structured interviews means the higher likelihood that data saturation will be achieved within the 6-12 participant range. This study was able to achieve both of these factors; homogeneity and structured interview. Homogeneity was achieved through purposive sampling since participants all were ischemic stroke survivors being discharged home. Structure of the interview was achieved through focused questions in the interview guide to understand PSSs' experience from hospital to home such as, what is it like to drive? Despite prior

research implying a range of 40-60 would be needed, this research on data saturation suggests that a sampling size of 20-30 may be appropriate as well. The larger sample size of 40-60 was implemented to increase the probability of understanding PSSs experiences. In the end, data saturation was achieved by 31 participants, which reflected the latter sampling size.

Inclusion Criteria

1. Documented CT or MRI confirming acute ischemic stroke
2. Discharged directly home from the hospital
3. English speaking
4. 21 years of age or older
5. Admitted to 1 of 2 specified neurological units at the hospital
6. Functioning telephone

Exclusion Criteria

1. Diagnosed with a hemorrhagic stroke
2. Discharged home on hospice care
3. Enrolled in another stroke study
4. If the primary investigator (PI) has cared for the participant as a nurse

Only survivors of ischemic stroke were eligible for the study since the underlying pathophysiology of a hemorrhagic stroke can lead to a different trajectory of care (Hickey, 2009) and also yield a completely different transitional experience. As this study aimed to understand PSSs' experiences after discharge home from the hospital,

patients were ineligible who were discharged to a rehabilitation unit from the hospital, but patients who received physical therapy or occupational therapy at home remained eligible for participation. English speaking was required since an interview is a partnership between the interviewer and the respondent (Hesse-Biber & Leavy, 2011) and the use of an interpreter leads to an alteration in this partnership, which could alter analysis of the interview. To allow for equitable selection of participants, the study did not restrict people by gender, ethnicity, or if English was a secondary language. Age of 21 years or older was deemed necessary since the developmental stages of growth is different for someone less than 21 years of age compared to someone who is older (Berger, 2001). Furthermore, the underlying pathology of a stroke prior to age 21 is inherently different from that of an adult stroke (Hickey, 2009; Steinlin, 2012) and hence would require a separate study to understand that unique transitional experience. The study required the participants to communicate via telephone, therefore, participants were required to have a functioning telephone that the PI used to conduct the phone interviews. Participants were excluded if they were being discharged home on hospice care since this population would experience a different type of transition that was not being researched in this study. Overall, inclusion criteria were kept to a minimum to encourage a variety of participants to remain eligible for the study, to increase the potential variation of participants in the transitional experience from hospital to home for PSSs.

Enrollment

Recruitment. An advanced practice nurse (APRN) who worked with the stroke team at the site determined potential participants for the study. The APRN provided a list

of possible candidates for the study based on the initial inclusion requirement, which was a candidate who was diagnosed with an ischemic stroke and would be discharged directly home from the hospital. This list of patient names was then provided to the PI. The PI asked the primary registered nurse caring for the potential participant if the potential participant was willing to talk to the PI about the study. Potential participants were then approached by the investigator who explained the study, and sought and gained informed consent.

Consent. Consent was obtained while participants were medically stable, but still hospitalized. The researcher completed the eligibility/ineligibility section of the Enrollment Form prior to obtaining consent (refer to Appendix B for a copy of the Enrollment Form). The enrollment form indicated the telephone number and the preferred time to reach a participant. Once informed consent was obtained, all signed consent documents and the enrollment form were kept in a locked cabinet, in a nursing office, at the hospital. The approved informed consent used for the study is located in Appendix C. To determine if a participant had decisional capacity, the PI followed the outline suggested by Lim and Marin (2011). To determine decisional capacity candidates had to: communicate a choice of either yes or no to participate in the study, verbalize understanding of the risks and benefits for the study, and verbalize their rights as a research participant. Each participant was provided with a copy of the consent form.

Cohort sampling

The day of the interview was determined by the cohort placement of a participant and cohorts were defined by the time post discharge. Participants were placed in one of

four cohorts. The first cohort of participants was interviewed within the first 24-48 hours after discharge home: this was the Week One Cohort Participants. Week Two, Three, and Four Cohort Participants were interviewed 2-4 weeks after being discharged home. Please refer to Table 7 for the separation of cohorts based on time post discharge.

Table 7. Separation of cohorts by time post discharge

	Week 1 Cohort	Week 2 Cohort	Week 3 Cohort	Week 4 Cohort
Interview time post discharge	24-48 hours	10-11 days	17-18 days	24-25 days

Rationale for cohort sampling. Cohort sampling was deemed necessary to provide an understanding of the transitional experience of PSSs during the first four weeks of discharge home by examining the transitional experience at various stages of transitions. Four groups were created as each PSSs experience hidden and subtle differences that can be difficult to detect with periods of plateaus and frequent changes (Backe, Larsson, & Fridlund, 1996; Carlsson et al., 2004; Doolittle, 1992). Having four cohorts that were interviewed at different points in time within the transitional experience allowed for comparisons between cohorts' experiences to determine the patterns of experiences during the first four weeks after being discharged home. While, Saldana (2003) suggested that increasing the frequency of interviews increased the content researchers receive, hence increasing the likelihood of detecting some of the subtle differences, four cohorts were also created to decrease burden on participants. If one PSS was interviewed four times in one month, this could increase the risk of burden and decrease the willingness to participate in study, which would lead to concerns of feasibility of the study. According to Saldana (2003), data collection is not about

standardized numbers, but the quality of the data. To ensure quality of data, other standards were taken which are discussed in future sections: trustworthiness and validation of research. A limitation of this current method is the inability to follow a specific PSS's experience overtime. A pattern of experiences could be determined by this study design however the trajectory of any specific PSS's experience cannot be determined (Burns & Grove, 2009). However, by contrasting the experiences between cohorts the researcher may be able to make conclusions about timing of experiences to guide future PSS transitional interventions.

Determine interview date and time

Initially the researcher determined the cohort that a participant was placed based on participants descriptive demographics such that each cohort had equal diversity based off of purposive sampling. Participants cohort was also determined if the participant had a particular week they wanted the interview to occur. In general, participants were encouraged to provide an optimum day and time for the interview. Allowing the participant to optimize the time of the interview decreased undue burden on a participant, decreased the power gradient between the interviewee and interviewer (Creswell, 2007), and increased the likelihood of participation (Friedman, Furberg, & DeMets, 2010). However, when participants provided an unfeasible time for an interview or would rather interview during a different time than their assigned cohort, a discussion was used to formulate a plan that worked for both the researcher and participant. Each participant was informed of the interview date during the consent process and Week Two, Three, and Four Cohort Participants received an appointment card with the date and time of the

interview prior to leaving the hospital. Participants also received a telephone reminder 3-4 days prior to the scheduled interview time to remind them of the scheduled interview and determine if the predetermined date and time were still appropriate for the participant. The appointment card and telephone call served as a reminder for participants, especially Week 3 and 4 Cohort Participants, about the interview time to increase adherence and participation for the study. As suggested by Friedman, Furberg, and DeMets (2010), reminders to participants about the study increases adherence. The telephone reminder also offered the ability for participants to optimize the time of the interview.

Due to the availability of the APRN, enrollment for the study occurred between Monday and Friday. Participants were first enrolled into the study and placed in one of the four cohorts. Each day up to four participants that were going to be discharged that day could be enrolled, which lead to one participant per cohort. The goal was to enroll one participant per cohort in a sequential order to keep the cohorts balanced. Range of how many participants were enrolled on a particular day was zero to three. The original intention was to enroll participants in phases, such that phase one would have at least five participants per cohort and phase two would have 10 participants per cohort. This was to allow the PI to analyze interviews and determine if/when data saturation occurred. However, data saturation was achieved between phase one and phase two of enrollment, where the number of participants interviewed was 31, therefore enrollment of additional participants was not needed. Overall, recruitment for the study took approximately 3 months.

Rationale and limitations for enrollment plan

Enrollment in a sequential order and separating enrollment into phases allowed for increased efficiency of the study analysis. First, this process allowed for a maximum of two interviews to be conducted on the same day. Since interviews are an active process of asking, listening, and talking (Hesse-Biber & Leavy, 2011), increasing the number of interviews to more than two a day could decrease the quality of the interview. One potential limitation of this enrollment plan was that on any given week 20 PSS's may not be discharged home. In this study, enrollment of participants varied from 1-10 participants for any given week. Based on preliminary recruitment from pilot and personal communications, it was estimated that 20 participants could be enrolled after a month. During enrollment, after a month and half 25 participants were recruited and scheduled for an interview. Overall, recruitment was still completed within the originally predicted 2-6 months as data saturation was achieved earlier than anticipated. If enrollment had not occurred within a sufficient rate, a contingency plan was created. Enrollment of cohorts sequentially also allowed the researcher to adjust interview questions or techniques for future interviews based on the preliminary analysis of findings, thereby preventing a bias in interview techniques between cohorts. The procedure of analyzing interviews and altering interview questions and techniques was implemented through a pilot study that interviewed PSSs with 24-48 hours after discharge home from the hospital. The pilot study analysis informed the interview questions and techniques for the proposed research. However, interview questions and

interview technique were analyzed throughout the study due to the iterative nature of qualitative analysis (Hesse-Biber & Leavy, 2011).

Interviewing Design

The interviewing design section will provide the following: an overview of the interview procedure; rationale for the use of semi-structured interviews; and rationale for telephone interviews and the estimated length of the interviews.

Overview of interview procedure

When an interview needed to be performed the PI removed the enrollment form from the locked cabinet to retrieve the phone number and designated time of day to call the participant for the interview. Prior to starting the recording of the interview the participant had to state his or her name to verify identification; however when describing and analyzing the data, pseudo-names were provided for confidentiality. The researcher used a semi-structured interview guide for all interviews. The researcher used field notes to record relevant data during the interview. Field notes will be described in detail in the data analysis section. All interviews were recorded on a Secure Digital (SD) recorder. After an interview was completed, the recordings were immediately transferred to an encrypted hard drive. All computers used for data transcription were encrypted and only accessible by the PI through authentication.

Interviewing Methods

Interviews were based on a semi-structured interview guide, which allowed for flexibility and sensitivity to understanding PSS's experiences. According to Hesse-Biber

and Leavy (2011), semi-structured interviews allow the interviewer to use a specific set of questions to guide the conversation. Semi-structured interviews also allow the participant the ability to discuss areas of interest or importance on a topic. Hesse-Biber and Leavy also discussed how interview questions are an iterative process, even within semi-structured interviews, where the researcher can analyze the questions and responses and alter the questions for future interviews. A preliminary interview was created and piloted on three PSSs who described their experience after discharge home from the hospital during the first 48 hours. Alterations to the interview guide were implemented based on the pilot analysis and in conjunction with qualitative experts. This allowed the interviewing guide for this study to better reflect how to inquire about and address PSSs unique experiences. The revised interview guide based off of pilot data is provided in Appendix D. The guide provides a framework for conducting the interview, however not every question on the guide was asked during each interview. The guide begins with an open question thought to encourage dialog (Hesse-Biber & Leavy, 2011). However, above the first question is a list of goals as a reminder to the interviewer to focus on when a PSS described an experience. When a participant explained an experience, the PI asked specific questions regarding the experience, such as: when the experience started; what was occurring around the experience; and how often the experience occurred. Focusing questions on the situation surrounding the experience helped determine the timing and context of experiences to aid future interventions. A limitation of semi-structured interviews is participants may not feel open to discuss their experience; to encourage

dialog open ended questions were used throughout the interview to understand the PSS's experiences.

Due to the success of telephone interviews in prior research (Green & King, 2009; Jones, Duffy, & Flanagan, 2011), this study also collected data through telephone interviews. According to Creswell (2007), a telephone interview is appropriate when researchers do not have direct access to participants. Furthermore, telephone interviews allow the participants to choose the setting for the phone interview, which increases a participant's comfort level and quality of the interview (Munhall, 2012). According to Siemiatycki (1979), telephone interviews can provide high quality data and have a higher response rate than other methods. Recently, a transitional intervention for arthroscopy patients used a telephone call to assess each patient's response to surgery and establish a time frame for anticipated outcomes (Jones et al., 2011). Interviews over the phone have been successful in other studies assessing the PSS's experiences (Green & King, 2009). Korner-Bitensky, Wood-Dauphinee, Siemiatycki, Shapiro, and Becker (1994) found that when discussing the health related post discharge information, telephone interview are just as reliable as face-to-face interviews for stroke patients with minimal disability.

PSSs who were eligible for the study needed to be able to communicate over the telephone. Initial verification was determined during the consent process and further verification was completed at the beginning of the interview. Participants verified their willingness to participate in the study and was allowed time to ask any questions about the study prior to the start of the interview. If a participant was having difficulty talking during the interview and unable to attend to the interview, the participant would no

longer be eligible for the study. However, in this study no participants experienced this problem. Only one interview was interrupted and then continued since a visiting nurse arrived during the interview and two interviews had to be restarted due to mechanical failure of the recorder. However, the interviews that had to be restarted due to mechanical failure were within 10 minutes of the interview starting. All attempts were made to decrease distractions by asking the participant prior to the interview if it was an appropriate time for the interview.

It was estimated that interviews would take approximately 30-90 minutes depending on each participant. This time frame was determined by prior studies conducting interviews for PSS experiences (Salter et al., 2008) and preliminary data from the pilot study. This was found to be an accurate prediction as the average length of interview time was 39 minutes for this study. Participants were asked at 30 minute intervals during the interview if they needed a break, to prevent fatigue during the interview. If the participant needed a break, a new interview time would have been scheduled.

Data Analysis

Throughout the data analysis section, a variety of qualitative researchers are cited for their applied methods for analyzing qualitative research. This does not imply that these qualitative researchers are experts in qualitative description, rather their applied methods of analyzing data are being implemented for this study. Hesse-Biber and Leavy (2011) describe four phases in analysis of qualitative data. The phases listed in order are the preparation phase, exploration phase, data reduction phase, and reporting phase. The

preparation phase for this study includes the transcription of interviews, memos, and field notes. Field notes are written experiences generally recorded after leaving a setting (Hesse-Biber & Leavy, 2011). For this study field notes will be taken during and shortly after interviews. A field note template is provided in Appendix E. The preparation phase was an interactive process that allowed the PI to focus on what participants were saying, how they were saying it, and what the PI was thinking throughout the process.

Transcription process was aided by the use of HyperRESEARCH, a qualitative research tool that can help organize qualitative data for analysis (Faherty, 2010). The PI completed all transcription of interviews by listening to the audio-recorded interviews and writing down word for word all verbal data during the interview such as laughter, pauses, or emotional changes. Transcription of interviews was started while interviews were taking place. After interviews were transcribed the PI re-listened to the interview while reading the transcription to check for and correct any errors. To increase the rigor of the study, Lincoln and Guba (1985) suggest keeping a diary of decisions made throughout the research process from the interview to data analysis. For this study, the diary included the following: decisions that were made; thoughts of the PI at the time; and the reasons supporting the decision. For this process I used memoing. Memoing is the writing down of ideas throughout the data analysis (Creswell, 2007). Using memos allowed for continued interpretation and reflection throughout both the data collection and analysis (Hesse-Biber & Leavy, 2011). For example, memos described why one phrase was placed in a particular category or why one category would be found more important to discuss. Memos were used to summarize each PSS experience during initial

coding and determine if the two sources of data were similar. HyperRESEARCH also allows a researcher to memo throughout the process; in this case the memo template provided was not used extensively, because it was easier to see all memos in one document. Throughout the analysis memos were analyzed with each code and category in order to provide insight into the findings (Hesse-Biber & Leavy, 2011).

Exploration and data reduction phase

The exploration phase and data reduction phase occurred simultaneously. The exploration phase includes reading text through to get a general meaning, assigning codes, clarifying codes, and writing memos throughout this process. The data reduction phase entails linking codes that are similar or how new data relates to the existing data (Hesse-Biber & Leavy, 2011) codes can then be placed into a larger category. According to Creswell (2007), a category is a unit of information like an event, instance, or a happening. Categories can also be phrases that go together (Denzin & Lincoln, 2005). Each category requires a definition of the properties. A definition allows the researcher to determine if future phrases fit within a particular category, if a sub category is required or if a new category can be created (Lincoln & Guba, 1985). Connected with each category will be in-vivo codes. In-vivo codes are created directly by a participant's language. In-vivo codes are not constructed terms by the researcher but are from the participants' words to allow for more participant-centered analysis (Salda a , 2003). HyperRESEARCH was used to code, create categories, and display in-vivo codes to increase organization during the exploration and data reduction phase.

Reporting phase

The final phase of data analysis is the reporting phase. The initial coding analysis included eight interviews, two interviews from each cohort. These eight interviews provided evidence of common codes which served as a guide to subsequent analysis. The analysis and codes were reviewed by the dissertation committee members. On further analysis of the interviews, the categories that emerged were similar across all cohorts.

As suggested by Patton (1990) when there is variation in sample, analysis of data can be a challenge. However, categories can emerge such that the larger variation captures the core experiences of shared impacts of the group. This is what occurred during the analysis of this study. Discharge between cohorts created a variation in the core experience of PSSs within each group, so data saturation was achieved sooner than anticipated.

The reporting phase entails making sense of all the existing data. Various ways to conceptualize and organize data can be to provide a frequency of codes, display results in a graph, or begin to combine codes together based on the iterative process of analyzing the data (Hesse-Biber & Leavy, 2011). This means specifically that how data will be displayed was unknown prior to data analysis due to the iterative process of the reporting phase.

According to Saldana (2003), to contextualize an experience the researcher needs to analyze the influence of a person's physical and social world and how this creates a deeper meaning of the person's synthesis of any experience. Similar to this idea is

Margaret Newman's theory of expanding consciousness (2008), which describes how one experience can be influenced by prior key periods in a person's life. This means the reporting phase cannot merely state what a person is experiencing, but must describe how that experience relates to the participant through the participants own words. Since this was a qualitative description, the use of the participant's own words in describing an experience was vital in creating categories. This does not mean the researcher did not interpret findings throughout the study; in fact, interpretation of findings was implemented by determining how the categories could be interpreted by forming themes that represented PSS's experience. According to Gale, Heath, Cameron, Rashid, and Redwood (2013) a theme is an interpretive concept to explain the data by analyzing categories through comparisons between and within cases. According to Gale et al. (2013) categories can be within a theme or sub theme. However, the in-vivo codes, which are in the participants' own words, provided the contextual situation surrounding the experience for PSSs and the backbone to the analysis. The process to interpret how the categories were used to create the larger themes was reviewed by the dissertation committee. Since qualitative analysis is an iterative process the PI reviewed memos, field notes, in-vivo codes, and categories to interpret the findings.

Validation of research

Creswell (2007) outlines eight categories for validation of a qualitative research study. Of these eight categories, at least two of the categories should be implemented to employ a valid study. The eight categories are prolonged engagement, triangulation, peer review, negative case analysis, clarifying research bias, member checks, thick

description, and external audits. For this study member checking and peer review were used for validation of the findings from this research study. Member checking allows for the participant to verify the findings and determine if the PI has described true depiction of the participant's ideas (Creswell, 2007). After the data analysis was completed, eight participants were invited to discuss the preliminary findings of the study, by telephone, with the PI as a form of member checking. An example of the member checking guide implemented is found in Appendix F. Since member checking was a voluntary process for participants, it was not feasible to assume all participants would want to participate, however after each interview each participant was asked if they would be willing to discuss the analysis and all participants at that time were willing to participate in member checks. Positive outcomes related to member checking are described by Doyle (2007) who states, member checking for the older population should encourage the interviewee to realize she/he is a mentor to the researcher and is the expert in understanding the phenomenon. This encourages empowerment and active participation of participants to assure that the study has achieved the goal of describing the phenomenon based on a participant's point of view. All eight participants agreed with the findings during member checks. If the participants had not agreed with the findings, further analysis would have been completed by reviewing memos, interviews, the analysis process, and the interpretation in relation to the comments described by the participants in member checking. Furthermore, a discussion would have been elicited with a qualitative expert to further evaluate the findings. As described by Sandelowski (1993) and Angen (2000), member checking may not always increase validity due to the lack of a static truth or

reality, and member checking can also deter researchers from the art of qualitative research. Due to this concern, peer review was used to increase validity for this study. Peer review is an external check of the research process (Creswell, 2007). In this study, peer review was accomplished by having the dissertation committee members review the findings throughout the analysis process. Peer review was started after three interviews were transcribed and analysis was continued throughout the analysis process. This allowed for future interviews to reflect changes that may be necessary for a valid research study. For example, after about 12 interviews had been completed the PI noticed the interviews were straying from the interview guide and potentially missing further description of an experience. Due to this analysis, future interviews remained closer to the interview guide.

Trustworthiness

For this study, the criterion for enhancing rigor was derived from Lincoln and Guba's (1985) criterion of rigor called trustworthiness. Lincoln and Guba describe four elements to trustworthiness that a qualitative study needs to enhance rigor. These elements are: credibility, transferability, dependability, and confirmability. During the data analysis, credibility was achieved through member checking and peer review (Creswell, 2007; Lincoln & Guba, 1985). Transferability shows that findings of the study can be used in other contexts (Lincoln & Guba, 1985). In this study transferability was supported by the thick description of findings. According to Lincoln and Guba, thick description is achieved by explaining a phenomenon sufficiently. This was achieved through data saturation, member checking of results, peer review of findings, and through

analysis of memos. Once a thick description was achieved, the findings then can be transferred to other situations or contexts similar to those of the study. For example, even though this study examined PSSs at one metropolitan hospital in New England, by offering a thick description of the findings other researchers can transfer the findings to other PSSs discharged from hospital to home.

Dependability is showing that findings can be repeated (Lincoln & Guba, 1985). For dependability to be achieved, an external audit is required. An external audit is when a researcher who is not connected to the study will review my process and findings to determine if the analysis was supported (Creswell, 2007). For this study three professors with expertise in qualitative research reviewed the procedure and analysis to determine if my conclusions are supported by the data. The last element to trustworthiness was confirmability. Confirmability is when the study findings are shaped by the study, not by researcher bias or other interests (Lincoln & Guba, 1985). Confirmability for this study is achieved through an external audit to assess my analysis of findings through memos, which were already described in the data analysis section, which was completed by the dissertation committee. Confirmability can also be assessed by the reflexivity of the researcher or the context of how the findings were constructed by the researcher (Creswell, 2007). For reflexivity to be achieved for this study I will use memos, which will offer my overall experience and perception of the data analysis process. As suggested by Hesse-Biber and Leavy (2011), I also completed an exercise about reflexivity before implementation of the study noted later in the Reflexivity section of Chapter 3.

Ethical Considerations

The study was approved by the institutional review board (IRB) at the large metropolitan hospital and Boston College. The IRB approval for both of these institutions are in Appendix G and Appendix H. There were minimal risks for this investigation. Participants were informed and reminded during the interview that participation for the investigation is voluntary. At the beginning of each telephone call, participants were asked if they were in a place where they could talk openly in order to protect their privacy and confidentiality. Other possible risks anticipated were increased stress or burden related to answering interview questions. Interview questions could also elicit emotional responses. If a participant described or displayed an increased emotion such as crying or shouting, the researcher remained an active listener and asked if the participant was willing to continue the interview or if the participant needed to take a break, in which case the interview can be completed at a later time. No interview needed to be rescheduled, however some participants did become emotional during the interview, but felt comfortable to keep talking. The participant was instructed to contact their primary care physician if strong emotional responses remained after the interview.

Although not a risk of participating in this research, unique to PSSs is the increased risk for a recurrent stroke (Go et al., 2013). Due to this increased risk of experiencing another stroke and the requirement to ensure safety during the interviews, if a participant complained of any distressing or concerning symptoms the investigator would have stopped the interview and referred the participant to his/her primary care physician or 911 if symptoms are suggestive of a recurring stroke. Based on the

American Heart Association's *Stroke Awareness*, if participants voiced a new facial weakness, arm & leg weakness, or speech problems they were instructed to dial 911. If the participant was unable call, the PI would have remained on the line and dialed 911 on a different telephone until help arrived. The PI did not need to call 911, however did encourage some participants to call their primary care physicians when they asked the PI questions about their care.

All clinical data collected in the study was supervised by Ellen Mahoney RN, DNS who ensured safety of data and monitoring. No adverse events needed to be reported to the appropriate Human Studies Committee at the IRB in accordance with the guidelines for adverse events reporting for non-interventional studies. As previously stated, all data was encrypted when placed on an electronic device. Only the enrollment and consent form contained the participant's name. Pseudo-names were used for all data analysis. All information sent to Ellen Mahoney, participants performing member checks, and experts performing peer review was de-identified. All hard copies of data were kept in a locked cabinet in a secured room at the research site.

Since the PI worked as a staff nurse on one of the neurological units for this study participants were excluded from the study who had received nursing care by the PI. This eliminated any coercion that participants could potential feel and prevent blurring of boundaries of who is the health care provider and who is the researcher.

Reflexivity

Reflexivity allows researchers to acknowledge and describe the bias a researcher can bring forth to research, hence increasing the rigor of the qualitative study (Newton,

Rothlingova, Gutteridge, Lemarchand, & Raphael, 2012). As suggested by Hesse-Biber and Leavy (2011), to acknowledge biases that can impact the study, beginning researchers should answer a few questions. Some of these questions are listed below with my response.

What particular biases if any do I bring to and/or impose onto my research?

My current bias can be created through my existing knowledge on PSSs' experiences both through interventions and prior qualitative literature. This can lead to researchers forcing prior themes or categories from other studies onto the data. As already described memoing will be completed throughout the data analysis to encourage the researcher to focus on the current data for analysis.

How do my specific values, attitudes and theoretical perspectives influence the research style I take on?

The theoretical and empirical work of both Afaf Meleis and Mary Naylor guide my research. I think each transitional experience is unique due to the interplay of multiple experiences, but there are overarching similarities that healthcare professionals should be aware of. I am also guided by Margaret Newman's theory of expanding consciousness (2008), which depicts how nurses can help patients evolve after an illness.

Do I ask questions only from my own perspective?

A semi-structured interview was deemed necessary to allow for a guided interview, but also allow for an open dialog for participants to provide their perspective. To listen to a PSS requires the researcher to have an open mind to their experiences, a cleared

mind of prior knowledge, and the ability to focus on PSS's story.

How does my own agenda shape what I ask and what I find?

Since I have been a neurological nurse throughout my nursing career I do have added knowledge about the community. I have baseline beliefs that any stroke can create life changes and issues that can be addressed. Although my study is not suggesting linearity in experiences I am anticipating an evolution of experiences over time.

How does my position on these issues impact how I gather, analyze, and interpret my data? How do I perform these actions?

Since I am trying to understand and project experiences both weekly and overall for the first month, my focus is on understanding the contextual surroundings of experiences of the post stroke population. My own agenda in understanding an experience could blind me to a deeper meaning. However, the process of memoing, member checking, and peer review will decrease and bolster the analysis process.

Chapter 4

Results

Introduction

The purpose of this exploratory qualitative descriptive study was to describe the transitional experiences of post stroke survivors (PSSs) during the first four weeks after being discharged directly to home following hospitalization. The PSS experience was described by participants as a story grounded in uncertainty. Prior to experiencing a stroke, PSSs understood their daily routines, thinking processes and recognized themselves and their environment in a familiar way. Following a stroke, PSSs reported their routines changed, their cognitive process was re-evaluated, and their sense of self needed to be rediscovered. While experiences varied for each PSS, many reported similar struggles regarding changes in lifestyle and thinking process along with increased concerns over their lives in the present as well as future life challenges.

The findings of this study are initially presented temporally in an effort to follow more closely the general progression of events that each participant experienced once they returned home after hospital discharge following a diagnosis of a stroke that could be considered mild, since they did not require inpatient rehabilitation admission. Although participant interviews began with the PSS's transition to home, their transitional experiences were colored by vivid recollections of how they experienced the initial event that created the context in which their stories unfolded.

After the transition home, participants described unique responses to situations linked to their post stroke recovery. When analyzed, the situations reflected similar types

of experiences, which were described categorically rather than linearly due to the temporal variance of these experiences. What made PSSs' experiences so unique was the influence of multiple factors. These included interactions with their friends, family, work, their own inner thought processes, the extent and timing of symptom improvement, and health care professionals' responsiveness to them as individuals. Based on qualitative descriptive analysis of data from each semi-structured interview and dwelling with data across all the interviews, findings revealed five general themes and 15 sub themes that represented the PSSs' perceptions and human responses during the post stroke transitional period.

The PSS Experience

The qualitative description of the post stroke transitional experience begins with PSSs' accounts of how they recognized something was wrong, a significant recollection that remained with them as they began their journey toward recovery. Following discharge directly to home from the hospital, PSSs described a feeling of relief to be home but were disappointed to discover that their thought processes had changed accompanied by a feeling that they could get back to their "normal" selves. While the transition to home was a smooth process for some PSSs, for others it was a time when life seemed riddled with confusion about how to respond to physical and cognitive residual symptoms and their meaning as well as concern about the possibility of experiencing another stroke. This uncertainty brought on feelings of worry, anxiety, or fear. Concern about the potential for another stroke increased PSSs desire for knowledge around how to prevent another stroke experience.

Once home, PSSs described many common experiences about their journeys to discover a new sense of self. PSSs desired a return to a known sense of normal which included working, exercising or visiting with friends. PSSs faced the challenge of preventing another stroke with the use of medication or other life style changes including exercise. PSSs expressed the continued need for good support systems to help them transition into a new sense of self. Finally, PSSs wanted their questions addressed by health care professionals in a timely manner and desired goals of care tailored to their unique situations. The ability to achieve a new sense of self depended on each PSS's ability to cope with uncertainty, which was augmented or diminished by varying factors. The results are depicted in five major themes: the shock of a stroke interrupting a normal day, transition to an unfamiliar home, experiencing life riddled with uncertainty, a journey to a new sense of self, and adjusting to a new sense of self.

Sample

A total of 45 PSSs were approached to participate in the study. Of the 45 participants: one was discharged before consent could be obtained and 7 declined to participate. In total 37 PSSs agreed to participate in the study however two interviews were lost due to mechanical failure of the recorder and four interviews could not be completed due to hospital readmission or inability to contact PSSs via telephone. The final number of interviews completed and analyzed was 31.

Demographic characteristics of the study sample are presented in Table 8 labeled Descriptive Characteristics. The average age of the enrolled participants was 56 years, minimum age was 25 years and maximum age was 83 years. The study sample consisted

of slightly more males than females, with the majority of participants white and living with someone at the time of discharge. The most common comorbidities were hypertension and hyperlipidemia none of the participants had diabetes. Only five PSSs received tPA during hospitalization. Overall, 22 PSSs were given prescriptions for either outpatient therapy or in home therapy. Specifically, almost half of all PSSs received either outpatient or in home occupational therapy. Length of interviews ranged from 11 minutes to 71 minutes. The average time for interviews was 39 minutes. For a detailed layout of descriptive data please refer to Table 8.

Table 8. Descriptive Characteristics

Characteristic	Value
PSSs (n=31)	
Age, <i>mean (SD), yr</i> <i>median, yr</i>	55.94/16.87 58
Gender, <i>n(%)</i>	
Male	17(54.8)
Female	14(45.2)
Race, <i>n(%)</i>	
White	24(77.4)
Black	5(16.1)
Asian	1(3.2)
Not reported	1(3.2)
Ethnicity, <i>n(%)</i>	
Non-Hispanic	29(93.5)
Hispanic	2(6.5)
Comorbidities, <i>n(%)</i>	
Hypertension	18 (58.1)
Hyperlipidemia	11(35.5)
Atrial fibrillation	5(16.1)
Smoking	3(9.7)
Migraines	4(19.4)
Previous Stroke or TIA	6(19.4)
Coronary Artery Disease	2(6.5)
Received tPA, <i>n(%)</i>	5(16.1)

Characteristic	Value
Outpatient services, <i>n</i> (%)	
PT	9(29)
OT	15(48.4)
Speech	3(9.7)
Nursing	6(19.4)

SD=Standard deviation, TIA=transient ischemic attack, tPA=tissue plasminogen activator, PT=physical therapy, OT=occupational therapy

The shock of a stroke interrupting a normal day

Participants described “just an ordinary normal day” suddenly interrupted by the shock of having a stroke. They consistently referred to the shock and emotional reactions they initially experienced when recalling the day their strokes first occurred. The experience reflected their awareness of physical changes such as the inability to move an arm or cognitive changes such as the inability to concentrate. This shock was followed by a description of how participants interpreted their symptoms and then determined the next course of action, that is, whether or not to seek medical attention. Some PSSs described being unable to make this decision on their own because they were either physically unable to or were not aware of what was occurring. PSSs discussed a range of initial symptoms and reactions. Some did not remember what occurred during their stroke while others drove to the hospital with only the awareness that something was different. The dimensions of the shock experience and the scope of PSSs responses to this unexpected interruption were captured by four sub-themes: emotional reaction to stroke onset, physical symptoms, cognitive symptoms, and determining a course of action.

Emotional reaction to stroke onset. PSSs described their reaction to stroke symptoms as a sudden, scary, and shocking experiences that disrupted a normal day. Jason alluded to the normalness of his day prior to his stroke by stating *“it was like any other day running around doing what I had to do”* or Donna who reiterated this point that it was *“just an ordinary normal day...nothing abnormal nothing unusual.”*

Helen described her shock by stating *“I was so shocked I was so so shocked. I felt like they were just gonna tell me I was dehydrated and ya know over tired”* Elizabeth also reported significant fear, *“it surprised me I’ve known people who’ve had strokes....(I’ve) often wondered as a I visited them...what is it like and so forth and it was very scary. Very.”*

Physical symptoms. Some PSSs expressed their onset of stroke symptoms by describing sudden changes in their ability to move their bodies. Generally, the changes they experienced in their bodies occurred on just one side, but some PSSs experienced a complete loss of bodily control. Additionally, some PSSs were unable to speak or had difficulty speaking. George described how he was driving to work in his truck when all of a sudden *“my right side was numb.”* Diane referred to being in a meeting at her place of employment and feeling different, so she went to the restroom and as she tried to return to the meeting from the restroom she stated:

I took about two steps out of the restroom door and my left leg went completely dead and I had to drag it like physically use my hands and hold my pant leg and drag my leg back to the conference room.

Scott alluded to waking up from a dead sleep with a headache and trying to walk downstairs to take some ibuprofen, *"I realized that I had very limited use of my arms and leg...I had no control no strength...I actually had some slurred speech at the time I still had the headache."*

Cognitive symptoms. Other PSSs described their onset of stroke symptoms as changes in their mental processes or thoughts. This was manifested as a vague understanding of their symptoms and often as difficulty interpreting the issue. For example, Charles described how his normal work day was affected by his cognitive changes, *"my mental capacity was just not functional as well as normally ya know trying to do e-mail and, and kinda talk on the phone and things like that seemed to be a little more difficult."* Paul described a routine task at work that normally would have required little thought and stated *"I have the combination memorized and I knew what the combination was and I tried to open the safe and I couldn't do it and I was really dazed and confused and I tried like 13 times."*

Determining a course of action. In response to a sudden, unexpected onset of stroke, the PSSs in this study interpreted their symptoms in their own way and followed different paths to seeking medical attention and getting admitted to the hospital. How or when PSSs got to the hospital depended on how they interpreted their own physical or cognitive changes. The severity and duration of symptoms provided additional insight for PSSs to determine whether or not to seek medical attention immediately or to wait. For example, when symptoms were vague and went away, PSSs were less likely to seek medical attention right away. However, if symptoms were prolonged or impeded their

ability to function they were more likely to seek medical attention quickly. Regardless of the speed or manner in which medical attention was sought, every study participant was eventually admitted to the hospital. PSSs response to their stroke symptoms included seeking medical attention immediately, waiting to seek medical attention, and requiring assistance to seek medication attention.

Most PSS participants sought immediate medical attention. Responses included to either calling 9-1-1 for help or going to the hospital by car. For the participants who went to the hospital by a car, they either drove themselves or had someone else drive them to the hospital. For example, Michael described feeling some numbness on his face and some anxiety and stated *"I said let me go seek some medical attention."* Scott, on the other hand, referred to his headache and blurred vision which quickly worsened and he explained *"I was wobbly um had a hard time using my hands and leg; hands, arms, and legs. So at that point I called 9-1-1."*

In contrast to seeking medical attention immediately, some PSSs allowed significant time to pass between experiencing symptoms and going to the hospital. Delays in seeking treatment revealed some participants' difficulty interpreting the potential cause for changes in their physical or cognitive abilities. To illustrate, Charles described his delay in seeking medical attention:

Wednesday I woke up and my leg was, my right leg...[had] like fallen asleep...[I]went to work, but my everything seemed to be well. My leg was ok, didn't seem to be a big problem at all at this point...Thursday got up and still not feeling well at all, but I did go

to work...Friday morning we didn't have work so I stayed home and then I just felt continually not very clear and accurate on my choice of words...eventually around early afternoon I just said let's go [to the hospital].

Furthermore, PSSs who required assistance to seek medical attention either did not understand that their symptoms required medical attention or they were physically unable to seek medical attention. For example, Jerry described not receiving help until his wife arrived home. Jerry thought he was dehydrated or tired and stated, “*at no time really when I was having the stroke did I realize that I was having a stroke.*”

Peter was running errands and was talking with a receptionist at a store when all of a sudden he could not talk. Given this sudden change, the receptionist had to intervene to get him medical attention. He explained:

I could not talk the only thing that came out was a grunt...I tried to talk again and I could not. And that is when she had me do a couple [of] quick tests because she worked at a hospital at one point and she said I think you're having a seizure and she asked me to sit down and she went next door and got the fire department.

Although the interviews took place after PSSs had returned home, they expressed the shock of the sudden onset of their symptoms and described a variety of responses to an unexpected interruption in their prior normal life. The initial impact of the stroke experience created the context for their beginning recovery as they underwent the transition of discharge home.

Transition to an unfamiliar home

The transition home was a time of anticipation and initial relief. However, there were shadows of disappointment that seem to unexpectedly emerge as PSS's path to recovery took unexpected detours. When comparing the hospital to home, PSSs described home as a place of comfort, but yet unknown given the changes they had experienced, whereas the hospital was just unfamiliar. PSSs experienced difficulty sleeping during their hospitalization and were unable to rest until they returned home. The hospital was discussed as a place where PSSs depended on health care providers for many of their needs. Hospital restrictions were experienced by PSSs as constraints that compromised progress on their physical activity.

PSSs were glad to return home, because they viewed the return home as a milestone and a movement toward gaining control over their lives once again and expecting to get back to their prior routine. However, within the first few days, PSSs realized that home was not the same place as it was prior to their stroke. Some PSSs even described home as a "miserable" place. Other PSSs experienced an overwhelming amount of fatigue once they returned home. For many, returning home was the first step towards getting back to normal. However, PSSs were disappointed to find that the continued symptoms linked to their stroke hindered their ability return to "normal". As such, PSSs described recovery as requiring major adjustments to lifestyles and personal values. Although PSSs classified themselves as mild stroke survivors, the life changes needed to adjust to physical and emotional response to the stroke became overwhelmingly evident during the transition home.

The *theme transition to an unfamiliar home* is characterized by two subthemes: *initial relief of being back home* and *home is not back to normal*. Home as not back to normal was evident with PSSs describing increased fatigue once they were home. In addition, it did not matter the size of a PSSs stroke, PSSs described the stroke as a huge event in their life, that significantly effected how they were experiencing a change in their in values and thoughts as they transitioned home.

Initial relief of being back home. PSSs expressed happiness and relief leaving the hospital and being allowed to return back to their prior routine. PSSs commonly discussed home positively and the hospital negatively. For example, William described his emotional response to being home as “*I do more exercise I feel more comfortable because here [home] I can do more.*” Donna, who almost went to a rehabilitation center instead of home, described her feeling of home by stating, “*oh good I’m fine I’m home.*” Richard described his happiness to be independent at home:

I felt like I was more independent when I get home. When I was at the hospital I felt like I needed, I depended on these people, the healthcare people to help me with stuff, but when I get home I thought I was more independent and could do some more stuff. So I felt better when I got home.

Home is not back to normal. After the initial relief of home wore off, PSSs described how they did not feel comfortable being home or how they did not return to their prior routines. PSSs described situations early within their experience that reflected how home was no longer normal. While full of expectations, recovering at home post

stroke was influenced by changes in function, independence, fatigue, activity intolerance, and symptom distress. PSSs described experiencing fatigue and frequently described tasks as difficult to complete since they did not have the energy. Even though PSSs attempted to understate the effects of their strokes by vocalizing them as minimal or small, they also asserted the need to adjust to the changes brought on by the stroke that were often not minimal or small. Additionally, their thoughts about their life values changed after having a stroke.

One of the participants, Dennis, discussed being glad to be home, but also described becoming increasingly frustrated with how slow his progress toward recovery was and how his inability to return to his prior routine was being impacted. He tried to get back to who he was before the stroke, but perceived himself as unable to actually achieve his own expectations. Based on his wish to get back to normal, he explained why home was not the same for him anymore:

I've been home and I've been numb and I'm fairly miserable I must say... I'd just like to get back to the old Dennis. I liked him I don't like this one. I wish I could get back to normal, that's my only wish and I'm not, I'm far from it.

Another participant Diane described experiencing increased anxiety upon returning home “*I was waking up in the middle of the night gasping for breathing like it was just like really bad the anxiety....it was really, really bad in the beginning...like as soon as I got home.*”

Fatigue once home. PSSs focused on specific symptoms that made transitioning to home different. One of the most compelling symptoms was fatigue. PSSs described experiencing fatigue immediately upon transitioning back home from the hospital. PSSs described how exhaustion hindered their ability to resume a variety of activities which was often related to a need for more sleep. Fatigue fluctuated for all PSSs and most described an overall decrease of fatigue in the first few weeks, but the profound fatigue early during their transition home disrupted their ability to function at home.

For example, Brian discussed having personal fatigue stating *“the day that I got home I slept for a couple of hours...the first couple of days I was real tired too.”* For the first few days, Brian referred to being too tired to walk outside more than a block. Similarly, Joseph described being exhausted when he arrived home and needing to sleep, but also having appointments to schedule with occupational therapy, speech therapy, and his primary care physician. He described himself *“as just constantly exhausted and didn't feel well and stuff for a week.”*

Linda also recalled living with fatigue when she first got home explaining, *“I'm not getting too tired like I was before. The first two weeks of when I left the hospital was very hard,”* but goes further to allude to how her exhaustion lessened over time as:

I was quite exhausted from the experience...I felt good about being home....when I got back to my house....then I slept better and like right now I'm no longer exhausted like I was.

My stroke was so small. PSSs perceived their stroke as small but significant. Once transitioning home PSSs began to reflect on their stroke. Most PSSs downplayed

the severity of their stroke. Adjectives PSSs used to describe their stroke and stroke symptoms were slight, minimal, small, or mild. PSSs focused on how many aspects of their life were similar since the stroke, yet also reflected that having a stroke was a big event in their life with challenges both mentally and physically. Richard described his stroke using words like “slight” and “minimal” but also viewed the experience of having a stroke as significant. When describing his eyesight, he stated *“when I look there I see a very slight um ya know double vision right there, it is very minimal compared to what it was before.”* He later goes on to describe how his stroke was *“minor, but it could be a major too...I am not handicap I just have some problems,”* yet later when reflecting on his experience he stated that it was a *“big recovery mentally and physically.”*

Change in awareness, values and thoughts. Once home PSSs described taking time to reflect on their values and determine if revisions were needed based on their new situations. Once PSSs transitioned home they recognized that they were not the same person they once were prior to the stroke and that they had been changed by their stroke experience. PSSs explored the person they were before the stroke and the person they wanted to be after a stroke. They reflected on what was important in their lives and described things that needed to be changed. As a result of both physical and mental changes caused by the stroke, some PSSs needed to reframe how they focused on certain tasks or respond to specific situations that were part of their lives.

Cassandra described how her life philosophy changed each day since her stroke. Now she believed it was important to, *“use every moment to accomplish something.”* Lisa described how particular tasks required more focus since having a stroke. She

realized how a stroke altered what she could do and how she needed to change her perceptions. Lisa reported that now when she pours a glass of water she has to focus on the task so she doesn't spill it. She stated *"it's getting the perspective ya know I'm not dealing with two eyes so I've got to...be conscious of that."* Jason reflected on his behavior prior to having a stroke and concluded that he wanted to be less aggressive and argumentative with his family and other people. He stated *"I used to be a bit of a hot head...[now] I'm not going to get aggravated."*

As PSSs transitioned home, the realization that home was not the same was more difficult to grasp for some participants than for others. For each PSS, their ability to adjust to life changes strongly depended on their perception of uncertainty and their ability to cope with that uncertainty. The resolution or persistence of post stroke symptoms likewise played an important role influencing each PSS's transition home.

Experiencing life riddled with uncertainty

As each PSS tried to settle in at home, they began to think forward more and experience uncertainty about their future. This was manifested by expressions of concern and anxiety about the future. While PSSs were not constantly thinking about their stroke, they noted that the stroke and possibility of a future stroke was always in the back of their mind and certain situations triggered their thoughts, fears, and anxieties. Due to the sudden onset of their first stroke, PSSs expressed immediate concerns about if or when another stroke would occur. Uncertainty was intensified by the realization that a stroke could happen anywhere without any warning signs. In addition, the ambiguity that permeated the lives of PSSs as they tried to make meaning of symptoms or events they

experienced in their new context of life after a stroke. Several PSSs had difficulty interpreting what symptoms were related to a stroke and which were related to another condition. The uncertainty manifested itself as increased anxiety and ambiguity that permeated their lives during the early post stroke time. Two subthemes characterized experiencing *life riddled with uncertainty: anxiety about having another stroke and ambiguity of symptoms*.

Anxiety about having another stroke. Anxiety was described by PSSs' constant mental awareness that another stroke could occur without warning. This unsettling awareness lingered close in their thoughts, sometimes revealing itself as a feeling of uncertainty. For example, when Peter was asked about his stroke he stated it was always "*in the back of my mind*" which is similar to other responses like William who, referring to his stroke, stated he must "*forget but not forget.*" PSSs did not necessarily think about having another stroke all the time, but described how the next stroke could be much worse. This sense of unpredictability concerned them. For example, Jason stated "*I mean a lot of people just get one stroke and that's it...they're dead or ya know their whole life they're paralyzed for life.*"

Several PSSs worried specifically about having another stroke while they were driving. George commented "*you are driving down the street and thinkin' hey this would be a good place to have a stroke I could pull over right here*" or Helen "*the only thing that I worry about is if I had a stroke driving with my kids.*" Mark described his nervousness about driving "*I'm a little nervous about driving because one of the strokes I had was when I was on the road.*" Donald expressed concern about experiencing another

stroke stating *“it’s so unknown what happened what triggered it...could it come back?”* Linda asked a variety of questions that reflected her concern about the unpredictability of having another stroke *“if I had the one stroke that was small or something like that what’s the [probability] that I will have another one ya know, what can I do ya know, what caused that, what can I do to ah avoid that happening again?”* Mark, wanting to know how to prevent another stroke, asked his physician *“are you more liable to have one [a stroke] ...what I could do and what I couldn’t do...what is the outcome gonna be.”*

PSSs discussed their concern about having another stroke as a major issue.

Elizabeth expressed her fear of having her symptoms return after being discharged home, *“I had a recrudescence of this [stroke symptoms] and ended up back in the hospital and that was scarier than scary.”* William explained that his worry about another stroke occurring as *“well you have to be worried...you have to[be] more careful now.”* Helen described her anxiety related to coming home and constantly worrying about having another stroke. She described her emotional response to anxiety as:

The first week was really hard I felt very anxious...so the feeling of something bad like a stroke happening at any second is a little bit...I’m nervous if it will happen again especially [since] I have two kids

Ambiguity of symptoms. Another way in which PSSs found their lives riddled with uncertainty, manifested itself as difficulty interpreting the difference between stroke symptoms and other symptoms. Indicators that might have previously gone unnoticed, ignored or attributed to some other phenomenon, took on new meaning in the context of

anxiety about having another stroke. For example, Nancy was concerned if some of her cognitive difficulties were reflective of a stroke, old age, or a precursor to Alzheimer's. She explained, "*I spend most of my days trying to decide if I am depressed or just tired. I mean it's hard to separate aging and Alzheimer's and stroke.*" When asked about his ability to maintain his home, Mark had difficulty determining if some of his physical limitations were related to stroke or age. He explained:

I'm not as young as I was....I think it's more age related than stroke related although I really don't know it is hard to kinda of separate the two for me...I get tired and I don't know whether it is the stroke or just age.

The combination of anxiety and ambiguity about the meaning of symptoms underscored the uncertainty that riddle the lives of PSSs recovery at home. PSSs described their emotional responses as feelings associated with nervousness, anxiety, worry, or fear. Helen was concerned that something bad was going to happen and would frequently ask questions during the interview to determine if her symptoms were indicative of another stroke or required further medical attention.

A journey to a new sense of self

As PSSs navigated their journey towards a new sense of self post stroke, many referred to uncertainty and how it could be resolved throughout the journey following the post stroke experience. The scope of responses to uncertainty, and how PSSs were able to cope with it, were influenced by various factors that the researcher labeled as facilitators and barriers in the journey to a new sense of self including the interaction of

facilitators, (which helped them cope with uncertainty), and barriers, (which impeded their ability to cope with uncertainty). Despite each PSS's unique response to the stroke experience there were commonalities that were similar enough to provide insight into how PSSs balanced several interacting factors. These factors are captured in the following subthemes: *return versus non-return to a prior routine; knowing versus not knowing what caused their stroke; support systems perceived as helpful versus unhelpful; and answered versus unanswered questions.*

Facilitating factors were classified as personal, interpersonal, and cognitive. Personal factors included activities such as engagement in work and exercise, interpersonal factors included visiting with friends and having a good support system, and cognitive factors involved coming to understand the cause or underlying reasons for a stroke. PSSs also had to balance the quality of interactions with the health care system.

Barriers to the recovery experience often manifested by challenges that were the counter to facilitators with examples including inability to return to prior routine, unhelpful support system, unanswered questions by health care professionals, and delay in follow-up after discharge home. In trying to cope with uncertainty, PSSs described these facilitators and barriers and their experiences as they explored a new sense of self. As PSSs adjusted to a new sense of self they reflected on their current situation and searched for ways to gain the confidence needed to manage with their new life as a PSS.

Returning versus non-returning to a prior routine. How soon, and how completely PSSs were able to return to meaningful aspects of their pre-stroke routine was a key factor that directly impacted their ability to integrate the PSS experience into their

new sense of self, as described in the following section illustrating the significance of return versus non-return to a prior routine.

PSSs described their integration and ability to return to their prior routine as facilitating their coping with uncertainty. Facilitators were reflected in experiences such as PSS's ability to go back to work, exercise, and/or go out with friends. Each PSS perceived the speed and ability to return to their prior life routines as increasing their comfort with resuming or attempting further activities. For example, Scott went on a business/vacation trip shortly after discharge home and stated, "*then the following week I went to [state] for a little bit of business and a little bit of pleasure. Just kinda got away for a little bit, played some golf.*" During this trip he learned he was able to work, visit with his friends, and play golf. Once he returned home he was confident that he would be able to complete his job duties and continue to try other activities that he enjoyed.

Charles, in a similar manner, described a steady increase in his ability to do exercise and feeling comfortable in that aspect of this functioning:

Every day seems to kinda improve on all aspects of what I'm doing ya know... [I] keep walking up the hills...so that was the first step...it was less of a problem and yesterday I basically walked for 3 miles and don't seem to have any, very few walking problems at all its just I'm just normally walking...so I feel fairly comfortable in that aspect of my activity.

Later in the interview Charles described how he wanted to return to work because he now felt he was strong enough based on his ability to tolerate walking. He now felt he wanted to focus on improving his mental activity.

Conversely, a barrier was perceived by PSSs as factors that made it difficult for PSSs to cope effectively with uncertainty as the delay or inability to return to work, visit friends, exercise, or experiences. When these barriers occurred PSSs described the interference of these barriers in achieving their expectations.

PSSs expressed their uncertainty as fear or questions about their ability to recover. For example, Mary described going out one day for a doctor's appointment, visiting family members, and going out for a light snack with her partner. When she got home that day she could barely walk up the stairs due to exhaustion. She stated "*that was way too much I should have just gone to the doctors and come home.*" Mary later expressed "*I was really scared. The feeling of weakness in my limbs was frightening.*" Due to this experience she expressed uncertainty about when she would ever be able to return to work or do multiple tasks in a day like visiting friends and going to the grocery store.

Richard also described his desire to ease back into prior activities, but noted that he was uncertain he had the energy to maintain his prior routine. He explained:

I am still limiting myself from doing any heavy lifting or being too active...I am just trying to get back into that groove again I think...when I jump in and do too much I notice I am just a little bit more tired.

PSS's ability to return to their prior routine in a timely, smooth, and anticipated way was one of many interacting factors that PSSs expressed as salient personal experiences facilitating or hindering their journey to a new sense of self. This was not the sole factor, but rather one tipping point along PSSs' path toward integrating the experiences of having had a stroke into a new sense of self.

Knowing versus not knowing what caused their stroke. PSSs described how understanding the cause of their stroke was an important factor in their journey towards a new sense of self. An explanation of the cause of their stroke decreased feelings of uncertainty and gave PSSs a sense of control and ability to engage in purposeful actions to prevent another stroke. Lack of knowledge about the cause of their stroke left PSSs with feelings of frustration and uncertainty and compromised their feeling empowered to prevent another stroke from occurring.

PSSs described how knowledge about the cause of their stroke helped them cope with uncertainty and move forward. PSSs conveyed wanting to comprehend the exact reason for experiencing their stroke. PSSs described exact reasons for a stroke as hypertension, atrial fibrillation, or a patent foramen ovale. Once the cause for the stroke was understood, PSSs felt they could then take specific action to prevent another stroke from occurring. More specifically, PSSs explained how they were able to institute specific lifestyle changes such as taking a medication for hypertension, increasing exercise, improving nutrition and reducing their weight, or having surgery to close a patent foramen ovale.

The following example illustrates how these specific actions mitigated the uncertainty over whether or not another stroke would occur. In many cases PSSs expressed relief in knowing that they could engage in actions to prevent another stroke with lifestyle changes. For example, Elizabeth was diagnosed with hypertension and started a new medication regimen. She was glad to take her anti-hypertensive medications and explained:

*I think it's comforting to know ok one's going to take care of this.
One's gonna take care of that...I think that's the more reassuring
part about the medication.*

Another example was Mary who knew she had atrial fibrillation but had been off her Coumadin for over a year due to complications. Prior to her stroke she explained that she procrastinated on a follow-up with her cardiologist to determine if she should start Coumadin again. She thought the cause of her stroke was due to her atrial fibrillation and her lack of Coumadin with this condition. She explained:

*That is probably why I ended up this way in the first
place...Coumadin was probably the most important part of the
equation that I was missing and I guess I'm really lucky that
nothing worse happened because of the blood clots.*

After her stroke, Mary made an appointment with her cardiologist and was prescribed Coumadin, an anticoagulant medication that helps prevent stroke. Since being discharged, she follows her Coumadin levels closely and made an appointment with her cardiologist for continued management. Despite feeling apprehensive about meeting

with her cardiologist, she felt in control of her current situation and her ability to follow through with actions that could help prevent another stroke from occurring.

However, medication only lessened uncertainty if the PSS was convinced it would decrease their chances of another stroke occurrence. PSSs expressed the need to feel comfortable and assured of the actions suggested by their health care team that would likely prevent future strokes. Lisa described how she was placed on a medication, but was unconvinced of that particular medication's effectiveness. When the medication was changed to one that she thought would be more preventative of another stroke, she described experiencing less uncertainty. Similarly, Lisa, who had a history of atrial fibrillation described how she was sent home from the hospital on an aspirin, not her prior medication of Pradaxa for atrial fibrillation. She remembered being instructed to see her cardiologist, but she could not get an appointment for a few weeks after being discharged home. Not being able to get an appointment soon made her nervous as she thought about having another stroke. To manage her anxiety she scheduled an earlier appointment with a different cardiologist. With the appointment, Pradaxa was restarted. Lisa described how her nervousness changed once she was no longer just taking aspirin:

Interviewer: when did the nervousness happen?

Lisa: by the time I got home and I was just thinking about it and I thought geez after just having gone through what I'd gone through I don't want to wait a couple of weeks [to see her prior cardiologist] ...I just didn't want to wait...

Interviewer: When did the nervousness end?

Lisa: so it ended once I saw the other doctor [cardiologist] and he put me on Pradaxa.

PSSs also described situations where they felt they were in control and could choose what course of action they could take to prevent another stroke. Sometimes the options included surgery while other times it was lifestyle changes such as increasing exercise or diet changes. Scott's physician diagnosed him with a patent foramen ovale and he was given three options to decrease his chances of having another stroke. He described weighing the benefits of each option, trying to determine which option would decrease his chance of another stroke and have the least amount of potential repercussions. He explained his story:

...and one of the options is to go on a low dose of aspirin....the second option was to go through and use the Coumadin which is a much more advanced blood thinner than the aspirin...the last option was to go in and close the hole a little surgical procedure it's invasive not a big deal...it's a hard decision to make.

Similarly, Richard described his options to decrease the probability of having another stroke based on his ability to control his lifestyle habits. He felt the need to change his diet and exercise. He explained:

I should exercise more and I should eat better and I think this was just like a kicker. Yeah maybe I should even though my blood work and stuff seems to be normal, but I think I think I do need a lifestyle change too.

Conversely, PSSs expressed uncertainty when they were unsure what caused their stroke and what specific actions they could take to prevent another one. This uncertainty was expressed by questions about the future and feelings of frustration associated with recovery. For example, George described his reaction about not knowing the cause of his stroke

...cause then...then there is an end. You can fix it, you can stop it, you can cut, you can repair it. You can replace it.....what happened to me nobody knows.

George believed he lacked specific actions that could decrease his risk for another stroke. He even described how he wanted a solution to his stroke such as surgery or another solution. George explained his conversation with health care professionals that fostered his uncertainty:

Your blood pressure phenomenal, your heart rate phenomenal, your blood sugar phenomenal, you're trying to think what else. Whatever else they [physicians] took of me phenomenal ...and I said...what the heck am I doing here then....if everything is perfect what am I here [for], why am I here...that sort of is what blows my mind. I'm your perfect health perfect patient perfect, perfect what happened to me why am I here?...That was frustrating because you want to know it's almost like sometimes I wished they said well you have a little thing here. Ok well alright I had something how do we get rid of it? We zap it, we flush it we cut it out we put

whatever you do to it. Then you have a definitive answer. This is what happened to you this is how we fixed you. Cut and dry. Ok good. Whatever it takes cut you open give you this, take this pill, whatever it is. Not knowing, I'm like yeah whoa. I'm like on the one hand awesome I'm perfect health they couldn't find anything wrong with me that is great. But then I almost wished they found something so then I could treat it and do something with it.

When PSSs knew the cause of their stroke and could identify specific actions that they believed could prevent another stroke and integrate these into their lives, enabling them to convey a sense of control that facilitated their being able to move forward with their lives. Conversely, PSSs who expressed not knowing the cause of their stroke lacked perceptions of specific actions that could prevent another stroke from occurring. This response engendered feelings of vulnerability, helplessness, and uncertainty and created barriers that compromised their journey toward a new sense of self. The phenomenon of knowing versus not knowing about the cause of a stroke was important both for the individual PSS and across all PSSs that influenced the way each PSS's journey to recovery unfolded.

Support systems perceived as helpful versus unhelpful. PSSs described how a support system provided yet another element that affected their journey to a new sense of self. A helpful support system allowed PSSs to believe they had someone they could work in conjunction with as the PSS learned how to cope with their new life situation. PSSs noted that having supports perceived as unhelpful hindered their ability to feel

comfortable and compromised their momentum to lead them into their new environment as a PSS.

Among the helpful aspects of a support system, PSSs described how a support system helped them cope with uncertainty after a stroke. A support system was explained by PSSs as including individuals such as family, friends, or medical professionals. PSSs also placed great emphasis on particular traits and behaviors of their support person that were helpful and how their support system motivated them along the journey to recovery.

During each PSS's transition back home, helpful support systems played the important role of reinforcing and assisting in changes. Richard described how his wife was part of his support system. He discussed how she helped him to change his lifestyle by stating "*she also put me on a diet which ya know was ok by me now because I should have been on a diet a long time ago.*"

Similarly, Diane described how her nurse was her positive support. The nurse helped her feel less alone, since she did not have support from family and friends once she was discharged to home. Diane described her follow-up phone conversation with the nurse,

I mean she called not only once but twice...after hearing me describing what happened and everything, she did call again just a few days later to see how things were going. Seeing if I needed any more information. She gave me a number where I could call

there at the hospital...even in the middle of the night....it was comforting to know that I had that option.

PSSs described a variety of traits associated with a helpful support person. They included empathy, patience and listening. PSSs also described the importance of having a support system that did not stigmatize them because of their stroke or treat them as though they were disabled. Cassandra described helpful traits of her family and friends as “*they haven't tried to put me in to a place of being some kind of victim or a patient.*”

Theresa explained helpful traits for a support system as:

Some of them [support person] are easily able to be natural and empathetic... they wait and watch and listen for signals from you in terms of how much you're ready to talk...[let you know] that you're not in this boat alone.

There were PSSs who did view their dependents as part of their support systems. They did so because they perceived to be motivated to work towards a desired goal and be there for those who relied on them. For example, Jason wanted to be a part of his daughter's life. She was less than two years old and he wanted to change his eating and smoking habits, so he would be there for her in the future. Mark described that even though his children were older with children of their own, he still wanted to be around for them and he was unsure if his children were ready to not have a dad. Mark was unwilling to say after his stroke his life was over, rather affirming that his life was important and he wanted to be there for his children.

Conversely, PSSs described qualities of their support systems that made it harder to integrate their experience into a new sense of self. Support systems that were depicted as unhelpful were generally viewed by PSSs as negative or demeaning. While PSSs acknowledged that these supporters did not intend to be demeaning, PSSs perceived them to be. An absent or unhelpful support system created situations where PSSs felt they were being held back in their recovery. This often created another challenge for the PSSs to cope with situations that were already perceived to be difficult. For example, Theresa described unhelpful traits in her support system as someone who was “*pitying*.” She explained that when people pitied her they would finish her sentences instead of allowing her the time to try and complete them herself. She felt this prevented her from practicing her speech and hindered her recovery. Likewise, Frank also described characteristics of support systems that he perceived as not helpful such as “*acting like I’m fragile that will be unhelpful*.” After being discharged home, Diane discussed her difficulty in dealing with her PSS experience. She did not have a good family or friend support system. She responded:

no one came by to see me afterwards no one offered to do anything for me no one called me so that has been something ya know on top of what I went through that made it harder to kind of deal with what happened to me.

The experience of being helped by a support system during recovery following a stroke was another key factor described by PSSs that challenged their journey to a new sense of self. While the concept of support systems was perceived by PSSs as helpful in

achieving a new sense of self there were experiences where support systems left PSSs feeling even more uncertain about themselves and their future. Though PSSs described the importance and qualities of a support system, a support system was not a sole factor that determined a PSSs ability to adjust to a new sense of self. Again this factor was important both uniquely and interactively in creating the context for recovery. Another significant part of this context described by PSSs in this study was interactions with the health care system.

Answered and unanswered questions. Answered and unanswered questions represent a series of critical factors that focused on PSSs recollections of their interactions with the health care system. Across this early phase of recovery, first four weeks after discharge directly home from the hospital, PSSs described interactions with the health care system as being important to them. This included how health care professionals addressed their questions, the timing of follow-up appointments after discharge home, and whether a cohesive plan of care was developed between PSSs and their health care professional. PSSs expressed being more able to achieve a new sense of self when their questions were answered quickly, when they had a follow-up within a few days of discharge, and when they created a plan of care together with their health care provider. In many instances, health care providers were perceived as barriers to the ability to achieve a new sense when they were unavailable or unwilling to respond to specific needs based on each PSS's experiences.

When PSSs' questions were immediately answered by health care professionals, PSSs expressed being able to understand and address their concerns and determine a next

course of action. However, when questions were not immediately addressed, PSSs felt neglected and questioned what next course of action was appropriate.

PSSs explained that they had an easier time coping with uncertainty when their questions were perceived as answered quickly and adequately by health care professionals. Since questions and concerns could arise at any time, such as in the hospital, within the first day of being home, or weeks later, PSSs wanted their questions answered accurately and immediately. PSSs emphasized the importance of having the ability to contact a medical professional with concerns and questions to determine next steps.

For example, Lisa was having visual changes since being discharged home and was concerned the symptoms were indicative of another stroke. She called her neurologist right away instead of waiting for her follow-up appointment, which was days away. She described her conversation with the neurologist and said she felt it:

...was very reassuring he didn't tell me not to come [to the hospital] but he was very reassuring and um I felt better after I spoke with him and I thought well I'll just, just wait and see if things get better.

Similarly, Frank described how his health care team addressed his questions in the hospital, which was helpful once he got home. He remembered the health care team telling him that his patent foramen ovale may not be the cause of his stroke, because it was so small. However, Frank he did not have any other risk factors, so the physician explained to him that in many cases the cause of a stroke is unknown. After his

conversation with the physicians he stated *“I guess it was good that he kinda set my expectations.”* Frank felt his questions were adequately addressed in the hospital, so once at home he denied having questions regarding the cause of his stroke.

Conversely, there were PSSs who described their health care professionals as failing to respond to their specific needs. They perceived that this lack of response exacerbated their uncertainty as well as their ability to handle their unique situation. PSSs expressed frustration when health care providers failed to respond to questions and/or provide generalized care that did not take into account their specific needs or concerns.

As an example of this barrier, Jack frequently described frustration with his physicians and noted when he wanted further information about his diagnosis, prognosis for the future, and an explanation about his dizziness. He explained:

The nurses, doctors, and everybody they just look at me like I'm crazy so nobody wants to address it. And I, I don't know if they are just ignorin' me or what. But nobody will answer the question ya know that I have, they don't have any opinions on it either or theories...well I would like doctors particularly to be a little bit more informative to discuss your condition...They don't look at the whole picture they don't look at the person as an individual.

Similar to Jack, who felt his physicians were not looking at the whole picture, both Joseph and Cassandra expressed concern about how their health care providers did not take into account their specific situation. Joseph described a conversation with an

occupational therapist where he wanted to discuss his concerns about his concentration and vision. However, that is not how the conversation went. He explained “*I was wanting to focus on those [concentration and vision] and they were kind of locked into well we have to go through the procedure.*” Unfortunately the occupational therapist never addressed his concerns and Joseph described being frustrated and unsure what he could do to work on his concentration and vision that were his priorities. Similarly, Cassandra described her follow-up appointment with a neurologist:

[he] didn't really listen to me very well and so I'm a little concerned...it actually made me angry...he was treating me like I was straight out of some text book when in reality my symptoms might be, but I have a whole different set of life experiences and emotions to go with those textbook symptoms that makes me an individual...and he disregarded me as a person.

As emphasized by PSSs in this study, when questions and concerns were promptly answered questions by health care providers it allowed them to determine their next steps in their care leaving them in control of their own journey. When questions remained unanswered or perceived to be answered poorly, PSSs felt frustrated and restrained, impeding the adjustment to a new sense of self.

Early versus delayed follow-up. In order for health care providers to adequately address PSSs' questions and concerns, follow-up with a health care provider usually occurred within the first few days after discharge home as identified by participants in this study. PSSs expressed less uncertainty when follow-up after discharge home

occurred within the first few days. When there was a delay in follow-up, it was described by PSSs as a factor that increased their concerns and frustration.

PSSs felt they were able to address their uncertainty when they had an early follow-up with a health care professional. Follow-up after being discharged home was through a nurse, physician, or therapist usually in the form of a phone call, an appointment, or services at a PSS's house. A follow-up with the PSSs gave them an opportunity to ask questions and formulate a plan that would prevent them from having another stroke. For example, when Frank flew back home, he informed his primary care physician of his stroke. In less than a week he had appointments with a neurologist and cardiologist closer to home where he could discuss and address his health concerns associated with his patent foramen ovale. He felt his follow-up communication with the physicians was extremely helpful and explained:

I flew back home got back here Tuesday night...and I was keeping my general practitioner informed...and we set up for a neurologist here on the following Monday. An then I set up for a cardiologist I just saw him this past Monday [a week later than neurologist] and he ordered some more tests...I'm grateful that I had the care that I had and that they [physicians in the hospital] did everything they were supposed to do and then they released me home and I'm getting the appropriate follow-up here and so no I think that's been all as I'd like it.

Conversely, PSSs also expressed difficulty handling uncertainty when they experienced a delay in follow-up care after being discharged home from the hospital. Delay in follow-up care with PSSs was described as difficulty coordinating follow-up appointments or experiencing multiple weeks passing after discharge without contact from a health care professional. PSSs expressed their frustration when appointments were not scheduled or questions were left unanswered. When this occurred, PSSs experienced increased uncertainty with their recovery.

Several PSSs described difficulty with scheduling follow-up appointments that were recommended by their physician while they were in the hospital, but were not scheduled prior to discharge. Donald, for example, described his difficulty coordinating his care after discharge home as, *“I think they should have a follow-up....they never submitted my records to my primary care physician I had to do that myself...they don't have post follow-up skills.”* Dennis reported being unable to schedule his home therapy or follow-up appointments as well. He stated *“I've been trying to and apparently it's not covered by my insurance...but that is something that's on my target list for today because I really do want to do that.”*

Some PSSs had follow-up appointments scheduled, but the appointment was weeks after discharge home, so PSSs expressed a lot of concerns or questions during their interview. Helen, had unanswered questions about symptoms she was still experiencing after discharge from the hospital to home. She reported that her follow-up appointment was scheduled to occur over a month after being discharged home. Frequently during the

interview process, Helen would ask the interviewer “*is that normal?*” At the end of the interview she expressed what would have been more helpful as:

I think just having a follow-up, like if I had an appointment with my neurologist this week it would be more settled and ya know I've had a few weeks to kind of live with the new way things have been that I think probably that if it was standard for someone ya know getting discharged from the hospital to meet with the neurologist in like two weeks. I think that would probably be, I just think that would have been a lot better.

Timely follow-up with a health care provider was described as supportive to PSSs' goals and offered them an effective strategy to help prevent the occurrence of another stroke. Follow-up after discharge from the transition from hospital to home was described as helpful in assisting PSSs recovery to their new lives. Delays in follow-up care were reported to leave PSSs feeling unsure about their remaining symptoms and prevented them from moving forward in their life journey.

In addition to early follow-up by health care providers, the transitional experience for PSSs was enhanced and facilitated by the creation of a cohesive plan between health care providers and PSSs. PSSs described unique examples of how their health care providers worked with them to develop plans of care that reflected their unique responses to their stroke experience. Cohesive plans of care helped PSSs adequately address their concerns and reflected their personal goals as they began to experience an adjustment to a new sense of self.

PSSs expressed less uncertainty when they established a unified plan of care with their health care professionals. A unified plan was described by study participants as one created by the health care professional in conjunction with the PSS. This approach enabled PSSs to identify their meaningful goals and desires with their health care professional and then determine the next steps to achieve them. Whether the health care professional was a nurse, physician, or therapist, PSSs described how much they wanted to be a part of the decision making process of determining their goals for recovery. To illustrate, Joseph, who considered himself a fast reader prior to his stroke, was irritated by his inability to read with his prior speed. He described how his speech pathologist took the time to understand his situation and determine the next course of action that would benefit him. He described his conversation with the speech pathologist as:

I have some short term memory impact...She [speech pathologist] said you're in the normal range already it's just not as good as you're used to and it will get better over time and there are things that you can do to re-train it if you use it like that. But you just need to realize, and she actually said you don't really have to come for any speech therapy, which would include reading too, but I think [speech pathologist] we might be able to at least help you to understand better your range of deficits and some strategies for dealing with them...[I think] that will be helpful at least to get better characterized....And she was great.

Creating a cohesive plan of care was viewed by PSSs as requiring health care providers to listen to PSSs needs and concerns to help them achieve their specific goals. When PSSs learned how to understand their symptoms and their new situation, it supported their adjustment to a new sense of self.

As PSSs journeyed to a new sense of self the interactions of the health care system either made their journey easier or difficult. PSSs expressed an easier transition to recovery when they could discuss their questions and concerns with health care providers within a few days following discharge and when health care providers were responsive and took the time to determine each PSSs unique goals and wishes.

Although a positive interaction with the health care system was described as a large factor in contributing to a new sense of self. PSSs noted that interactions with the health care system were another important factor both uniquely and interactively in creating the context for recovery. The impact of the return versus non-return to a prior routine; knowing versus not knowing what caused their stroke; helpful versus unhelpful support system; answered versus unanswered questions; and early versus delayed follow-up all created unique experiences for PSSs. All of these experiences influenced PSSs journey to recovery. PSSs then had to process their new situation and learn to cope with their situation to adjust to a new sense of self.

Adjusting to a new sense of self

As PSSs described their journey toward a new sense of self they provided detailed explanations around how they adjusted their lives based on their unique transition from hospital to home following a stroke. The experience of adjusting to a new sense of self

after a stroke is a complex process, unique for every individual and requires PSSs to effectively cope with uncertainty, within the context of balancing facilitators and barriers. For many PSSs this process began once PSSs were discharged to home and continued across the first four weeks of being home, based on the focus for this study. PSSs expressed how they interpreted their thoughts and activities as they tried to gain confidence, return to their prior activities, and feel comfortable with changes associated with their new situation.

For PSSs, a part of their ability to recover was linked to PSSs accepting some level of uncertainty in their lives. The ability to adjust to a new sense of self was reported to be influenced by the PSSs ability to address barriers and facilitators that PSSs experienced. PSSs described that having just one barrier could create enough of an imbalance to disrupt a PSS's ability to achieve a new sense self. While some PSSs discussed being able to achieve a new sense of self within days, others required more time to adjust to feelings of uncertainty due to their reported imbalance of facilitators and barriers. The process of making meaning, balancing the interplay of facilitators and barriers, and the importance of timing are elaborated in the following sections.

Interpreting their situation. As PSSs described the process of adjusting to their new sense of self, they began to actively engage in making meaning of their situation as part of their journey of accepting their new life as a PSS. This new understanding involved reorganizing their thoughts, accepting some level of uncertainty, and accepting of their new sense of self. Not every PSS progressed in the same way, but PSS's stories indicated that many were acclimating to their new post stroke situation in their own

unique way. Ryan, for example, reflected on how he was currently coping with his situation since having a stroke as:

Originally I was very concerned when I heard I might need a pacemaker...I guess at this point I am kinda over it if I have to have a pacemaker I have to have a pacemaker. I'm not gonna get more concerned than that. I mean it's not actually ideal, but it could be a lot worse I guess.

Similarly, Scott described how he was coping with his situation since being placed on blood thinners for a patent foramen ovale as:

It's like alright here's what happened here's why it happened. What am I doing to increase my chance of having this happen again? Well nothing, ok well move on ya know, I don't really have a hard time being able to compartmentalize that and move on.

Michael added another dimension as he described his situation based on what he thought it would be like in the future for him:

I realize that these are symptoms and issues you are gonna have to resolve...and find a solution for...so it's fine for me it's just getting' it done and finding a way to prevent them from occurring...because eventually, eventually you have to be well that is why I say on the mend these things are just on the mending now in the process of mending.

Balance of facilitators and barriers. Balancing facilitators and barriers affected how PSSs were propelled or hindered along their journey to their new sense of self. While in general, more barriers than facilitators appeared to hinder each PSS's ability to adjust to a new sense of self, this does not mean having just one barrier could not cause significant perceptions of uncertainty, nor that multiple facilitators could outweigh certain barriers. The personal and health care system related factors were described as interacting during the PSS early post stroke experience. PSSs described balancing facilitators and barriers that occurred on their journey, which required them to reflect on their stroke experience overall, taking into account all the experiences they had encountered throughout their transition. They highlighted the importance of their story as a whole through their unique interplay of their experiences. Attending to just one or two barriers did not address the totality of a PSS's experience as they described the complexity of this transition.

Dennis described a negative experience that left him feeling miserable and aggravated while at home. He attributed his response due to his continued numbness and tingling he experienced after the stroke. He wondered when these symptoms would stop and frequently expressed frustration about having them. In addition he was unable to schedule his follow-up appointments and was unsure when or if he would be able to work again. Dennis described that during this period his family was very supportive and noted that his relationship with his wife had improved since coming home. Dennis's barriers appeared to be overpowered by his facilitators, which prevented his ability to cope with uncertainty such that he could not adjust to his new sense of self. He stated:

The not knowing of the length of time it takes to recoup, the not knowing, ya know you wake up with some flu the 4th or 6th or 7th day you wake up and feel better. Ya know and I'm not feeling better and... I'm just wondering whether I've ever be me again... I wish I could get back to normal, that's my only wish and I'm not, I'm far from it.

In contrast, Paul, described a more positive experience, during his post stroke experience. For Paul, the majority of his physical symptoms were resolved and he was able to return to work, and was in the process of changing his lifestyle habits to decrease his risk for another stroke. Paul had an endarterectomy and a visiting nurse came to his house after he was discharged. He described how the visiting nurse answered his questions, addressing his needs and concerns. Paul described his stroke experience as:

That's kinda weird isn't it but I mean it would be it kinda stupid to say it was a pleasant experience, because it wasn't a pleasant experience but it was...it was a lot different than I would have ever thought that it would have been after having a stroke.

While time was a factor for some study participants for balancing facilitators and barriers, there was little evidence to suggest that the journey to a new sense of self could be adequately portrayed by a specific period within the first four weeks. For each PSS adjusting to a new sense of self was based more on the timing of PSSs' unique experiences, as opposed to a predictable timeframe that would apply to PSSs in general.

Time and timing. PSSs perception of time through their unique set of experiences was not based on a determined day post discharge. In the examples above, Paul described his experience in the past tense, suggesting his adjustment was more solidified than Dennis, who described his adjustment in the future tense and likely still trying to move forward on his journey. Generally, PSSs who spoke in the past tense were more likely to have already achieved their new sense of self, while those who spoke in present or future tense were likely still adjusting. Though PSSs did not always specifically refer to time, many described a process of learning and adjusting as one that occurred over time. For example, Elizabeth required some time to adjust as she started a hypertension medication and had several weeks to gain control of her situation. She decided going to a center to get her blood pressure checked weekly, so she could be sure her blood pressure was being controlled by her medication.

In contrast, Donna after only a few days, appeared to be adjusting to her current situation. She was using a walker, but had not attempted to take a shower at home due to her unsteady gait. She described how her family helped her with chores around the house such as making her bed and providing food. She had not driven due to vision issues, but did not dwell on that subject. Overall, Donna expressed that everything was going well and could not think of anything else that would help. However, Donna elaborated on her adjustment using gerunds, suggesting she was still in the process of adjusting to her situation. She explained:

Donna: Yeah I'm finding that I'm doing quite well for what I had, with the stroke and all that I'm comin' along fine...I understand that is part of the game and it's gonna disappear...

Interviewer: do you have any concerns right now?

Donna: no I think everything is coming along.

Evolution of Data analysis

The experiential data provided by the study participants illuminated how the PSS transitional experience from hospital to home during the first four weeks. The data was best understood by examining the transitional period of PSSs in its entirety, that is over the first four weeks rather than separating experiences by weekly cohorts. Cohorts were originally separated by interview time since days post discharge, where the first cohort of participants were interviewed within the first 24-48 hours and week two, three, and four cohorts were interviewed 2-4 weeks after being discharged home.

While categories were analyzed separately for each cohort during the initial data reduction phase, it became clear as data collection continued the experiences of PSSs during the first four weeks as a whole provided increased clarity of the transitional time for PSSs, rather than the original plan of separating the experiences by cohort. Thus, the a priori concept of time in the study's purpose was revised based on the data from this study. As suggested by Patton (1990), describing the larger experience of PSSs transition home during the first four weeks also captures the core experiences of each cohort. Furthermore, describing cohorts as one group allowed for a better description of the central themes that emerged from the stories of the participants. Therefore, the decision

was made to collapse cohorts 1, 2, 3, and 4 into one group of PSSs during the first four weeks after discharge home from the hospital. Despite the collapsing of cohorts PSSs adjusting to a new sense of self did have an element of time, but understanding time shifted from the original purpose of the study

Summary

This investigation focused on the post stroke experience of individuals who were discharged from the hospital directly to home. The study findings illuminated several important elements related to the uncertainty PSSs experienced as they transitioned from hospital to home. After the initial shock of their stroke and related symptoms, PSSs discovered that their sense of self had changed. Discharge to home brought PSSs a sense of relief, but as their transition home continued, they became disappointed that they were not returning to their perceived prior self. Rather, PSSs discussed dealing with their physical and cognitive symptoms that potentiated feelings of worry, anxiety or fear. They wanted to know strategies to prevent another stroke from occurring so they could lessen their uncertainty.

The unique experiences of PSSs also created common themes that related to the transitional period from hospital to home which occurred at different times across their early recovery and could not be separated by pre-determined time frames. The facilitators and barriers experienced by PSSs after being discharged home directly from the hospital, affected how PSSs were able to adjust to a new sense of self. Balancing these facilitators and barriers was essential for PSSs to address their uncertainty and journey toward a new sense of self. Several key experiences that impacted the journey

toward a new sense of self included the ability to return to a prior routine, understanding the cause of their stroke, and a helpful support system. The findings also highlight the importance of PSS's interactions with health care professionals. PSSs wanted questions to be answered quickly, timely follow-ups, and an established plan of care with their health care professional that reflected their concerns, needs and goals. In many cases health care professionals who did not provide individualized care for PSSs exacerbated PSSs uncertainty and feelings of frustration.

PSSs described that they adjusted to their new sense of self by accepting some level of uncertainty and learning how to cope with their unique situation. The findings from this study contribute to the important role that health care professionals, such as nurses, play in facilitating PSSs journey to recovery by creating a relationship which offers understanding of their unique situations and assisting them in balancing the facilitators and barriers that impact recovery and the movement towards a new sense of self.

Chapter 5

Discussion

This chapter summarizes post stroke survivors' (PSSs) experiences during the first four weeks of returning home and how those experiences relate to and inform prior stroke research. This discussion is followed by implications for nursing practice, research, and policy to improve transitional care for PSSs. A synthesis of the findings and specific examples of how nurses can change and guide future care of PSSs is provided. Several implications are discussed for nursing practice such as how advanced neuroscience nurses can tailor PSS care that reflects both their physical and psychological needs. Based on the current state of knowledge there are several policy implications at the hospital level such as restructuring the follow-up care for PSS and on a global level of rethinking stroke awareness for the public. There are several implications this study has that support changes in stroke research, such as the implementation of the Transitional Care Model (TCM) by Mary Naylor (2011) for all PSSs regardless of age or physical impairment after discharge from the hospital.

Overview

The purpose of this study was to describe PSSs' experiences during the first four weeks after discharge home to understand the content and timing of challenges they encountered on their journey to achieving a new sense of self. Knowledge gained from this study provides a framework for redesigning care of PSSs during their early transition from hospital to home. While previous research has shown that PSSs in the community suffer from physical, psychological and cognitive sequelae even years after a stroke

(Erikson et al., 2010; Green & King, 2009; Reed et al., 2010; Schmid et al., 2009; van Veenendaal et al., 1996), there has been limited research to address patient's early transitional experiences during the beginning process of recovery. This gap in research has limited the ability to develop interventions for PSSs that reflect their unique experiences to facilitate the immediate post-hospital transition to home with the long term goal of improving outcomes over time.

This investigation is the first study to focus specifically on the PSSs experiences when they were discharged directly home following hospitalization of a stroke during the first four weeks of their recovery. The severity of stroke for this study was not measured; rather participants were selected based on criteria of being able to discharge to the home environment from the hospital. A descriptive qualitative design was used to explore the PSS journey during the first four weeks after discharge home. Semi-structured telephone interviews with 31 PSSs were conducted, transcribed and interpreted using thematic content analysis. Findings from this investigation will inform future transitional interventional studies for PSSs.

The original aims of the study were to:

1. Identify the needs, concerns, frustrations, and experiences of PSSs from the first 24 hours up to four weeks after discharge home from the hospital from the patient perspective.
2. Describe the experiences of four different cohorts of PSSs at 1, 2, 3, and 4 weeks after discharge home from the hospital.

3. Compare and contrast the similarities and differences in experiences between cohorts to identify both the unique and consistent themes along this 4-week transitional period.

Aims two and three were revised during the iterative process of data collection and analysis to provide increased clarity of the journey described by PSSs in this study. Cohorts were collapsed into one group which created a better description of the central themes that emerged from the participants. Hesse-Biber and Leavy (2011) described that through reflexivity and the iterative process of data collection and data analysis researchers are able to acknowledge bias and use the data to support the analysis. In this case, the bias was the a priori concept of time. As suggested by Patton (1990), when there is variation in sample, categories can emerge such that the larger variation captures the core experiences of shared impacts of the group. Therefore, it was determined that PSSs early transition home was best described as a whole instead of describing PSSs experiences each week.

Results

PSSs experiences during the early transition from hospital to home were described by five major themes: *the shock of a stroke interrupting a normal day; transition to an unfamiliar home; experiencing life riddled with uncertainty; journey to a new sense of self; and adjusting to a new sense of self*. PSSs first described the initial shock of experiencing a stroke.

After discharge directly home from the hospital, PSSs described a feeling of relief, but were disappointed to discover that their thought processes had changed

accompanied by a realization that they could not get back to their “normal” selves rather they had to adjust to a new sense of self. While the transition to home was a smooth process for some PSSs, for others it was a time when life seemed riddled with confusion about how to respond to physical and cognitive residual symptoms and their meaning as well as concern about the possibility of experiencing another stroke. This uncertainty was manifested by expressions of worry, anxiety, or fear. Concern about the potential for another stroke increased PSSs desire for knowledge around how to prevent another stroke experience.

Once home, PSSs in general described many common experiences about their journey to discover a new sense of self. PSSs desired a return to a known sense of normal which included working, exercising or visiting with friends. PSSs focused on preventing another stroke with the use of new medication or other life style changes including exercise. PSSs expressed the continued need for a good support systems to help them transition into a new sense of self. Finally, PSSs wanted their questions addressed by health care professionals in a timely manner and desired goals of care tailored to their unique situations. The ability to achieve a new sense of self depended on each PSS's ability to cope with uncertainty, which was augmented or diminished by varying factors.

Key Findings. Several key findings emerged from this study that contribute to the growing science of transitional care and neuroscience nursing. First, PSSs experienced uncertainty as they transitioned home from the hospital and understanding their uncertainty in this context was a complicated process, because of the variance of

PSSs' experiences. Uncertainty reflected each PSS's unique combination of their experiences and their ability to balance many factors that acted as facilitators and barriers in the PSS transition. Second, no matter the stroke severity or how minimal the physical, cognitive, or psychological symptoms appeared on the surface, PSSs who were discharged directly home from the hospital faced numerous personal and interpersonal challenges along their journey toward constructing a new sense of self. Finally, health care system facilitators and barriers to coping with uncertainty and moving forward were identified especially early follow-up and person-centered partnerships. Together these major findings provide the foundation for designing transitional care for PSSs.

Uncertainty in post stroke survivor recovery

Experiencing a stroke was a sudden change that started feelings of uncertainty for PSSs. To prevent another stroke PSSs became aware of the signs and symptoms, yet remained cognizant of the speed at which a stroke can occur, which generated feelings of uncertainty. Overall, the stroke onset was the beginning of their PSS journey to a new sense of self.

Throughout their PSS journey, uncertainty was a pervasive theme. Uncertainty began at the onset of symptoms and continued during the four weeks after discharge home. The first experience of uncertainty was during PSSs initial self-interpretation of their stroke symptoms. In some cases, PSSs were able to interpret and relate their symptoms to classic stroke symptoms: face drooping, arm weakness, or speech difficulty. During the initial symptom onset, PSSs were questioning what was happening to their

body or mind and their initial reaction to symptom onset provided the foundation for the continuous nature of uncertainty as they journeyed to a new sense of self.

PSSs initial interpretation of their stroke symptoms was difficult to recognize for many PSSs, family, and friends. To deal with this known issue, the American Stroke Association implemented a stroke awareness program to encourage the public to recognize signs of a stroke early to decrease the length of time between stroke symptoms and receiving medical attention (Jauch et al., 2013). Currently, the acronym the American Stroke Association uses is FAST, which stands for F for face, A for arm, S for speech, and T for time (American Stroke Association, 2014). Though this acronym can detect close to eighty-nine percent of strokes, FAST does not provide the public with all the symptoms PSSs may experience such as dizziness, change in cognition, or visual disturbances (Kleindorfer et al., 2007). Furthermore, public awareness to identify stroke symptoms remains stagnant at 71% (Go et al., 2013). While PSSs in this study recognized they had a problem, some PSSs did not interpret their symptoms as a stroke though they decided that their symptoms warranted medical attention. Other PSSs recognized their symptoms were consistent with a stroke after their hospitalization, but at the stroke onset did not believe they were experiencing a stroke. For PSSs who did not seek immediate medical attention, their symptoms did not fit easily into the FAST category. Detecting stroke symptoms at the time of onset can be further hindered by potential cognitive deficits that can accompany a stroke (Carlsson et al., 2009). Though not a direct focus of this study, several PSSs described their cognitive deficits and had difficulty determining a course of action. The data from this study is not sufficient to

determine if these PSSs delayed seeking medical attention due to their cognitive symptoms directly.

This study supports other research that detecting stroke symptoms may not be as simple as instituting an acronym due to variable cognitive impairments and the emotional shock that PSSs experienced at the time of a stroke. The uncertainty PSSs experienced due to the initial shock of stroke symptoms followed by their difficulty interpreting symptoms supports the need for further education regarding stroke symptoms to PSSs. PSSs need to be aware of not only the FAST acronym, but other stroke symptoms that are not depicted by the acronym, so PSSs can feel confident in their ability to address stroke symptoms in the future and limit the amount of uncertainty they feel after experiencing a stroke.

Experiencing a new sense of self

PSSs continued to express uncertainty as they journeyed to their new sense of self once they were home. PSSs realized the next stroke could be worse, where they would be paralyzed for life or possibly die, if they did not act fast with the next stroke. Uncertainty has been found to have lasting detrimental effects on PSSs (Sturm et al., 2004). This study supports that uncertainty is prevalent in all PSSs regardless of physical or cognitive symptoms after discharge home from the hospital.

Uncertainty is an established phenomenon for PSSs and described throughout prior qualitative studies (Green & King, 2009; Jones et al., 2008; Klinke et al., 2014; Morris et al., 2013; Pallesen, 2013; Salisbury et al., 2010; Yeung et al., 2011). In this study, PSSs described continuing to have varying amounts of uncertainty after discharge

to their home. PSSs uncertainty manifested through their concern and anxiety about their future. Concerns PSSs described were if another stroke were to occur and how to interpret future symptoms. PSSs lacked the confidence to determine if their symptoms were indicative of another stroke or would warrant further medical intervention.

Coping with uncertainty was a process that all PSSs experienced as they journeyed to a new sense of self. How PSSs coped with uncertainty was vital to their ability to adjust to their new life as a PSS. According to Green and King (2009), feelings of vulnerability or uncertainty are associated with anxiety and depression. This study provides further evidence that uncertainty is a root problem PSSs experience that can lead to further issues. Sturm (2004) suggests depression after experiencing a stroke is prevalent and associated with decreased quality of life. This association among uncertainty, depression, and quality of life makes it imperative that health care providers address uncertainty early to prevent long term complications. This study did not assess for depression or anxiety specifically, however PSSs described situations of uncertainty that manifested through anxiety. PSSs also described their journey to a new sense of self and how they had to cope with the anxiety arising from varying levels of uncertainty.

In this study PSSs who transitioned home directly from the hospital continued to be faced with multiple challenges and increased sense of uncertainty about the future, despite few physical or cognitive symptoms. Other researchers have described the negative effects of uncertainty for PSSs (Green & King, 2009; Sturm et al., 2004). This supports the position that PSSs who are discharged directly home from the hospital are susceptible to similar consequences. Health care professionals need to be aware that a

stroke is a life altering event for any PSS and severity of stroke and minimal physical or cognitive symptoms after discharge is not an indicator of the potential ramifications faced by PSSs.

Transition Home

The findings from this study support prior research that the transition to home is a welcomed shift in their recovery process. However, the results from this study also provided unique insight that PSSs experienced symptoms early within the transition home. PSSs begin their journey of re-exploring their lives once they transition home further supporting that PSS recovery begins early and is a time of uncertainty.

Prior researchers discussed the importance of transitions for PSSs, such as the transition to home as a marker to normalcy (Lawrence, 2010). This study found that PSSs hoped they would return back to normal and their prior routine after discharge home, but the transition encompassed both relief and a stepping stone to their recovery. The data suggests transitioning home was a welcomed outcome after hospitalization for PSSs, but led to new challenges as they struggled with their ability to adjust to a new life. Furthermore, the transition home continued to mark a time of uncertainty as PSSs realized that home was not the same post stroke. Some of the struggles PSSs expressed after returning home during the first four weeks were fatigue and a change in their values and thoughts.

Fatigue

Several researchers have described PSS fatigue as a physical experience that starts at stroke onset and continues for months after a stroke, and identified a lack of

understanding about fatigue by PSSs once they are home (Eilertsen et al., 2013; Flinn & Stube, 2010; White, Gray, et al., 2012). This study corroborates these findings that fatigue was prevalent and consequential once PSSs arrived home. Fatigue lasted a week or two for some PSSs, while others were still experiencing fatigue up to four weeks after discharge. Fatigue also fluctuated over the course of the first few weeks. Fatigue was found to alter PSSs ability function at home such as exercising or returning to their prior routine. Exercise and returning to their prior routine were factors identified by PSSs that inhibited their ability to return to normal. These findings are similar to Eilertsen et al. (2013) who described how fatigue can prevent PSSs from performing daily activities, how easily PSSs can tire from activity, and how fatigue can increase stress sensitivity. These findings support the position that fatigue is a prevalent issue for PSSs that can hinder their ability to set up appointments with health care providers, resume prior activities, or exercise. PSSs in this study experienced these factors as salient markers along their journey to recovery. This study continues to emphasize that fatigue is an experience that PSSs continue to battle and that severity of stroke is not a determining factor if a PSS will experience fatigue.

PSSs also started to explore and adjust to their new self-image once they transitioned home. Prior researchers described how PSSs expressed their self-image as either a negative image such as worthless or a positive self-image such as their ability to adapt and cope with challenges (Brunborg & Ytrehus, 2013; Carlsson et al., 2009). In this study, as PSSs transitioned home they started grappling with these feelings by thinking about how they had been changed since the stroke. This study did not address

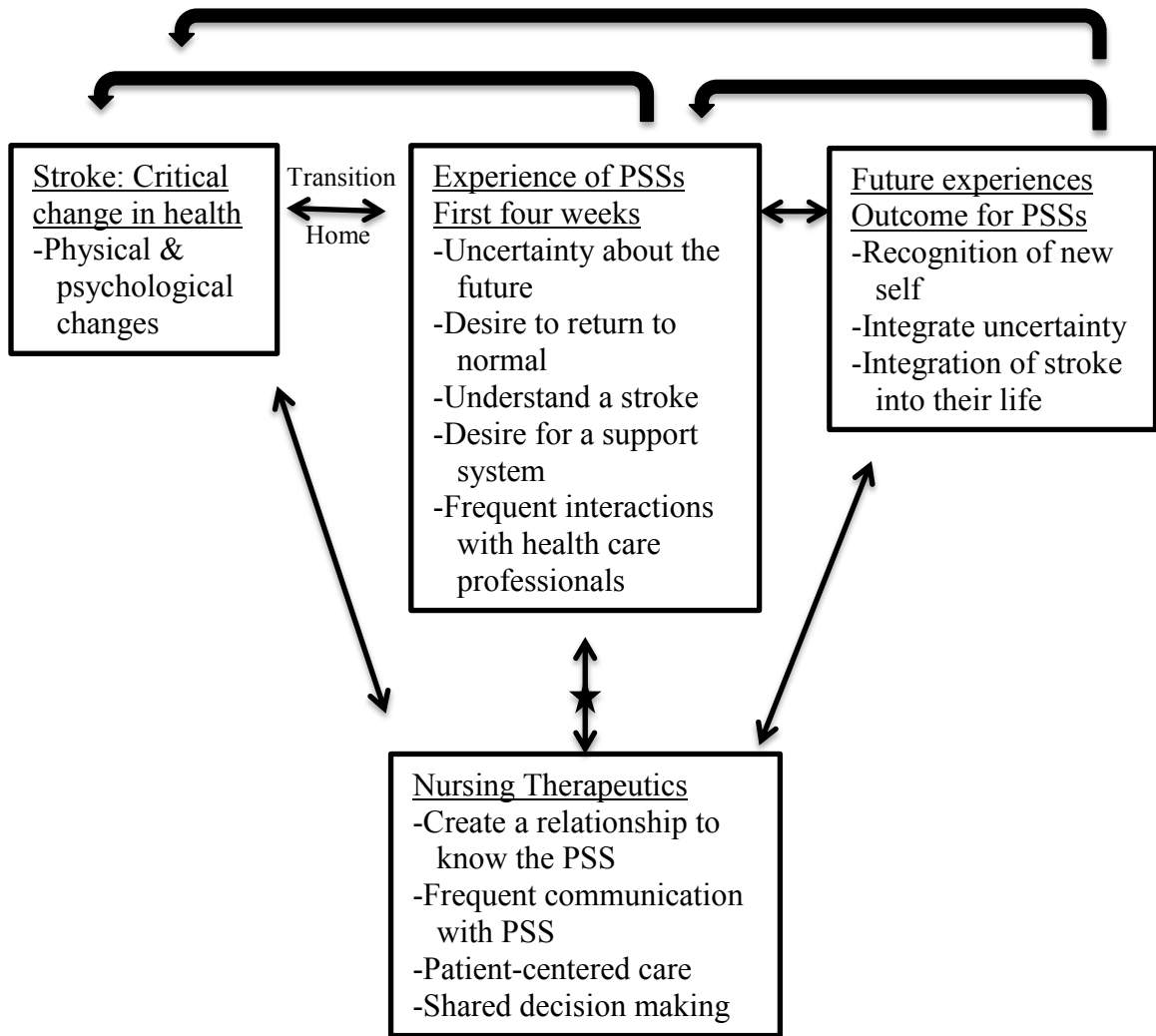
PSS's self-image, however it does reflect how PSSs were re-examining their thoughts reflecting the beginning foundation of PSSs new self-image. Specifically, PSSs were focusing on the type of person they wanted to be now, such as less angry or willing to brush off small concerns. These combined findings imply that early within recovery of a stroke, regardless of severity, PSSs are trying to cope and adapt to internal challenges.

Research suggests that experiencing a stroke is a life altering event no matter the severity. Issues arise early within the discharge process home and can have lasting detrimental effects on PSSs. The transition home may mark a step in the right direction to recovery, but PSSs continue to adjust to their new life after being discharged home.

Nursing therapeutic interventions for post stroke survivors

Study findings suggest that it is essential for nurses to interact with PSSs as they transition home from the hospital. The conceptualization of transitional experiences of PSSs is depicted in Figure 2. Based on the study results, nurses can create a healing space for patients and families and develop interventions that address PSSs responses to the stroke as they transition home from the hospital by using patient-centered care and shared decision making between nurses and PSSs. Several areas of focus emerged from the data, return to a prior routine, knowing the cause of a stroke, helpful support system, and helpful interactions with the health care system. The results of this study emphasized that preventing just one negative experience from occurring will not prevent PSSs from experiencing uncertainty, nor will it guarantee that PSS can adjust to a new sense of self.

Figure 2: Conceptualization of transitional experiences for PSSs



For example, the initial PSS’s experience caused a change in their physical abilities which lead to uncertainty about the ability to perform tasks at work. Nursing therapeutics during that time can be to understand PSSs desires about returning to work and create a plan of care that reflects PSS’s goals. This is a critical interaction between the nurse and PSS, as demarcated by a star, this relationship can allow PSSs to integrate uncertainty into their life and adjust to their new sense of self. The following section will provide a synthesis of both prior research and the results of this study to provide potential

nursing therapeutic interventions during the first four weeks of discharge home from the hospital that can alter how PSSs experience uncertainty.

Return to prior routine

To aid with PSSs ability to adjust to a new sense of self nurses need to assess for PSSs ability to return to their prior activities and provide realistic expectations. Research supports that PSSs who return to their prior routine feel a sense of normalcy in their lives (Lawrence, 2010). The current study found that PSSs who were able to easily and quickly return to their prior routine described less uncertainty. Thus, nurses need to be fully present and establish a relationship over time and be responsive to PSSs difficulty to return to their prior routine due to the effects of a stroke. Nurses can provide the context for PSSs to create a realistic understanding of returning their prior routine. The findings from this study support that PSSs who rushed into too many activities were discouraged and concerned about returning to their prior routine. Other PSSs who eased into activities such as slowly increasing their exercise routine, expressed less uncertainty about their progression of recovery and ability to achieve their goals. Creating expectations with PSSs that recovery will have times of improvement, plateaus, and setbacks is a known part of the recovery process (Backe et al., 1996; Carlsson et al., 2004; Doolittle, 1992). Nurses can be aware of each PSS's response to guide assessment and create opportunities to alter PSSs reaction to difficulty of returning to their prior routine. Nurses need to provide PSSs with the knowledge about recovery to create expectations that are realistic for the PSS in order to facilitate recovery.

Understanding about the stroke

Understanding the cause of the stroke was helpful to decrease uncertainty, but PSSs who had specific actions to prevent another stroke felt empowered and a sense of increased control in their ability to prevent another stroke and move forward in their recovery. Despite over 30% of strokes having an unknown etiology, many PSSs exhibit risk factors for a stroke (Go et al., 2013). In this study, PSSs wanted an explanation for the cause of their stroke, such as hypertension or a patent foramen ovale, believing that there was a specific course of action they could take to prevent another stroke. However, many PSSs did not receive a specific cause of their stroke and were left with feelings of uncertainty. For these PSSs, that data suggests concrete actions that can prevent another stroke from occurring, such as lifestyle changes can be helpful at lessening uncertainty experienced due to not knowing the cause of the stroke.

Nurses who know their patients and their experiences can work with the individual to determine what modifiable behaviors PSSs can implement to prevent another stroke. There are several known modifiable risk factors for a stroke: diabetes, hypertension, hyperlipidemia, smoking, dysrhythmias, physical inactivity, nutrition, and sleep apnea. However, there are some non-modifiable risk factors as well such as: age, gender, family history, or previous stroke or transient ischemic attack (Go et al., 2013). In the case of modifiable risk factors nurses should explain specific actions to improve lifestyle habits that decrease the risk of stroke. Conversely, explaining to PSSs the non-modifiable risk factors that increase their risk may offer some reassurance as well. Nurses can encourage PSSs to describe both their modifiable risk factors and non-

modifiable risk factors. Explaining both risk factors can help PSSs cope with some level of uncertainty created by the non-modifiable risk factors.

PSSs feel empowered by acknowledging their behaviors that prevent another stroke. PSSs want to implement specific actions that decrease their risk for having another stroke. This allows PSSs to cope with their uncertainty. Nurses can provide PSSs with knowledge about understanding a stroke, which will address PSS uncertainty about the cause of their stroke and how to prevent the reoccurrence of another stroke.

Post stroke survivors need more than just a support system

The nurse can be the person to assess a PSSs support system and influence recovery. A support system is an important factor to cope with their new situation as a PSS. Nurses can provide ideas and directions to the support system, to enhance and encourage PSS's journey to a new sense of self.

Current research describes the importance of a support system; however the results from this study inform the characteristics of a supportive system. Research over the years has described how PSSs cope with recovery better when they have a good support system (Dickson et al., 2008; Erikson et al., 2010) and that lack of support early within stroke recovery can lead to increased frustration (Brunborg & Ytrehus, 2013). This study would not refute these findings, but does add some other insights. A support system can be health care professionals, family, and/or friends. Prior studies have found that PSSs described a lack of support by health care professionals in the rehabilitation setting (Flinn & Stube, 2010; Jones et al., 2008; Salisbury et al., 2010; Schmitz &

Finkelstein, 2010). All this research suggests that the relationship a nurse can create with a PSS is vital to their recovery.

PSSs expressed specific attributes of a support system that nurses can use as a foundation to facilitate a helpful support system for a PSS. For example, desired attributes of a support system by PSSs are: empathetic, encouraging, and work with PSSs as they adjust to their new sense of self. A recent systematic review and meta-analysis of the effectiveness of psychosocial interventions for stroke family caregivers described promising results when caregivers are also given frequent support either through the telephone, online, or internet. However, the researchers concluded that the exact timing and the most effective intervention for stroke caregivers was unknown (Cheng, Chair, & Chau, 2014). This study found that a support system is an important facilitator starting with the transition home and throughout their journey to a new sense of self. This suggests that a support system and PSSs are a team that nurses need to foster early within the transition to recovery. Further research is needed to adequately address how nurses can enhance PSS's support system that go beyond assessment of the desired traits of a support system.

A support system remains an important factor in PSSs recovery, but this study also emphasized the specific traits of a support system that PSSs perceive as helpful. Nurses can foster an empathetic and encouraging relationship with their patient and assess for these traits in a PSS's support system and encourage early dialog between PSSs and their support system about PSSs recovery.

Post stroke survivors interactions with nurses

One of the prevailing experiences of PSSs in this study was the interaction between PSSs and health care professionals such as nurses. Nurses interact with PSSs throughout the recovery process both in the hospital and once they are discharged home. Whether nurses facilitate PSSs journey to adjust to a new sense of self is dependent on the type of interaction nurses provide to PSSs. Nurses are in a position to create a positive healing space and promote interactions with PSSs that lessen uncertainty associated with the post stroke experience. For example, the results of this study described the importance of health care professionals immediately addressing PSSs' questions. Frequent interaction by a nurse about PSSs concerns and questions can facilitate conversation. A focused conversation should encompass asking PSSs questions and providing a thorough explanation of the questions. Providing this direct and instant feedback increases PSSs comfort.

Results from this study suggest that as more time passed between PSSs unanswered questions and health care professional's response, there was the likelihood that PSSs experienced increased uncertainty. When health care professionals ignored PSSs questions they felt frustrated and uncertain about their future. Though prior research has focused on how health care professionals don't always address PSSs needs (Anderson & Whitfield, 2013), the findings from this study encourage patient and nurse dialog so nurses address PSSs' questions. Specifically, PSS's questions need to be addressed early within the first four weeks of discharge home.

It is also critical for PSSs to have early follow-up care by a nurse post discharge from the hospital to home. As suggested by this study, a crucial foundation for PSSs ability to achieve a new sense of self was when PSSs had conversations early within the care and continued after discharge. Prior research emphasizes the importance of early follow-up. For example, Batchelor et al. (2012) created an individualized exercise program for PSSs, but the intervention was unsuccessful. A potential reason for lack of success could be since PSSs only received information from a health care provider once. In contrast, Joubert et al. (2008) and Allen et al. (2009) had increased success with their PSS intervention, due to the frequent follow-up of health care providers with PSSs. This study found that increased contact with PSS and nurses addresses PSS's concerns early within the recovery process.

Study findings suggest that nurses can alter PSSs uncertainty by working with them to create a cohesive plan of care with PSSs. Researchers have already reported that health care professionals need to determine PSS's personal goals in recovery (Eilertsen et al., 2013), yet until now health care professionals could not adequately address the needs of PSSs during the first four weeks. Overall, this study found that PSSs were not concerned about the checklist that health care providers needed to complete, rather PSSs wanted to cope with how a stroke will fit into their daily routine. PSSs wanted to know when they could return to work, begin exercising, or how to prevent another stroke. This implies that physical or psychological tests that health care professionals perform, albeit informative for the health care provider, may not address the PSS's needs and how health care providers need to address PSSs goals.

Nurses need to foster a patient-centered shared decision making model when providing care to PSSs. This requires nurses to listen to PSSs questions, concerns, and together create solutions that address the concerns of PSSs. Creating a tailored plan of care is not new to stroke research; however researchers have struggled on how to implement a tailored intervention (Batchelor et al., 2012). The results of this study provide a variety of nursing interventions that can address the specific needs of PSSs as they transition from hospital to home.

Implications for Nursing Practice

Building on the prior discussion, this study suggests a number of implications for nurses. Nurses can play a pivotal role in PSSs journey to a new sense of self by fostering a patient-centered plan of care that is based on the shared decision making model. This study provides the content that is relevant to PSSs and how nurses can address PSSs unique needs after experiencing a stroke. The results of this study also emphasize early follow-up by nurses with PSSs so nurses can intervene early during their recovery. Finally, the impact of the results of this study promotes a shift in nursing practice where nurses provide care that goes beyond a pre-determined plan that addresses patient needs, and focuses on the unique interaction between the nurse and the PSS that can alter their recovery process.

Patient centered care

PSS's in this study provided powerful data that addressed the need for nurses to be aware of the person and their unique response to a stroke and recovery at home after discharge from the hospital. Specifically, PSSs desire nurses to provide patient-centered

care that focuses on the unique needs of PSSs, this means nurses need to go beyond just the physical aspects of PSS recovery. Using relationship based care approach, where the nurse learns about the PSS experience, allows the nurse to address issues of uncertainty, realizing that uncertainty can fluctuate throughout the recovery process and requires constant vigilance of nurses to determine actions that can mitigate a PSS's uncertainty. Constant vigilance of nurses to understand PSSs' experiences enforces the importance of frequent dialog between the nurse and patient. Interventions that are tailored to PSSs responses are not a strict flow chart, because PSSs cannot be treated like a standardized procedure. By understanding general PSS experiences, nurses can gain insight and create tailored future interventions responsive to the person and where they are on their journey to recovery.

The results from this study provide the content to create a comprehensive plan of care that can address the needs for PSSs as they transition from hospital to home. Nurses can use a semi-structured interview guide, like the interview guide implemented for this study. The interview guide for this study has already provided rich information about PSSs and is effective in learning about PSS's experiences. After talking with PSS's about their experience nurses can create a patient-centered plan of care through Makoul and Clayman's (2006) shared decision making model. Specific to Makoul and Clayman's model that is in alignment with this study findings is the arrangement of follow-up after a plan is created to allow for future modification based on each individual's situation. According to Makoul and Clayman (2006) essential elements of a shared decision process include: define and explain the problem, present options, discuss

pros/cons, discuss patient values and preferences, discuss patient's ability, provide recommendations, clarify understanding, make or defer a decision, and arrange follow-up. Nurses can take these essential elements to create a patient-centered plan of care that is reflective of PSSs expressed needs. The implementation of the shared decision making model as described by Makoul and Clayman (2006) coupled with the findings from this study provide nurses with a foundation to foster patient centered communication between the nurse and patient to address PSSs needs during the first four weeks after discharge home from the hospital.

Fatigue in PSSs can occur early after being discharged home and can have lasting effects if not addressed. Fatigue can continue and impede PSSs ability to return to prior routine and nurses need to be cognizant that fatigue can occur in any PSS no matter the severity of the stroke. Fatigue was experienced early within the transition from hospital to home and affected PSSs ability to adjust to a new sense of self. Fatigue is often a hidden symptom that PSSs struggle to adapt with during their recovery (Carlsson et al., 2004; Flinn & Stube, 2010). Nurses need to be cognizant of hidden dysfunctions such as fatigue that impede PSSs ability to complete daily tasks such as scheduling follow-up appointments. To foster and environment of recovery for PSSs, nurses can arrange follow-up appointments for PSSs, so PSSs do not need to waste needed energy on tasks that could be completed by a nurse.

The transitional nurse

As described by Naylor et al. (2011) the advanced practice nurse can play a central role in transitions, however a study using Naylor's TCM has not been

implemented with PSSs. The TCM proposed by Naylor et al. (2011) encourages advanced practice nurses to interact frequently with patients either by telephone or face-to-face conversation. As described by Naylor et al. (2011) the advanced practice nurse can play a central role in transitions for vulnerable populations like PSSs. Specifically, advanced neuroscience nurses are a vital resource for PSSs due to their unique stroke knowledge and frequent contact with the PSSs (American Association of Neuroscience Nurses & American Nurses Association, 2013). A defining element of an advanced neuroscience nurse according to the American Association of Neuroscience Nurses and American Nurses Association (2013), is having “completed an accredited graduate-level education program with preparation in one of four recognized advanced practice registered nurse roles” (p. 21). To enhance the implementation of the TCM for PSSs future research should focus on interventions where advanced neuroscience nurses work with PSSs during the transition home. An advanced neuroscience nurse has a unique subset of knowledge and expertise with PSSs to adequately address the needs of PSSs that have been revealed in this study. The results of this study provide the framework for advanced neuroscience nurses to foster communication between the patient and nurse.

Naylor and Sochalski (2010) highlight several core features of the TCM, besides just the implementation of an advanced practice nurse. The core features are: a comprehensive assessment, care that is initiated at hospital and extends beyond discharge home, engagement and executing a plan of care, and coordinating services. The conceptual model depicted in Figure 2 aligns with the TCM in several ways. The conceptual model provides the foundation for the comprehensive assessment for PSSs.

Advanced neuroscience nurses can use the data about understanding PSSs' experiences from this study to enhance their comprehensive assessment of PSSs. Several elements of the TCM that are highlighted throughout the findings of this study are facilitating care such as follow-up, encourage active engagement of a support system, and foster communication between patient and family. The conceptual model in Figure 2 highlights the importance of creating a plan of care with PSSs by focusing on patient-centered care through communication and shared decision making, so PSSs can adjust to a new sense of self. This creates a holistic focus on PSSs needs by understanding their entire stroke journey from the initial onset of symptoms throughout the first four weeks.

A shift in nursing practice

The unique relationship that a neuroscience nurse can create during PSS's transition from hospital to home allows for nursing care to go beyond just a checklist of needs for PSSs. As supported by Newman (2008) just the presence of a nurse with a patient can alter their journey in a positive fashion. The results of this study further emphasize the need for the nurse to be the person caring for PSSs during a time of transition, because a nurse has the ability to create a dynamic relationship with patients. Though not specifically examined in this study, even the follow-up phone call during member checking reiterated how communication and interaction can impact PSSs. Many of the participants recognized the interviewer's voice and remembered the conversation and were eager to explain how their recovery evolved since the first interview. The interaction between a PSS and the interviewer, though not a planned intervention,

changed the PSS's recovery. As Newman's theory implies, the interviewer was present with the PSS during their journey, which impacted their future interactions.

The reciprocal interaction between the nurse and PSS as depicted in Figure 2 has a star on this interaction, due to the results of this study. The star implies that the interaction between a nurse and PSS has the potential to be a powerful intervention, especially when interactions are implemented in a timely manner with a purpose. The purpose of the nurse is to be present with the patient during a time of transition and create a plan of care that is based on the patient's needs and goals. By applying Newman's theory, the interaction between the PSS and nurse has then gone beyond symptom management and shifted to caring for the PSSs as a whole, where care is less focused on a specific checklist of tasks that a nurse needs to perform but instead care that supports PSSs journey.

In summarize, creating a tailored transitional intervention requires an advanced neuroscience nurse to have frequent communication with PSSs. Advanced neuroscience nurses need to be aware that addressing one area of concern for a PSS will not always mitigate the uncertainty PSSs experience. Constant vigilance in the early stages of PSSs transitions to home is needed to address both the physical and psychological components of PSSs journey to a new sense of self.

Implications for Policy

There are several policy implications that emerged from the findings of this study. Post discharge follow-up should be essential for all PSSs, since even PSSs with minimal physical or cognitive symptoms described a need for frequent follow-up. Not all PSSs

expressed the same frequency for follow-up, but follow-up within the first few days of discharge home would be helpful for all PSSs regardless of their stroke severity.

This study also informs future policy about stroke prevention and public knowledge of stroke signs and symptoms. The acronym FAST may not apply to all PSSs due to the lack of cognitive components within FAST. Specifically, in this study several participants described the sudden onset of their symptoms. Many of the cognitive symptoms experienced, such as difficulty concentrating, were not reflected in the FAST acronym. Due to the sudden onset of symptoms and difficulty some PSSs experienced accurately interpreting their symptoms as a stroke; PSSs require further education on the signs and symptoms indicative of a stroke to encourage an effective response. As described by Go et al. (2013), PSSs have an increased likelihood of experiencing another stroke and a delay in seeking medical attention could cause further damage. This study also has a large age range of participants from 24 to 83 years of age implying that a large demographic of people need to be aware of the signs and symptoms of stroke. Current research suggests that people who are greater than 65 years of age have a decreased awareness of the signs and symptoms of a stroke (Go et al., 2013). Since not all stroke symptoms fit into the FAST acronym and people continue to have difficulty recognizing signs of a stroke, further policies need to be in place that adequately instructs the public about stroke symptoms, so people do not delay seeking medical attention.

The final policy implication that emerged from this study is the implementation of an advanced neuroscience nurse to provide follow-up care for PSSs. Some participants in this study had follow-up with a primary care provider who then coordinated care with

other specialties. However, advanced neuroscience nurses have a unique subset of knowledge that could prove essential to enhancing PSSs' adjustments to a new sense of self. Stroke centers have been shown to decrease hospitalization (Centers for Disease Control and Prevention, 2011), but their implementation across states varies with minimal mention of the type of nurses that could best provide care for this unique population specifically during the transition from hospital to home. Furthermore, existing evidence by the TCM supports the implementation of an advanced practice nurse during the transition from hospital to home (Naylor & Sochalski, 2010).

Several implications for policy change found in the study are the timing of follow-up care for PSSs, stroke signs and symptoms, prevention and awareness, and fostering advanced neuroscience nurses as key providers for PSSs during the transition from hospital to home to enhance PSS's recovery.

Implications for Research

There are several research implications that emerged from this study. Due to the overwhelming number of PSS interventions that poorly defined the psychological component of their intervention (Askim et al., 2010; Askim et al., 2006; Batchelor et al., 2012; Björkdahl & Bjorkdahl, 2006; Chaiyawat & Kulkantrakorn, 2012a, 2012b; Globas et al., 2012; Hegyi & Szigeti, 2012; Ihle-Hansen et al., 2012; Su Fee et al., 2009; Torp et al., 2006; Watkins et al., 2011; Ytterberg et al., 2010), future research needs to focus on assessing for PSSs unique experiences and creating an individualized plan of care based on their experiences. This study provides the content to create an individualized plan of care.

Prior research that has implemented the TCM encourages the use of patient-centered care and follow-up within the first few days of discharge. The TCM fosters follow-up either by phone or face-to-face conversation within the first few weeks after discharge home which can improve outcomes for the chronically ill older adults (Naylor et al., 2011). This study provided evidence that not all PSSs are receiving the follow-up care desired for their recovery. Future research should focus on the use of the TCM in the PSS population. To enhance the TCM, advanced neuroscience nurses should work with PSSs during the transition home. Through the implementation of the TCM and the framework from this study, future research can determine if the longer term detrimental effects PSSs experience such as depression, anxiety, or decrease in quality of life are altered. Another outcome research could focus on is how uncertainty is altered based on the implementation of a patient-centered plan of care.

Interventional studies are important for all PSSs regardless of stroke severity or the physical symptoms PSSs have when they are discharged from the hospital. For many researchers, the population for this study would be defined as mild stroke survivors. Yet, mild stroke is a poorly defined, ambiguous term, and does not adequately describe PSS experiences. Results from this study found that PSSs may have described their stroke as mild or small, but experiencing a stroke was both physically and mentally challenging. As suggested by Danzl (2013), describing a PSS's stroke as small or mild conveys an expectation of full recovery, which may not be true. In this study, the data indicates that even with minimal physical post stroke symptoms PSSs can experience uncertainty that threatens their ability to recover after experiencing a stroke. This means that there are

still critical implications for PSSs who are discharged directly home from the hospital. Future transitional care research should focus on all PSSs regardless of stroke severity, since all PSSs can experience detrimental effects after a stroke.

Han, Klein, and Arora (2011) described the complexity of uncertainty in the health care system due to the absence of a unified meaning of uncertainty. This is a similar finding in PSS research where uncertainty can reflect PSSs lack of control, vulnerability, anxiety, questions, how to return to normal, or fear for the future (Green & King, 2009; Jones et al., 2008; Klinke et al., 2014; Morris et al., 2013; Pallesen, 2013; Salisbury et al., 2010; Yeung et al., 2011). The findings from the current study provide specific insights to address PSSs uncertainty such as addressing PSSs questions early within the transitional period from hospital to home. Further research is needed to determine if using this conceptual model, as depicted in Figure 2, will alter PSSs uncertainty early within the transition from hospital to home and prevent future anxiety, depression, or decrease in quality of life. Research can also focus on what therapeutics are most helpful to address uncertainty based on each PSSs situation such as their stroke severity.

Limitations

There are several limitations to this study. First, this study was from a small sample size of 31 participants, which limits generalizability to the population. However, the transferability of findings is supported through the description of findings that was achieved through analysis of memos, data saturation, member checking, and peer review.

Second, this study only interviewed PSSs from one large metropolitan hospital in New England and as suggested by (Danzl et al., 2013), PSSs experiences can differ by geographical location. Further studies would be warranted to determine the unique differences of population based on region and demographics.

Third, this study had some representation of different populations including Black and Asian, but did not adequately address minorities PSSs' experience. However, this study had almost an equal amount of male to female participants so that gender was adequately represented. According to Go et al. (2013) there is a growing number of Hispanic Americans experiencing strokes, so future studies should focus on this population as they transition directly home from the hospital, since only two participants identified themselves as Hispanic in the current study.

Finally, during data analysis findings can always be impacted by researcher bias. Throughout this study multiple procedures were implemented to minimize or prevent research bias such as peer review and member checking to validate the findings of the study.

Conclusion

All PSSs described uncertainty as they transition home from the hospital. Until now research has been unable adequately address PSSs needs during the first four weeks of the transition home from the hospital. PSSs first experienced uncertainty with their onset of symptoms and their uncertainty continued throughout the first four weeks after discharge directly home from the hospital. Being able to adequately address PSSs uncertainty may prevent long term complications. The first steps to addressing PSSs

uncertainty is by further education about stroke symptoms to decrease the time between stroke onset and hospital admission.

Experiencing a stroke is a life altering event regardless of the stroke severity. This study found that even PSSs with minimal physical or cognitive symptoms experienced fatigue, uncertainty, and difficulty adjusting to their new sense of self. Recovery for PSSs has times of improvement and plateaus and nurses need to create realistic expectations that correlate with PSSs needs and concerns. During recovery PSSs desire specific actions to prevent another stroke, a perceived helpful support system, increased contact with health care professionals that focus on the needs and concerns of PSSs.

Nurses play a key role in guiding care, translating knowledge in to practice, and studying the effectiveness of care in PSSs recovery. Advanced neuroscience nurses can implement a patient-centered plan of care that uses a shared process of decision making in PSS recovery. Advanced neuroscience nurses can create a semi-structured interview guide to determine PSSs needs and then craft with the PSSs a tailored plan of care. Follow-up by advanced neuroscience nurses within the first few days of discharge allows for PSSs needs to be addressed early within the recovery period. Nurses need to engage a constant vigilance in the early stages of PSSs transition to home to adequately address the needs of PSSs, through frequent communication. It is through the communication that advanced neuroscience nurses build a relationship with a PSS that can alter PSSs recovery process.

Future research can focus on the implementation of the TCM using the advanced neuroscience nurse to create an individualized plan of care for PSSs and determine if the current framework provided by this research alters PSSs outcomes such as decreasing uncertainty, anxiety, or depression. This study can provide the platform for advanced neuroscience nurses to implement with PSSs to improve their recovery and adjustment to a new sense of self.

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Appendix A: Research Procedure

1. Obtain consent and complete enrollment form, provide appointment card when applicable
2. Discuss and complete descriptive data form
 - Descriptive data to obtain
 1. Age
 2. DOB
 3. Gender
 4. If the participant is living alone or not
 5. Comorbidities
 6. Race/Ethnicity
 7. Location of stroke
 8. History of prior stroke
 9. If participant will receive any services at home (PT/OT/Speech/Nursing)
3. Perform a chart audit to answer any descriptive data the participant is unable to provide and to determine the specific location of the stroke
4. Discuss with the primary nurse caring for the participant on the anticipated day of discharge.
5. Confirm discharge of patient from floor by chart or primary care nurse
6. Call Week 2, 3, and 4 Cohort participants 3-4 days to remind participants of interview date
7. Complete interviews as determined by participant's discharge date and slotted interview week
 - During the interview the PI will
 1. Require the participant to verify their name at the beginning of the interview
 2. Remind participants of their ability to stop the interview at any time
 3. Remind participants that confidentiality will be maintained throughout the study
 4. Remind participants of the ability to withdrawal from study at any point
 5. Remind the participants that the interviews will be audio recorded
8. Transcription of all interviews will be done after the interview is completed.
9. After initial data analysis member checking will be completed (2 participants per cohort) participants will be randomly selected to verify analysis of participant findings.

Appendix B: Enrollment Form

Subjects Name _____

Subjects Pseudo-name _____

Study ID number _____

Date for interview _____

Phone number for interview _____

Eligibility criteria Checklist

- Documented CT or MRI confirming acute ischemic stroke
- Discharged directly home from the hospital
- English speaking
- 21 years of age or older
- Admitted to Lunder 7 or Lunder 8
- Functioning telephone

Subjects will be excluded if:

- Diagnosed with a hemorrhagic stroke
- Inability to communicate via telephone
- Discharged home on hospice care

If subject meets all inclusion criteria and no exclusion criteria is found subject can be enrolled in the study assuming consent form is signed.

Sign off of enrollment document by PI Teresa Connolly

Date Completed

Appendix C: Informed Consent

**Partners HealthCare System
Research Consent Form**

Subject Identification

General Template
Version Date: February 2010

Protocol Title: Post Stroke Survivors' Experiences During the First Four Weeks of Discharge Home from the Hospital

Principal Investigator: Teresa Connolly, RN, PhD (c)

Site Principal Investigator: Teresa Connolly, RN, PhD (c)

Description of Subject Population: Post stroke patients being discharged home

About this consent form

Please read this form carefully. It tells you important information about a research study. A member of our research team will also talk to you about taking part in this research study. People who agree to take part in research studies are called "subjects." This term will be used throughout this consent form.

Partners HealthCare System is made up of Partners hospitals, health care providers, and researchers. In the rest of this consent form, we refer to the Partners system simply as "Partners."

If you have any questions about the research or about this form, please ask us. Taking part in this research study is up to you. If you decide to take part in this research study, you must sign this form to show that you want to take part. We will give you a signed copy of this form to keep.

Why is this research study being done?

The purpose of this study is to understand experiences of stroke patients after being discharged home. We are asking you to take part in this research study because you had a stroke and are being discharged home. We would like to learn about your experience as you transition from hospital to home. About 40-60 people will be enrolled into this study at Massachusetts General Hospital. This research is partially funded by the Neuroscience Nurses Foundation.

Page 1 of 7

Subject Population: Post stroke patients being discharged home

IRB Protocol No.: 2011p002483 **Sponsor Protocol No.:** N/A

Consent Form Valid Date: 03/27/2013 **IRB Amendment No.:** 2 **Sponsor Amendment No.:** N/A

IRB Expiration Date: 05/30/2013 **IRB Amendment Approval Date:** 03/25/2013

**Partners HealthCare System
Research Consent Form**

General Template
Version Date: February 2010

Subject Identification

How long will I take part in this research study?

It will take about 1 hour to complete the telephone interview.

What will happen in this research study?

Teresa Connolly RN, CNS the principle investigator will call you at a predetermined time and date after being discharged home to conduct a telephone interview. You will be asked about your experience being discharged home after your stroke. The telephone conversation will be audiotaped. If Teresa Connolly is unable to contact you within 2 days of the scheduled interview you will become ineligible for the study, unless another interview date can be scheduled. You may also be called a few weeks after the first interview to confirm that we have described your experience accurately. Any medical information that you are not able to answer will be retrieved or verified by your medical record by Teresa Connolly.

What are the risks and possible discomforts from being in this research study?

Risks for the study are minimal, but some subjects could view the interview topic to be emotional in nature. If you become tired during the interview we can continue the interview at a later time.

What are the possible benefits from being in this research study?

There is no direct benefit to you. However, subjects may benefit from discussing their experience of being discharged home from the hospital after being diagnosed with a stroke. This study will inform future research on understanding and creating interventions to aid with the transition from hospital to home after a stroke.

Can I still get medical care within Partners if I don't take part in this research study, or if I stop taking part?

Yes. Your decision won't change the medical care you get within Partners now or in the future. There will be no penalty, and you won't lose any benefits you receive now or have a right to receive.

Taking part in this research study is up to you. You can decide not to take part. If you decide to take part now, you can change your mind and drop out later. We will tell you if we learn new information that could make you change your mind about taking part in this research study.

Page 2 of 7

Subject Population: <u>Post stroke patients being discharged home</u>		
IRB Protocol No.: <u>2011p002483</u>	Sponsor Protocol No.: <u>N/A</u>	
Consent Form Valid Date: <u>03/27/2013</u>	IRB Amendment No.: <u>2</u>	Sponsor Amendment No.: <u>N/A</u>
IRB Expiration Date: <u>05/30/2013</u>	IRB Amendment Approval Date: <u>05/25/2013</u>	

**Partners HealthCare System
Research Consent Form**

General Template
Version Date: February 2010

Subject Identification

What should I do if I want to stop taking part in the study?

If you take part in this research study, and want to drop out, you should tell us. We will make sure that you stop the study safely. We will also talk to you about follow-up care, if needed.

It is possible that we will have to ask you to drop out before you finish the study. If this happens, we will tell you why. We will also help arrange other care for you, if needed.

What will I have to pay for if I take part in this research study?

Although study funds will pay for certain study-related items and services, we may bill your health insurer for, among other things, routine items and services you would have received even if you did not take part in the research. You will be responsible for payment of any deductibles and co-payments required by your insurer for this routine care or other billed care. If you have any questions about costs to you that may result from taking part in the research, please speak with the study doctors and study staff. If necessary, we will arrange for you to speak with someone in Patient Financial Services about these costs.

We will call you at the number you provided. If this is standard house phone there should be no additional costs to you. You are responsible for any cell phone charges acquired during the interview. No other costs are associated with this study.

What happens if I am injured as a result of taking part in this research study?

We will offer you the care needed to treat any injury that directly results from taking part in this research study. We reserve the right to bill your insurance company or other third parties, if appropriate, for the care you get for the injury. We will try to have these costs paid for, but you may be responsible for some of them. For example, if the care is billed to your insurer, you will be responsible for payment of any deductibles and co-payments required by your insurer.

Injuries sometimes happen in research even when no one is at fault. There are no plans to pay you or give you other compensation for an injury, should one occur. However, you are not giving up any of your legal rights by signing this form.

Subject Population: <u>Post stroke patients being discharged home</u>		
IRB Protocol No.: <u>2011p002483</u>	Sponsor Protocol No.: <u>N/A</u>	
Consent Form Valid Date: <u>03/27/2013</u>	IRB Amendment No.: <u>2</u>	Sponsor Amendment No.: <u>N/A</u>
IRB Expiration Date: <u>05/30/2013</u>	IRB Amendment Approval Date: <u>05/25/2013</u>	

**Partners HealthCare System
Research Consent Form**

Subject Identification

General Template
Version Date: February 2010

If you think you have been injured or have experienced a medical problem as a result of taking part in this research study, tell the person in charge of this study as soon as possible. The researcher's name and phone number are listed in the next section of this consent form.

If I have questions or concerns about this research study, whom can I call?

You can call us with your questions or concerns. Our telephone numbers are listed below. Ask questions as often as you want.

Teresa Connolly, RN, a doctoral student is the person in charge of this research study. You can reach her by calling her academic advisor Ellen Mahoney, RN, PhD at 617-552-4262 M-F 9-5. You can talk either with Teresa Connolly or Ellen Mahoney with questions about this research study.

If you have questions about the scheduled interview date, call Ellen Mahoney at 617-552-4262 M-F 9-5.

If you want to speak with someone **not** directly involved in this research study, please contact the Partners Human Research Committee office. You can call them at 617-424-4100.

You can talk to them about:

- Your rights as a research subject
- Your concerns about the research
- A complaint about the research

Also, if you feel pressured to take part in this research study, or to continue with it, they want to know and can help.

If I take part in this research study, how will you protect my privacy?

During this research, identifiable information about your health will be collected. In the rest of this section, we refer to this information simply as "health information." In general, under federal law, health information is private. However, there are exceptions to this rule, and you should know who may be able to see, use, and share your health information for research and why they may need to do so.

Page 4 of 7

Subject Population: <u>Post stroke patients being discharged home</u>		
IRB Protocol No.: <u>2011p002483</u>	Sponsor Protocol No.: <u>N/A</u>	
Consent Form Valid Date: <u>03/27/2013</u>	IRB Amendment No.: <u>2</u>	Sponsor Amendment No.: <u>N/A</u>
IRB Expiration Date: <u>05/30/2013</u>	IRB Amendment Approval Date: <u>03/25/2013</u>	

**Partners HealthCare System
Research Consent Form**

General Template
Version Date: February 2010

Subject Identification

In this study, we may collect health information about you from:

- Past, present, and future medical records
- Research procedures, including research office visits, tests, interviews, and questionnaires

Who may see, use, and share your identifiable health information and why they may need to do so:

- Partners research staff involved in this study
- The sponsor(s) of this study, and the people or groups it hires to help perform this research
- Other researchers and medical centers that are part of this study and their ethics boards
- A group that oversees the data (study information) and safety of this research
- Non-research staff within Partners who need this information to do their jobs (such as for treatment, payment (billing), or health care operations)
- The Partners ethics board that oversees the research and the Partners research quality improvement programs.
- People from organizations that provide independent accreditation and oversight of hospitals and research
- People or groups that we hire to do work for us, such as data storage companies, insurers, and lawyers
- Federal and state agencies (such as the Food and Drug Administration, the Department of Health and Human Services, the National Institutes of Health, and other US or foreign government bodies that oversee or review research)
- Public health and safety authorities (for example, if we learn information that could mean harm to you or others, we may need to report this, as required by law)
- Other:

Some people or groups who get your health information might not have to follow the same privacy rules that we follow. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy. However, once your information is shared outside Partners, we cannot promise that it will remain private.

Because research is an ongoing process, we cannot give you an exact date when we will either destroy or stop using or sharing your health information.

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Subject Population: <u>Post stroke patients being discharged home</u>		
IRB Protocol No.: <u>2011p002483</u>	Sponsor Protocol No.: <u>N/A</u>	
Consent Form Valid Date: <u>03/27/2013</u>	IRB Amendment No.: <u>2</u>	Sponsor Amendment No.: <u>N/A</u>
IRB Expiration Date: <u>05/30/2013</u>	IRB Amendment Approval Date: <u>05/25/2013</u>	

**Partners HealthCare System
Research Consent Form**

Subject Identification

General Template
Version Date: February 2010

Statement of Person Giving Informed Consent and Authorization

- I have read this consent form.
- This research study has been explained to me, including risks and possible benefits (if any), other possible treatments or procedures, and other important things about the study.
- I have had the opportunity to ask questions.
- I understand the information given to me.

Signature of Subject:

I give my consent to take part in this research study and agree to allow my health information to be used and shared as described above.

Subject

Date/Time

Witness to Consent of Subjects Who Cannot Read or Write

Statement of Witness

I represent that the consent form was presented orally to the subject in the subject's own language, that the subject was given the opportunity to ask questions, and that the subject has indicated his/her consent and authorization for participation by (check one box as applicable):

Making his/her mark above

Other means _____
(fill in above)

Witness

Date/Time

Consent Form Version: 2

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Subject Population: <u>Post stroke patients being discharged home</u>		
IRB Protocol No.: <u>2011p002483</u>	Sponsor Protocol No.: <u>N/A</u>	
Consent Form Valid Date: <u>03/27/2013</u>	IRB Amendment No.: <u>2</u>	Sponsor Amendment No.: <u>N/A</u>
IRB Expiration Date: <u>05/30/2013</u>	IRB Amendment Approval Date: <u>05/25/2013</u>	

**Partners HealthCare System
Research Consent Form**

General Template
Version Date: February 2010

Subject Identification

The results of this research study may be published in a medical book or journal, or used to teach others. However, your name or other identifying information **will not** be used for these purposes without your specific permission.

Your Privacy Rights

You have the right **not** to sign this form that allows us to use and share your health information for research; however, if you don't sign it, you can't take part in this research study.

You have the right to withdraw your permission for us to use or share your health information for this research study. If you want to withdraw your permission, you must notify the person in charge of this research study in writing. Once permission is withdrawn, you cannot continue to take part in the study.

If you withdraw your permission, we will not be able to take back information that has already been used or shared with others.

You have the right to see and get a copy of your health information that is used or shared for treatment or for payment. To ask for this information, please contact the person in charge of this research study. You may only get such information after the research is finished.

Informed Consent and Authorization

Statement of Study Doctor or Person Obtaining Consent

- I have explained the research to the study subject.
- I have answered all questions about this research study to the best of my ability.

Study Doctor or Person Obtaining Consent

Date/Time

Page 6 of 7

Subject Population: <u>Post stroke patients being discharged home</u>		
IRB Protocol No.: <u>2011p002483</u>	Sponsor Protocol No.: <u>N/A</u>	
Consent Form Valid Date: <u>03/27/2013</u>	IRB Amendment No.: <u>2</u>	Sponsor Amendment No.: <u>N/A</u>
IRB Expiration Date: <u>05/30/2013</u>	IRB Amendment Approval Date: <u>05/25/2013</u>	

Appendix D: Interview Guide

Start of interview/introduction

Hello my name is Teresa Connolly a nursing doctoral student at Boston College and I am hoping

to talk with [subject name]. Is now a good time to talk are you about your experience freely? Please verify your name for me, thanks. I am interested in learning about your experiences from being discharged home from the hospital after having a stroke. [Subject name] you had expressed an interest in my study, would you still like to participate in this study? [Thank you for being willing to participate or Thank you for your time.] I want to remind you that at any point you can stop the interview or withdrawal from the study completely. Your confidentiality is very important to me and it will be maintained throughout this study. As a reminder, I am audio recording the interviews however at the beginning of the interview I will refer to you on this tape as [study ID number]. I will not use any specific name including places in reporting what I learn from the interviews or identify you or anyone you mention in any way. I will not share this information with anyone except individuals who are consulting on this study with me. If at any time during the interview you have questions or concerns please let me know.

The interview may take about an hour, is that ok? Do you have any questions for me before I

start the interview and the recorder is turned on? Ok, let's get started [turn on recorder].
[State
study Id number]

Goal for interview

When describing an experience make sure I know

When it occurred

How often it occurred

What was the context surrounding the experience

Interview questions

1. Tell me about the day you had your stroke?

2. What has it been like for you since being discharged home?

Purpose of questions 1 and 2

These open ended questions allows for the participant to reflect back on his or her transitional

process from hospital to home. The statement also allows me to get an overall sense or feeling

of the transitional process, starting with their stroke. It may highlight overall key points for the participant. By using an open ended statement I am encouraging the participant to guide the interview and offer his or her experience.

3. What things have been changed or affected once you got home, can you give examples?

Probing questions

How would you describe your role within your family?

How are your relationships with family/friends been affected?

Describe any physical symptoms you are experiencing, do they affect your daily functioning?

Describe a typical day for you?

What is it like to drive?

What is it like to get out of the house to run errands?

Purpose of question

The main question provides the description of the transition process. It allows the participants to reflect on all aspects of their life from both a physical and psychological aspect. The probing questions allow for an increased discussion on possible areas that may have been affected or not affected.

4. Please describe any concerns you have at this time.

Probing questions

When you are sitting by yourself, what do you think about?

Concerns about your health, family, job?

Do you have concerns about working or your social life?

5. Did you have different concerns now than when you were in the hospital, please describe.

6. What do you feel is different about you since you had a stroke?

Probing question

Please describe any symptoms you are experiencing right now.

Can you manage them?

How are they affecting your recovery?

7. Did you have different symptoms now than when you were in the hospital, please describe.

Purpose of question

Question 4-7 are wording experiences differently to see if responses change, for example are concerns the same as the symptoms people are experiencing. The questions also encourage a discussion about the recovery process up to the point of each participant's recovery.

8. Are there things that have or have not been helpful once you got home, can you give examples?

Probing questions

What was not helpful? Please give examples.

Did you ever feel frustrated with your care? Please give examples.

What was helpful? Please give examples.

What caused you the most difficulty when you got home?

How could you have been better prepared for going home?

Purpose of question

This question offers insight into what could be used or removed from current transitional needs of the mild stroke population. It also offers examples of unhelpful aspects or parts of care. I need to highlight that I am not talking just about information when asking the participant. For example other needs described for a positive recovery could be a conversation with a health care professional, better transportation to home, or a follow-up phone call once the patient had been home for a week.

9. Describe the ideal process that would enhance your stroke recovery starting from your stay at the hospital up until now.

Purpose of statement

This allows for a thick description of each participants perspective and reflection on what

he/she may have wanted or did not get. The statement encourages the participant to answer the

problem by using a story, which may be easier to talk about than just listing examples.

Also, this

statement may further enhance the information that was already given or validate responses from prior questions or statements.

10. Is there anything you would like to add about your experience of being discharged home from the hospital?

Purpose of question

I want to end the interview with the participant open to discuss any final thoughts or ideas

when talking about stroke recovery and the transition from hospital to home.

Appendix E: Field Notes Template

Participant Name:

Interview Date:

Number of weeks past discharge:

Interview Start Time:

Interview End Time:

Tone of Interviewee:

Number of attempts to reach participant:

Were there distractions during the interview? What were they?

How well was the participant able to answer the questions?

Overall reflection on current transitional process of hospital to home, positive or negative?

Technical difficulties?

Language barriers, did the patient and residual word finding difficulty or dysphagia?

Other notes

Appendix F Member Checking Guide

This is Teresa Connolly and I interviewed about a year ago after you were admitted to Massachusetts General Hospital for a stroke. Now that I have interviewed over 30 stroke survivors and looked at the findings I wanted to know if you would be willing to listen to my results and see if they fit with your story. This is voluntary and you do not have to do this. It will take maybe 10-15 minutes. I will not be recording this conversation.

I am going to read to you a brief summary of the findings. I want you to tell me what of this summary you can relate to, what you cannot relate to, and if I missed describing an important part of your stroke experience?

Your experience is a story of uncertainty. Before a stroke, you understood your routine and yourself. After a stroke, your routine changed and you had to think about life differently. You described very unique experiences with your friends, family, work, health care professionals, and the extent and timing of your symptom improvement.

The day the stroke happened, you or someone around you recognized something was wrong and you went to the hospital. Your symptoms were shocking because they occurred quickly and without warning. After being discharged home, you described the relief of being home, but may have been disappointed to discover that your life had changed. You may have felt like you couldn't get back to their normal routine or you may have felt that going home was a smooth process. After returning home you experienced a lot of questions and concerns, such as worrying about the potential for another stroke, which brought on feelings of worry, anxiety, or fear.

As you continued to adjust to life after a stroke you may have experienced several different situations. Many of these experiences made it easier to cope with having a stroke where many of these experiences may have been negative and unhelpful in your journey to recovery. For example, you may have desired to return to your prior routine such as working, exercising, or visiting with friends. You might have started taking new medication or wanting to change your lifestyle. You may have expressed the need and importance of a good support system, where a support system was empathic and listened to you. Finally, you may have wanted health care professionals to be involved in your recovery. Ways health care professionals could be more involved with your recovery were being available to answer your questions in a timely manner, provide follow-up shortly after discharge, and/or tailor your stroke recovery based on your situation. Overall, your experience was unique and your needs and concerns were best addressed when health care professionals listened to what you were saying.

Appendix G: IRB Approval Metropolitan Hospital



Partners Human Research Committee
 Partners Human Research Office
 116 Huntington Avenue, Suite 1002
 Boston, MA 02116
 Tel: (617) 424-4100
 Fax: (617) 424-4199

Amendment: Notification of IRB Approval/Activation

Protocol #: 2011-P-002483/3; MGH

Date: 03/28/2013

To: Teresa Connolly, RN
Neurology

From: Thelma L Bennett
 PHS Research Management
 116 Huntington Ave Suite 1002

Title of Protocol:	Post Stroke Survivors' Experiences During the First Four Weeks of Discharge Home from the Hospital
Version Date:	11/07/2011
Sponsor/Funding Support:	None
IRB Amendment #:	2
IRB Review Type:	Expedited
Minimal Risk:	45 CFR46.110 and 21 CFR56.110
Expedited Category/ies:	(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis). (7) Research on individual or group characteristics or behavior, or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or QA methodologies.
IRB Approval Date:	03/25/2013
Approval Effective Date:	03/27/2013
IRB Expiration Date:	05/30/2013

This Amendment to ongoing approved project has been reviewed and approved by the MGH IRB. During the review of this Amendment to ongoing approved project, the IRB specifically considered (i) the risks and anticipated benefits, if any, to subjects; (ii) the selection of subjects; (iii) the procedures for securing and documenting informed consent; (iv) the safety of subjects; and (v) the privacy of subjects and confidentiality of the data.

NOTES: *The following changes are noted and approved by the IRB: A revised protocol summary, (version date 02/15/2013), Informed Consent (version 2, and interview guide/script reflect the changes made.*

1) The study title changed to Post-Stroke Survivors' Experiences During the First Four Weeks of Discharge Home from the Hospital".

2) Increase the number of participants, interview times, changes to the specific aims of the study to reflect the purpose of understanding the post stroke survivors' experience after discharge home.



Partners Human Research Committee
Partners Human Research Office
116 Huntington Avenue, Suite 1002
Boston, MA 02116
Tel: (617) 424-4100
Fax: (617) 424-4199

As Principal Investigator you are responsible for the following:

1. Submission in writing of any and all changes to this project (e.g., protocol, recruitment materials, consent form, study completion, etc.) to the IRB for review and approval prior to initiation of the change(s), except where necessary to eliminate apparent immediate hazards to the subject(s). Changes made to eliminate apparent immediate hazards to subjects must be reported to the IRB.
2. Submission in writing of any and all adverse event(s) that occur during the course of this project in accordance with the IRB's policy on adverse event reporting.
3. Submission in writing of any and all unanticipated problems involving risks to subjects or others.
4. Use of only IRB approved copies of the consent form(s), questionnaire(s), letter(s), advertisement(s), etc. in your research. Do not use expired consent forms.
5. Informing all physicians listed on the project of changes, adverse events, and unanticipated problems.

The IRB can and will terminate projects that are not in compliance with these requirements. Direct questions, correspondence and forms (e.g., continuing reviews, amendments, adverse events, safety reports) to Thelma L. Bennett, (617) 424-4116.

Appendix H: IRB Approval Boston College



BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 13.219.01

DATE: April 9, 2013
TO: Teresa Connolly
CC: Ellen Mahoney
FROM: Institutional Review Board – Office for Research Protections
RE: Post Stroke Survivors' Experiences During the First Four Weeks of Discharge Home From the Hospital

Notice of IRB Review and Approval
Expedited Review as per Title 45 CFR Part 46.110, FR 60366, FR, # 5, 6 & 7
Waiver of Documentation of Informed Consent [Title 45 CFR 46.117 (c)]

The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
2. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
3. You will immediately inform the Office for Research Protections (ORP) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval dates stamped on them (approved copies enclosed).

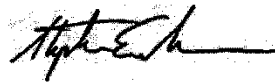
6. You will give each research subject a copy of the informed consent document;
7. You may enroll up to 60 participants. You may not enroll more than this number of participants without seeking IRB approval. To do so will be a violation of the conditions of IRB approval and, if federal funding is involved in your project, a matter of non-compliance that we must report to the federal government. This could significantly and negatively impact your research.
8. If your research is anticipated to continue beyond the IRB approval dates, you must submit a Continuing Review Request to the IRB approximately 60 days prior to the IRB approval expiration date. Without continuing approval the Protocol will automatically expire on April 8, 2014.

Additional Conditions: *Any research personnel that have not completed an acceptable education/training program should be removed from the project until they have completed the training. When they have completed the training, you must submit a Protocol Revision and Amendment Form to add their names to the protocol, along with a copy of their education/training certificate.*

Approval Period: **April 9, 2013-April 8, 2014.**

Boston College and the Office for Research Protections appreciate your efforts to conduct research in compliance with Boston College Policy and the federal regulations that have been established to ensure the protection of human subjects in research. Thank you for your cooperation and patience with the IRB process.

Sincerely,



Stephen Erickson
Director
Office for Research Protections

Enclosures

JN

Table 1: Description of article year, purpose, sample size and method

Authors	Purpose	Population	Methods
Anderson & Whitfield (2013)	Understand the way in which family, social and community resources might enhance stroke survivors' participation in personally meaningful activities over the long term	N=9	Grounded theory
Brunborg & Ytrehus (2013)	Describe the factors that promote subjective well-being in a long-time perspective of 10 years after stroke	N=9	Phenomenological
Carlsson et al. (2008)	Describe how people cope with their new life situation during the first year of stroke	N=18	Grounded theory
Danzl et al. (2013)	Describe the experience of stroke for survivors and their caregivers in rural Appalachian Kentucky	N=25, 13 stroke and 12 caregivers	Qualitative description
Dickson et al. (2008)	To investigate the beliefs and experiences of people with dysarthria as a result of stroke and explore the perceived physical, personal, and psychosocial impacts of living with dysarthria	N=24	Method not specified
Eilertsen et al. (2010)	Illuminate older women's experiences and the characteristics of the recovery process following a stroke	N=6	Method not specified
Ellis et al. (2013)	Explore stroke survivors' perceptions of their own recovery and residual impairments with specific emphasis on communication and cognition	N=9, males	Focus group: Grounded theory

Authors	Purpose	Population	Methods
Erikson et al. (2010)	To discover the meaning of acting with others in different places over the course of 1 year post stroke...not develop a theory but an abstract theoretical understanding	N=9	Grounded theory
Flinn et al. (2010)	To explore the experience and the impact of post stroke fatigue among individuals who had sustained a stroke, were living in a community, and were experiencing post stroke fatigue	N=19 18 stroke, 1 partner	Focus group exploratory
Gilworth et al. (2009)	Expectations and experiences of stroke survivors in relationship to return to work	N=13	Method not specified
Green et al. (2009)	Explore the factors that impacted patient's quality of life and wife caregivers strain over 12 months following a minor stroke	N=52, 26 married couples	Method not specified
Jones et al. (2008)	Learn about individual beliefs and personal strategies used to support the period of recovery after a stroke. Identify factors that were perceived to be enablers as well as challenges to recovery. Identify personal actions or experiences which were perceived to be effective in this process	N=10	Phenomenological
Jones & Morris (2013)	Explore the experiences of adult stroke survivors and their parent caregivers	N=17, 6 stroke 11 caregivers	Phenomenological
Kirkevold et al. (2012)	Describe how fatigue is experienced by stroke survivors, how they understand and deal with fatigue, how fatigue impacts their daily life	N=32	Method not specified

Authors	Purpose	Population	Methods
Klinke et al. (2013)	Explore and describe the experience of eating and eating related difficulties in stroke survivors living at home	N=7	Phenomenological descriptive
Kouwenhoven et al. (2011)	Describe the lived experience of stroke survivors suffering from depressive symptoms in the acute phase. Understand what the nature of depression experienced is and what it is like to live with depression in the first few weeks.	N=9	Phenomenological hermeneutic
Morris et al. (2013)	Explore the legal and access issues for people with aphasia and provide preliminary information to inform development of processes to ensure access to the legal information and services for people with aphasia	N=50	Qualitative description
Northcott et al., (2011)	Explore why people lose contact with friends, whether there are protective factors and how this loss of friendship is perceived.	N=29	Method not specified
Pallesen (2013)	Identify, from a long-term perspective, stroke survivors' self-identity, their views of any associated disabilities and how they manage their lives after stroke	N=15	Phenomenological
Salisbury et al. (2010)	Explore the individual experiences and perceptions of views of the health care system and services after a stroke	N=22, 13 stroke and 9 partners	Interpretive phenomenological analysis
Schmitz et al. (2010)	Study the perspectives and experiences of PSS and their partners regarding sexual issues and perceived rehabilitation needs	N= 29, 15 stroke and 14 partners	Thematic analysis

Authors	Purpose	Population	Methods
White et al. (2008)	Explore the long term experiences of mood changes in community-dwelling stroke survivors at 1, 3, and 5 years after a stroke	N=12	Grounded theory
White et al. (2009)	Explore the experiences of community dwelling stroke survivors at 1, 3, and 5 years.	N=12	Modified grounded theory
White, Gray et al. (2012)	To explore the experience of post-stroke fatigue in community dwelling stroke survivors with and without post-stroke mood disturbance within one year of stroke	N=33	Modified grounded theory approach
White, Miller et al. (2012)	Explore the impact of driving issues post-stroke in community dwelling stroke survivors	N=22	Thematic grounded theory approach
Williams & Murray (2013)	Investigate and describe older adults' lived experience of occupation adaptations following a stroke	N=5	Phenomenological
Wood et al. (2010)	To examine the process of community reintegration after stroke from the patient's perspective	N=10	Grounded theory
Yeung et al. (2011)	Explore concerns experienced by Chinese women stroke survivors during hospitalization and transition home	N=15 women	Phenomenological
Yilmaz et al. (2013)	Investigate the experiences of post-stroke women regarding their sexual issues as well as interactions in social life	N=16 women	Method not defined
Young et al. (2013)	Explore the patient perspective of fatigue and how it is experienced and its subjective impact on the patient	N=10	Phenomenological

Table 2: Time post stroke of interviews

Authors	Number of Interview(s)	Time Post Stroke of Interviews
Anderson & Whitfield (2013)	1	Not specified
Brunborg & Ytrehus (2013)	1	10 years
Carlsson et al. (2008)	1	1 year
Danzl et al. (2013)	1	1-14 years
Dickson et al. (2008)	1	2-36 months
Eilertsen et al. (2010)	12-14	Within first 2 years (unsure of interview times) interviews peaked within the first few months when improvements were the biggest, then interviews every 3 months by second year
Ellis et al. (2013)	1	Less than 2 years
Erikson et al. (2010)	4	1, 3, 6, 12 months
Flinn et al. (2010)	1	Vague sometime after acute phase when PSSs were living in the community
Gilworth et al. (2009)	1	2-8 years
Green et al. (2009)	6	1, 2, 3, 6, 9, 12 months
Jones et al. (2008)	1	6 weeks-13 months
Authors	1	1-7 years
Jones & Morris (2013)	3	6 months, 1 year, 2 years
Kirkevold et al. (2012)	2-3	>6 months
Klinke et al. (2013)	1	4-7 weeks
Kouwenhoven et al. (2011)	1	Not specified
Morris et al. (2013)	1	8-15months
Northcott et al., (2011)	1	5 years
Pallesen (2013)	1	2-9 years
Salisbury et al. (2010)	1	2-14 years
Schmitz et al. (2010)	3	1, 3, 5 years
White et al. (2008)	3	1, 3, 5 years
White et al. (2009)	5	Stroke onset, 3,6,9,12 months
White, Gray et al. (2012)	5	Stroke onset, 3,6,9,12 months
White, Miller et al. (2012)	1	1-14 years
Authors	5	Pre-discharge, 2 weeks, 3 months, 6 months, 1 year
Williams & Murray (2013)	1	Within 1 week of discharge home from the hospital
Wood et al. (2010)	1	Not specified
Yeung et al. (2011)	1	12-52 weeks

Table 3: Brief study description

Study and year	Sample size	Purpose	Description of intervention
Allen et al. (2009)	United States N=380	Determine the superiority of a comprehensive post discharge care management of PSSs to organized acute stroke department care on improving the profile of health and well-being	An advanced practice nurse performed an in-home assessment and then an interdisciplinary team developed an individualized plan of care. Control: usual post discharge care, every 2 months subjects received letter reminding them of involvement and provided with stroke educational materials
Askim et al. (2006)	Norway N=62	Evaluate the effect of an extended stroke unit services on early support discharge on balance and walking speed and explore the association between initial leg paresis, initial movement ability and balance one year after stroke	Subjects received a home based program coordinated by a mobile stroke team that offered early supported discharge and intensive task-specific exercise therapy during first 4 weeks after discharge. Control: usual post discharge care of either rehabilitation stay or follow-up with PCP

Study and year	Sample size	Purpose	Description of intervention
Askim et al. (2010)	Norway N=62	Evaluate the effect of a 4 week intensive motor training program combined with early supported discharge as well as evaluate the effect of the treatment on other function outcomes	A multidisciplinary team worked closely with the primary health care system in the first 4 weeks after discharge. Subjects received additional sessions of motor training that were individualized to patient's needs. Rehabilitation was administered at home, outpatient, or rehabilitation unit as required by patient's needs. Subjects were instructed to write about training in a diary Control: usual post discharge care of either rehabilitation stay or follow-up with PCP
Batchelor et al. (2012)	Australia N=132	To determine if a tailored multifactorial falls prevention program prevents falls in people with stroke who are at risk for recurrent falls and whether the program leads to improved gait, balance, strength and fall related efficacy	Subjects received usual care plus a physiotherapist creates and individualized home exercise program. Provides fall risk minimization strategies and education about fall risk both verbal and written such as a fall prevention booklet such as a fall prevention booklet Control: usual care and provided falls prevention booklet
Bjorkdahl & Bjorkdahl (2006)	Sweden N=109	Assess the effect of 3 weeks of rehabilitation in the home setting for younger PSSs to improve activity level	Subjects received 9 hours of individualized, tailored training based on patient's needs at home. Control: received normal day clinic rehabilitation

Study and year	Sample size	Purpose	Description of intervention
Chaiyawat & Kulkantrakorn (2012a)	Thailand N=58	Examine the effectiveness of an individual 6-month home rehabilitation program on ischemic stroke, middle cerebral artery patients, on disability and quality of life at 2 years	Subjects received home rehabilitation program once a month for 6 months with audiovisual materials. A physical therapist would focus on mobility and activities of daily living Control: Usual care as determined by physician as either home rehabilitation or outpatient rehabilitation
Chaiyawat & Kulkantrakorn (2012b)	Thailand N=58	To determine if a 6 month home rehabilitation program would improve activities of daily living as well as decrease disability, reduce depression and alleviate dementia	Subjects received home rehabilitation program once a month for 6 months with audiovisual materials. A physical therapist would focus on mobility and activities of daily living Control: Usual care as determined by physician as either home rehabilitation or outpatient rehabilitation
Globas et al. (2012)	Germany N=38	Test the efficacy of aerobic treadmill exercise (TAEX) in chronic stroke survivors aged 60 years and older compared to conventional care physiotherapy	Subjects were given an aerobic treadmill exercise program Control: usual care with no aerobic training, but after 3 months completed control group given TAEX with change of walking with inclination
Hegyí & Szigeti (2012)	Hungary N=50	Investigate whether acupuncture, especially Yamamoto's New Scalp Acupuncture, is of value in addition to standard post stroke motor rehabilitation	Subjects received acupuncture therapy using the dry needling method in addition to rehabilitation Control: received rehabilitation as determined by Hungarian standard rehabilitation protocol, without acupuncture

Study and year	Sample size	Purpose	Description of intervention
Ihle-Hansen et al. (2012)	Norway N=178	To determine if a multifactorial intervention program reduces the incidence of cognitive symptoms one year after stroke and TIA in first ever stroke patients without cognitive decline prior to stroke	<p>Subjects were invited to the outpatient clinic for consultation with a stroke nurse and physician. Information was provided regarding importance of lifestyle change. Tailored advice was given to subjects about risk factor management and plan was sent to general practitioner. Topics covered were based on secondary prevention such as blood pressure, cholesterol, physical activity, diet, smoking, and alcohol consumption. Subjects were also given information regarding medications about secondary prevention about secondary prevention</p> <p>Control: received usual treatment as determined by their general practitioner</p>

Study and year	Sample size	Purpose	Description of intervention
Joubert et al. (2008)	Australia N=233	To determine if combining educational and behavioral aspects of stroke care and screening for depression will be effective in finding and reducing depressive symptoms in PSSs	Created an integrated care model where pre-discharge subjects were told to nominate a caregiver. Subjects were given 3 monthly semi-structured telephone interviews. Interviews were focused on decreasing risk factors, discussing current problems with subjects, and monitoring follow-up from PCP appointments. Control: received normal discharge care as determined by PCP, with PCP receiving standard discharge summary documents
Su Fee et al. (2009)	Singapore N=20	Determine if early participation in outpatient rehabilitation for PSSs will alter compliance with attendance, functional status, and quality of life	Subjects discharged from rehabilitation unit were to attend an outpatient rehabilitation and assessed on the day of discharge or within one week of discharge Control: referral faxed to outpatient rehabilitation and subjects arranged assessment after discharge
Torp et al. (2006)	Denmark N=198	Determine if an interdisciplinary stroke team can reduce length of stay, readmission rate, increase patient satisfaction, and reduce dependency of help	Subjects received care of an interdisciplinary team. Therapists took over training the last 7 days of rehabilitation stay and carried out a comprehensive rehabilitation program for up to 30 days post discharge. Control: received normal discharge care post rehabilitation

Study and year	Sample size	Purpose	Description of intervention
Watkins et al. (2011)	United Kingdom N=211	Determine if motivational interviewing can benefit mood and mortality post stroke	A trained psychiatric nurse provided motivational interviewing to discuss the adjustment to stroke and concerns. Interviewing also allowed for subjects to elicit personal goals of recovery and perceived barriers. Control: Received normal care
Ytterberg et al. (2010)	Sweden N=50	Explore the changes on perceived health status over five years after receiving early support discharge intervention	Subjects discharged from rehabilitation unit early and received a tailored rehabilitation program by PT, OT, and ST completed in subject's home. Control: received normal discharge care on a rehabilitation unit or other facility if required

Table 4: Purpose of interventional studies

Study	Purpose	Physical improvement	Psychological improvement	Administrative improvement
Allen et al. (2009)	Determine the superiority of a comprehensive post discharge care management of PSSs to organize acute stroke department care on improving the profile of health and well-being		√	
Askim et al. (2006)	Evaluate the effect of an extended stroke unit services on early support discharge on balance and walking speed and explore the association between initial leg paresis, initial movement ability and balance one year after stroke	√		
Askim et al. (2010)	Evaluate the effect of a 4 week intensive motor training program combined with early supported discharge as well as evaluate the effect of the treatment on other functional outcomes	√		

Study	Purpose	Physical improvement	Psychological improvement	Administrative improvement
Batchelor et al. (2012)	To determine if a tailored multifactorial falls prevention program prevents falls in people with stroke who are at risk for recurrent falls and whether the program leads to improved gait, balance, strength and fall related efficacy	√		
Bjorkdahl & Bjorkdahl (2006)	Assess the effect of 3 weeks of rehabilitation in the home setting for younger PSSs to improve activity level	√		
Chaiyawat & Kulkantrakorn (2012a)	Examine the effectiveness of an individual 6-month home rehabilitation program on ischemic stroke, middle cerebral artery patients, on disability and quality of life at 2 years	√		

Study	Purpose	Physical improvement	Psychological improvement	Administrative improvement
Chaiyawat & Kulkantrakorn (2012b)	To determine if a 6 month home rehabilitation program would improve activities of daily living as well as decrease disability, reduce depression and alleviate dementia	√		
Globas et al. (2012)	Test the efficacy of aerobic treadmill exercise (TAEX) in chronic stroke survivors aged 60 years and older compared to conventional care physiotherapy	√		
Hegyí & Szigeti (2012)	Investigate whether acupuncture, especially Yamamotos New Scalp Acupunctures, is of value in additional to standard post stroke motor rehabilitation	√		

Study	Purpose	Physical improvement	Psychological improvement	Administrative improvement
Ihle-Hansen et al. (2012)	To determine if a multifactorial interventional program reduces the incidence of cognitive symptoms one year after stroke and TIA in first ever stroke patients without cognitive decline prior to stroke		√	
Joubert et al. (2008)	To determine if combining educational and behavioral aspects of stroke care and screening for depression will be effective in finding and reducing depressive symptoms in PSSs		√	
Su Fee et al. (2009)	Determine if early participation in outpatient rehabilitation for PSSs will alter compliance with attendance, functional status, and quality of life	√	√	√

Study	Purpose	Physical improvement	Psychological improvement	Administrative improvement
Torp et al. (2006)	Determine if an interdisciplinary stroke team can reduce length of stay, readmission rate, increase patient satisfaction, and reduce dependency of help	√	√	√
Watkins et al. (2011)	Determine if motivational interviewing can benefit mood and mortality post stroke		√	√
Ytterberg et al. (2010)	Explore the changes on perceived health status over five years after receiving early support discharge intervention		√	

Table 5: Intervention categories

Study and year	Physical Intervention	Psychological Intervention
Allen et al. (2009)	√	√
Askim et al. (2006)	√	
Askim et al. (2010)	√	
Batchelor et al. (2012)	√	
Bjorkdahl & Bjorkdahl (2006)	√	tailored intervention
Chaiyawat & Kulkantrakorn (2012a)	√	
Chaiyawat & Kulkantrakorn (2012b)	√	
Globas et al. (2012)	√	
Hegyí & Szigeti (2012)	√	
Ihle-Hansen et al. (2012)	√	
Joubert et al. (2008)	√	√
Su Fee et al. (2009)	√	
Torp et al. (2006)	√	comprehensive program
Watkins et al. (2011)		√
Ytterberg et al. (2010)	√	tailored intervention

Table 6: Study outcomes and findings

Study	Outcomes	Result
Allen et al. (2009)	<p>Main outcomes</p> <p>Neuromotor function: NIHSS, Timed get up and go, physical performance test</p> <p>Institution Time and Death</p> <p>QOL: stroke specific QOL scale</p> <p>Management risk: BP control, medication appropriateness, hemoglobin A1c, total cholesterol, self-reported falls and INC</p> <p>Stroke knowledge and lifestyle modification: using investigator-generated questionnaire</p>	Stroke knowledge and lifestyle modification significantly different between groups (p=.0003)
Askim et al. (2006)	<p>Main Outcomes</p> <p>BBS and walking speed</p>	Walking speed significantly different than control at 1 week (p=.04)
Askim et al. (2010)	<p>Main outcome</p> <p>BBS</p> <p>Secondary outcomes</p> <p>BI</p> <p>Motor Assessment Scale</p> <p>Step Test</p> <p>5-meter Walk Test</p> <p>Stroke Impact Scale</p>	<p>Motor assessment was significantly different between groups at week 4 (p=.04)</p> <p>There was a significant improvement of overall function in both control and intervention group (p>.001)</p>

Study	Outcomes	Result
Batchelor et al. (2012)	<p>Main outcome Fall rates Proportion of fallers at 12 months</p> <p>Secondary outcome Sit to stand tests Gait speed over 5 meters Step test Human activity profile FIM Falls efficacy scale Swedish modification Fall risk for older adults community setting Baking Tray test/Star Cancellation test Visual field confrontation test Abbreviated mental test score</p>	<p>No statistically significant between groups given individualized exercise program compared to control for both primary or secondary outcomes</p>
Bjorkdahl & Bjorkdahl (2006)	<p>Main outcome Assessment of motor skills: AMPS</p> <p>Secondary outcomes Complement scales used to measure activity level: FIM, IAM, NIHSS, BNIS, & Thirty Meter Walking Test Costs were estimated</p>	<p>No statistically significant difference between day clinic and home rehabilitation</p>
Chaiyawat & Kulkantrakorn (2012a)	<p>Main outcome BI</p> <p>Secondary outcome MRS: degree of disability EQ-5D: Monitors five dimensions mobility, ADLs, self-care, pain/discomfort, and anxiety/depression</p>	<p>Home rehabilitation group had increased functional improvement compared to control. BI (p<.05) MRS (p<.05) EQ-5D (p=.03)</p>

Study	Outcomes	Result
Chaiyawat & Kulkantrakorn (2012b)	<p>Main outcome BI</p> <p>Secondary outcome Depression and anxiety by HADS Thai MMSE to measure dementia</p>	<p>Home rehabilitation group had increased functional improvement and decreased depression compared to control.</p> <p>BI= (p=.03) HADs (p=.01) MMSE= no statistical significant</p>
Globas et al. (2012)	<p>Main outcome Peak exercise Sustained walking capacity in 6 minute</p> <p>Secondary outcome Gait velocity in 10 m walks BBS Functional leg strength Self-rated mobility Quality of life SF-12</p>	<p>An aerobic exercise program on the treadmill yielded greater cardiovascular fitness and gait compared to control</p> <p>Main outcome Peak exercise P (<.001) Sustained walking capacity in 6 minute p (<.001)</p> <p>Secondary outcome Gait velocity in 10 m walks p (<.001) BBS (P <.05) Functional leg strength (no statistical significance) Self-rated mobility (p=<.05) Quality of life SF-12 (no statistical significance on physical portion, mental portion of test p<.01)</p>

Study	Outcomes	Result
Hegy & Szigeti (2012)	<p>Main outcome BI</p> <p>Measurement of mobility: Rivermead Scale Index</p> <p>Visual Analog Scale: Describes general health and physical status</p>	<p>Acupuncture lead to increased mobility, ADL's, and general health compared to control</p> <p>BI (p<.01) Rivermead Scale Index (p<.01) Visual analog Scale (P<.05)</p>
Ihle-Hansen et al. (2012)	<p>Main outcome Changes in trail making tests A 10-word test</p> <p>Secondary outcome Diagnosis of dementia Mild cognitive impairment</p>	<p>No statistically significant for participants given individualized consultation to prevent risk for stroke compared to control for both main and secondary outcomes</p>
Joubert et al. (2008)	<p>Depression using the PHQ-9</p>	<p>Intervention group significantly less depressed than control (p=.003)</p>
Su Lee, et al. (2009)	<p>Main outcomes Attendance at outpatient rehabilitation Functional status: FIM Quality of life: SF-36</p>	<p>No statistical significant difference between groups on all outcomes</p>
Torp et al. (2006)	<p>Main outcomes Length of Stay Hospital readmission rates Patient Functional scores: BI, FAI, MMSE, CT-50 Depression: GDS QOL: SF-36 Costs of continued care</p>	<p>No statistical significant difference between groups on all outcomes</p>

Study	Outcomes	Result
Watkins et al. (2011)	<p>Main outcome Normal mood: GHQ-28</p> <p>Secondary outcomes Mortality Depression screen: Yale ADL: BI, NEADL SEQ: Beliefs and expectations of recovery</p>	Motivational intervening had a beneficial effect on mood (p=.02 at 12 months) and a protective effect against depression at 3 months (p=.03)*
Ytterberg et al. (2010)	<p>Main outcomes SIP Functioning: LMCA, 10 meter walk, Nine Hole Peg Test, Katz ADL index</p>	No statistical significant difference between groups on all outcomes

NIHSS=National Institutes of Health Stroke Scale, QOL= Quality of Life, BP= blood pressure, INC= incontinence, BBS= Berg Balance Scale, BI= Barthel Index, FIM= Functional Independence Measure, AMPS= Assessment of Motor and Process Skills, IAM= Instrumental Activity Measure, BNIS= Barrow Neurological Institute Screening, MRS= Modified Rankin Scale, ADL's activities of daily living, HADS= Hospital Anxiety and Depression Scale, MMSE= Mini Mental Status Exam, PHQ= Patient Health Questionnaire, SF= Short Form, FAI= Frenchay Activity Index, GDS= Geriatric Depression Scale, GHQ= General Health Questionnaire, NEADL= Nottingham Extended Activities of Daily Living, SIP= Sickness Impact Profile, LMCA= Lindmark Motor Capacity Assessment

Table 7: Separation of cohorts by time post discharge

	Week 1 Cohort	Week 2 Cohort	Week 3 Cohort	Week 4 Cohort
Interview time post discharge	24-48 hours	10-11 days	17-18 days	24-25 days

Table 8: Descriptive characteristics

Characteristic	Value
PSSs (n=31)	
Age, <i>mean (SD), yr</i>	55.94/16.87
<i>median, yr</i>	58
Gender, <i>n(%)</i>	
Male	17(54.8)
Female	14(45.2)
Race, <i>n(%)</i>	
White	24(77.4)
Black	5(16.1)
Asian	1(3.2)
Not reported	1(3.2)
Ethnicity, <i>n(%)</i>	
Non-Hispanic	29(93.5)
Hispanic	2(6.5)
Comorbidities, <i>n(%)</i>	
Hypertension	18 (58.1)
Hyperlipidemia	11(35.5)
Atrial fibrillation	5(16.1)
Smoking	3(9.7)
Migraines	4(19.4)
Previous Stroke or TIA	6(19.4)
Coronary Artery Disease	2(6.5)
Received tPA, <i>n(%)</i>	5(16.1)
Outpatient services, <i>n(%)</i>	
PT	9(29)
OT	15(48.4)
Speech	3(9.7)
Nursing	6(19.4)

SD=Standard deviation, TIA=transient ischemic attack, tPA=tissue plasminogen activator, PT=physical therapy, OT=occupational therapy

Figure 1: Theoretical conceptualization of transitional experiences for PSSs

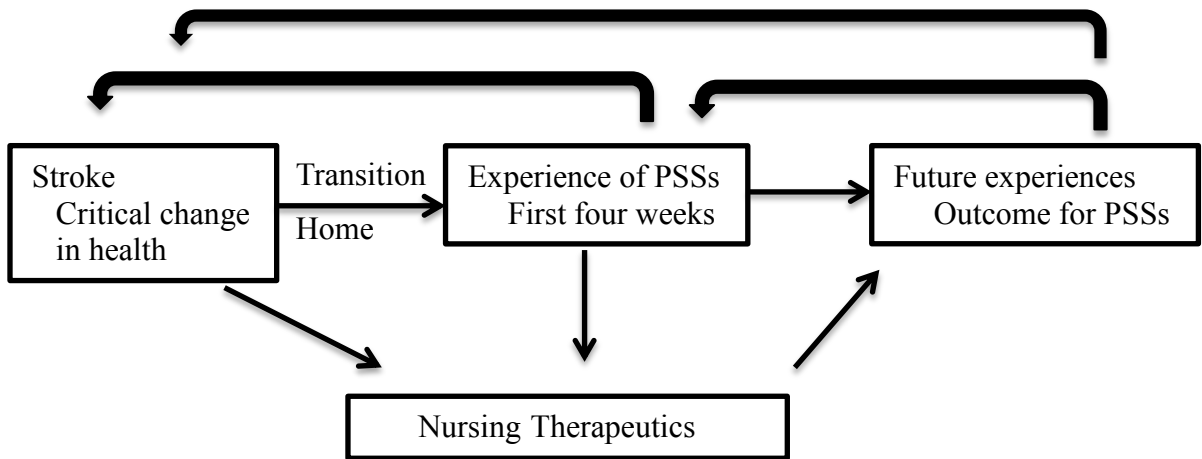


Figure 2: Conceptualization of transitional experiences for PSSs

