A Thesis

entitled

Actions Caregivers of Persons with Neurological Insult Take
to Prevent Hospital Readmissions

by

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Since the Patient Protection and Affordable Care Act law of 2010, hospitals are held accountable by payers for readmissions and have sought to identify the factors that lead to readmission, usually by examining medical issues such as comorbidities and medication prescriptions. While these factors may play a role, family caregiving is an essential, yet understudied, factor that can hasten, delay, or prevent patients’ hospital readmissions. The purpose of this study was to describe what actions family caregivers of persons with neurological insult take to prevent hospital readmissions, and if actions are taken, the reasons for those actions.

Friedemann’s Framework of Systemic Organization guided this study in which health/well-being is defined as congruence. Hospital admissions can lead to incongruence, or an imbalance in well-being, for the care recipient and the caregiver. Caregivers may perform actions or behaviors in an attempt to return to a state of well-being.

With IRB approval, a qualitative descriptive design was used. A one-time structured interview, with established content validity by experts in the field, was used to
explore actions taken by family caregivers to prevent hospital readmissions for care recipients with neurological insult, as well as the reasons for these actions. The data were analyzed using Colaizzi’s content analysis. Friedemann’s framework was applied to the themes that emerged from these data.

Four middle-aged, family caregivers of stroke survivors (one African American male; three White females) from northwest Ohio ultimately participated in the study. Five action themes emerged: consulting with healthcare providers (Friedemann’s process dimensions of system maintenance, individuation), encouraging the care recipient (individuation, coherence), observing the care recipient closely (system maintenance), assisting the care recipient with ADLs (system maintenance, coherence), and seeking information/education (system maintenance, individuation). Four reason themes emerged: promoting safety (system maintenance), increasing physical function (individuation), respecting individuality and dignity (system maintenance), and maintaining roles and relationships (coherence).

Understanding what actions stroke family caregivers take and the reasons for those actions, enables nurses to provide targeted education and suggest community resources to potentially reduce hospital readmissions. Nurses can also advocate/intercede with local, state, and federal legislatures, as well as insurance companies, on their behalf.

*Keywords*: caregivers, stroke, patient readmission, nervous system diseases
Dedication

To Amanda, Dominique, and Conor: may each of you keep your faith, value education, make the most of your opportunities, and remember to learn at least one new thing each day.
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Chapter 1

Introduction

This qualitative research study is focused on discovering ways family caregivers of persons with neurological insult try to prevent hospital readmissions after discharge from an acute in-patient rehabilitation hospital. The problem statement, purpose of the study, Friedemann’s (1995, 2016) theoretical framework to guide the study, and the research question with definitions of terms are presented in this chapter. The significance of the research is noted, as are the assumptions and limitations related to the theoretical framework. This chapter concludes with a summary.

Statement of Problem

In 2010, the latest year for which comprehensive data are available, there were substantial readmissions to hospitals in the United States. Readmission rates for the diagnoses specified in the Center for Medicare and Medicaid Services’ (CMS) Readmissions Reduction Program (CMS, 2016) are significant. In 2010, there were 209,017 (24.7%) persons with heart failure (HF) readmitted to hospitals, 85,932 (16.5%) persons with acute myocardial infarction (MI) and 144,894 (15.7%) persons with pneumonia readmitted among all payers, meaning Medicare, Medicaid, private insurance, and the uninsured (Elixhauser & Steiner, 2013). Specific to persons with neurological insult, readmissions to hospitals in 2010 are also significant: 71,174 (13.7%) readmissions for persons with the principle diagnosis of cerebrovascular accident.
(stroke); 1,609 (12.2%) readmissions for persons with the principle diagnosis of spinal cord injury (SCI), and 18,304 (11.3%) readmissions for persons with traumatic brain injury (TBI) for all payers (Elixhauser & Steiner, 2013).

Hospital readmissions within 30 days after hospital discharge are being targeted by the CMS (2016) as avoidable healthcare spending. Currently, as part of its Readmissions Reduction Program, fee for service programs are reducing reimbursement to hospitals with excessive readmissions of five diagnoses: acute myocardial infarction, heart failure, pneumonia, chronic obstructive pulmonary disease (COPD), and elective total knee or total hip arthroscopy (CMS, 2016). It is common knowledge that private insurers often follow the guidelines CMS implements. As hospital reimbursements are increasingly determined by these hospital readmission rates (CMS, 2016), the healthcare field must identify drivers of readmission rates and interventions to be implemented to reduce them, including care-related actions taken by family caregivers.

Multiple studies have been conducted on how to best meet the needs of hospitalized persons to reduce readmission rates. Fuji, Abbott and Norris (2012) conducted a qualitative study that found providers have difficulty meeting multiple care needs and that patient-centered care is needed to reduce readmissions. Another qualitative study by Feigenbaum et al. (2012) concluded that multiple factors contribute to potentially avoidable readmissions, including lack of appropriate referrals, medication errors, inadequate care and discharge plans, lack of family caregiver and/or patient understanding and abilities, and inattention to psycho-social needs, among other factors.
A randomized control trial by Coleman, Parry, Chalmers, and Min (2006) found that chronically ill persons and their family caregivers require teaching during the transition from hospital to home to make sure their needs are met and to reduce readmissions, indicating that the family caregiver plays an important role in reducing readmissions. However, none of these studies have specifically focused on persons with neurological insult being discharged from an acute rehabilitation hospital to home with a family caregiver.

Persons who have suffered a neurological insult are often admitted to an acute in-patient rehabilitation hospital upon discharge from the acute care hospital and are then discharged to home with a full-time family caregiver, such as a family member or friend, due to their need for around the clock and continuing care. The National Alliance for Caregiving [NAC] and AARP (2015) identify that 43.5 million adults in the United States are family caregivers. Feinberg, Reinhard, Houser and Choula (2011) estimated the value of family caregivers at $450 billion in 2009 alone, based on 42.1 million adult family caregivers at any given time providing an average of 18.4 hours of care per week. According to Senior Care Management (2004), hospitals are not focusing on the family caregiver, "a key member of the health care team" (p. 49). According to Feinberg et al., (2011) family caregivers complete a multitude of tasks on behalf of the care recipients, including, but not limited to: 1) personal care such as bathing and dressing; 2) medication management; 3) household tasks like handling bills, insurance claims, transporting, cleaning, and preparing meals; 4) coordinating care of services including direct care personnel and health care providers, as well as transitions from hospital to home; 5) being
an advocate for the care recipient; and 6) providing emotional support. In the United States in 2011, most caregivers were providing care for persons with Alzheimer’s Disease (21%), but if persons with stroke, SCI, and TBI are combined, they accounted for 23 percent of care recipients (National Family Caregiver Alliance [NFCA], 2011).

Although neurological insult (stroke, SCI, and TBI) is not among the top diagnoses for which the Centers for Medicare and Medicaid Services are already reducing payments, there are large numbers of these individuals being readmitted to hospitals with these conditions. Since most family caregivers are also caring at home for these individuals, they may be taking actions to prevent or curtail potentially avoidable readmissions as part of their caregiving tasks.

Statement of Purpose

The purpose of this study is to examine the actions that family caregivers of persons with neurological insult take to prevent potentially avoidable hospital readmissions, and if there are any actions taken, what are the reasons that those particular actions were chosen.

Theoretical Framework

The theoretical framework guiding this study is Friedemann's Framework of Systemic Organization (1995, 2016). Friedemann has taken the nursing metaparadigm of environment/person/health/nursing (Fawcett, 1989) and added the family and the family's
health, as well as social systems, as important concepts (Friedemann, 1995, 2016). The interactions between and among these concepts lead a care recipient toward or away from congruence, described as health or well-being (Friedemann, 1995, 2016). Friedemann's (1995, 2016) framework encompasses four process dimensions: system maintenance, system change, individuation, and coherence. The balance among these process dimensions leads the person toward congruence. The antithesis is incongruence or the absence of health or well-being, often evidenced by anxiety, stress, strain or depression (Friedemann, 1995, 2016). Specific to this study, registered nurses, including advanced registered nurse practitioners, are positioned to assist these family caregivers and their care recipients with neurological insult in the quest for health in their home environment following an acute inpatient rehabilitation hospital stay. The family caregiver, as a member of the family, needs to know what care to provide, how to provide that care, and when and where to seek assistance in order to exert influence on the process dimensions, helping to facilitate the congruence/well-being of the care recipient.

For this study, Friedemann's (1995, 2016) concept of system maintenance refers to the care recipient and family caregiver's family organization, including such specific elements as roles, decision making, and monitoring behaviors. For the person with a neurological insult (care recipient), the ability to continue residing in the community in one's own home may be achieved by conceding some control to the family caregiver by allowing him or her to provide necessary care. Changes to the family structure, especially in the areas of roles and decision making, would be common with the neurological insult care recipient and family caregiver. System change is defined as a
long process in which one adjusts to the changes resulting from the neurological insult that impact the family caregiver, care recipient, and entire family. Both the care recipient and family caregiver are redefining their individual identities based on the roles they are adapting to post-neurological insult. Individuation is described by Friedemann (1995, 2016) as ongoing self-development. For the neurological insult care recipient and his or her family caregiver, it is important to maintain relationships and involvement to the greatest extent possible. These strategies may help him or her to find new meaning through activities that expand a person’s horizon, teaches about self and others, and leads to new perspectives. Coherence is described within the context of family behaviors: bonding, identity, and respect within and commitment to family members. Maintaining an identity within the family, continuing family bonds, respecting, and maintaining commitment to the family and its members allow for a new stability for the person with the neurological insult and his or her family caregiver. While the neurological insult injury is beyond the control of this care recipient and family caregiver, learning to accept the results of the injury and adjust their lives accordingly leads to system change and growth. If balance among these process dimensions is not achieved, incongruence can occur, which is often manifested as anxiety, depression, or both, in the care recipient as well as his or her family caregiver (Friedemann, 1995, 2016).
Research Questions

The first research question is: are there actions that family caregivers of persons with neurological insult take to prevent hospital readmissions? Subsequently, if there are actions taken by the caregiver, what are the reasons those actions are chosen?

Definition of Terms

Persons with neurological insult.

Conceptual definition. These are persons who have sustained a neurological insult in the form of a stroke, SCI or TBI and who are discharged from the acute inpatient rehabilitation hospital to home under the care of a family member/friend. Friedemann (1995) states that disease is a malfunction of at least one human system. In these instances, the person is often dealing with both cognitive and physical deficits. Malfunctioning of these systems leads to the need for a family caregiver, though the person with a neurological injury retains autonomy in whatever capacities possible that reflects the best of his or her ability (Friedemann, 1995, 2016).

Orientalational definition. For this study, the neurological insult person is defined as someone with a stroke, SCI or TBI discharged from the rehabilitation hospital in the past six to twelve months and is being cared for by the self-identified family caregiver.
Family caregiver.

**Conceptual definition.** A family caregiver is an unpaid person, who may or may not be related to the patient and is the primary person responsible for the care of the person with a neurological insult. This family caregiver assists the person with a neurological insult to try to achieve congruence or health (Friedemann, 1995, 2016).

**Oriational definition.** For this research study, the family caregiver will have a care recipient who has been discharged six to twelve months ago from one university-affiliated inpatient rehabilitation setting in one Midwest City. These self-identified family caregivers are assisting the neurological insult patient in the home setting.

Hospital readmission.

**Conceptual definition.** Hospital readmission is defined as being admitted to an acute care facility within 30 days of discharge from an acute inpatient rehabilitation facility. These hospital readmissions are a result of incongruence or ill-health (Friedemann, 1995, 2016).

**Oriational definition.** Readmission to an acute care hospital for an overnight stay within 30 days of discharge from an acute inpatient rehabilitation facility constitutes a change in the person with neurological insult’s environment, producing further disharmony and incongruence (Friedemann, 1995, 2016).
Actions and reasons.

**Conceptual definition.** Actions are seen as behaviors displayed by family caregivers for the person with neurological insult. Reasons are cognitive decision making processes that may move the care recipient toward health/well-being or congruence (Friedemann, 1995, 2016).

**Orientational definition.** For this study, family caregivers will be interviewed as to their perceived actions that they used to try to prevent readmission to the hospital. In addition, if actions are taken, these family caregivers will be asked what their perceived reasons were for taking those actions.

**Significance**

The Centers for Medicare and Medicaid Services (CMS) note that health care costs can be lessened by reducing hospital readmissions, as inpatient care is far more expensive than outpatient care (Moy, Chang & Barrett, 2013). The average cost per individual stay for a person diagnosed with a stroke was estimated at $9,500 for an average five day hospital stay (Russo & Andrews, 2008). Additionally, Farhad et al. (2013) noted an average cost per hospital admission of a person with TBI to be $21,460 for a two to five day hospital stay in 2006-2007. Spinal Cord Injury Information Pages (2014) cite an initial hospitalization cost of $140,000 per person with SCI. They also note an average rehabilitation hospitalization of 44 days, though a cost estimate was not
given. None of these reports included costs incurred at an acute rehabilitation hospital, skilled nursing facility, or subsequent acute care hospital.

Understanding what actions family caregivers take to prevent hospital readmissions can have a tremendous impact on the provision of care at home. According to a Senior Care Management article (2004), family members (i.e. potential family caregivers at discharge) find more satisfaction with hospital care if they have been included and are involved with the patient's care. Subsequently, persons who are going to be family caregivers in the home who were involved during the neurological insult person's hospitalization would have more knowledge of this care recipient’s needs upon discharge. Better meeting those needs could correlate with decreasing potentially avoidable hospital readmissions. There was very little literature discovered on how family caregivers might prevent hospital readmissions in persons with neurological insult. More research is needed in this area to describe what actions these family caregivers might use to prevent hospital readmissions and, if actions are taken, the reasons that they chose these actions. The knowledge garnered from this study may assist registered nurses and other healthcare providers in determining best practices, best outcomes, and what interventions could help control health care costs nationwide. The nurse can then educate family caregivers and persons with neurological insult, if they are cognitively intact, on methods to reduce hospital readmissions.
Assumptions

There are assumptions related to this research about the ability of family caregivers to prevent hospital readmissions that are relative to Friedemann's (1995, 2016) framework of systemic organization which guides this study.

1. The person with neurological insult often requires a family caregiver to assist them in reaching the goal of congruence, health/well-being, and striving toward congruence due to the effects of his or her injury.

2. Hospital readmissions can be prevented by the actions of family caregivers. Friedemann's theory (1995, 2016) asserts that the family caregiver is part of the care recipient’s environment and, if allowed by the care recipient, can intervene to assist him or her toward well-being/health or congruence. This population experiences long lasting, sometimes lifelong, effects of the neurological insult that become integrated into the person’s definition of well-being.

3. While the effects of the neurological insult may create incongruence, if those effects direct that person toward health or well-being, congruence may result (Friedemann, 1995, 2016). For example, the care recipient with a neurological insult may experience anxiety or incongruence at the inability to dress himself/herself, but if he/she chooses to accept the dressing assistance of a family caregiver his/her anxiety may subside and congruence may follow. For the caregiver, the diagnosis of a family member with a neurological insult may also cause stress and anxiety, or incongruence. If that caregiver chooses to care for the person with neurological insult, congruence, or well-being, may be the outcome for both persons.
Limitations

There are also limitations in using Friedemann's (1995, 2016) framework of systemic organization that guides this research.

1. A framework is simply one way to organize information or look at the world. There is not one framework that is compatible with everyone’s individual views. Therefore, not everyone may view a hospital readmission as a problem, or as incongruence, a disruption of the patterned, compatible flow of energy between one's interacting systems (Friedemann, 1995, 2016).

2. The actions of family caregivers may be entirely dependent upon the individual with a neurological insult rather than the work of health care providers or family caregivers. For example: an individual may maintain autonomy to the point of detriment to his/her health, such as refusing certain care the family caregiver may try to provide. If this is the case, the family caregiver would not be empowered to improve health nor prevent hospital readmissions for a care recipient, but that empowerment would lie solely with the care recipient.

Summary

Inpatient hospital care is far more expensive than outpatient care (Moy, et al., 2013). The Centers for Medicare and Medicaid Services (2016) are reducing payments to hospitals with high levels of readmissions for some specific diagnoses. Since private
insurers often follow CMS guidelines, all reimbursements to hospitals for provision of care could be impacted by their payment rates for hospital readmissions in the future. The purpose of this study is to describe what actions a family caregiver of a person with a neurological insult might take to prevent hospital readmissions, and if actions are taken, the reasons for those actions. The findings could provide an initial understanding of how healthcare providers can intervene and educate family caregivers about actions that could potentially prevent hospital readmissions. Family caregivers’ actions may ultimately reduce health care expenditures among this population, as well as enhance the neurological insult person’s and his/her family caregiver’s well-being/health or congruence (Friedemann, 1995, 2016).

In the next chapter, Friedemann’s (1995, 2016) framework of systemic organization as applicable to this study’s research purpose and question is described. A conceptual map that links this framework to the research question is pictured and discussed. A review of the research literature pertaining to this study is also presented.
Chapter 2

Literature

In chapter one, the gap that this study seeks to fill was presented - discovering ways family caregivers of persons with neurological insults try to prevent hospital readmissions after discharge from the acute inpatient rehabilitation hospital stay. Friedemann’s (1995, 2016) framework of systemic organization is described in this chapter as the theoretical framework for this study. Current, research literature pertaining to family caregivers’ actions to prevent hospital readmissions is also presented.

Nursing Theoretical Framework

Introduction to the Framework

Friedemann’s (1995, 2016) Framework of Systemic Organization is the theoretical guide for this study. The framework encompasses the major concepts of environment, person, health, family, and family health all interacting together and influenced by one another to attain health or well-being, known as congruence (Friedemann, 1995, 2016). The environment is described by Friedemann as “open systems of energy and matter” (1995, p. 3) that are powerful, orderly, and rhythmic, including humans and nature. The concept of person is conceptualized by Friedemann’s (1995) by five propositions: 1) human discernment is limited by the physical configuration and operation of our bodies; 2) humans possess the faculty to appreciate
that we are subject to the environment in which we live and that we will all die; 3) humans preserve a sense of control by fashioning a simulated environment; 4) humans are capable of leaving their current state of being, changing, and creating new order and congruence within our environment; and 5) a human's culture is a life-long experience that is modified through the addition of new ideals and new patterns and passed to the next generation. The family is a group that shares responsibilities for building and maintaining culture and assuring basic needs are met, including safety, social skills, reproduction, emotional connections, sense of purpose, and opportunity for growth and change are met (Friedemann, 1995). Friedemann (1995) defines health as an unattainable "never truly present, never truly absent" (p. 14) goal, or system congruence, that is not fully dependent upon physical well-being. Friedemann (1995) opines family health is a dynamic process that includes: the existence of systematic plans within four process dimensions; fulfillment of all members; minimal anxiety among the members; and elicits affirmative environmental response from the community concerning the family. For example, a healthy family may have been one in which the father was the primary income provider and maintained the exterior of the family home, the mother handled all household tasks and cared for the children while working part-time, and the grandparents provided child care for occasional date nights for the parents. Suddenly the mother is afflicted with quadriplegia due to a SCI as the result of a motor vehicle accident. For the family to continue functioning in a healthy manner, the tasks and care the mother once provided would need to be provided by someone else. The mother would require assistive care with her activities of daily living; however, the mother's value to the family would still need to be appreciated, and the family would have to accept this new reality.
Thus, Friedemann’s (1995) framework of systemic organization is based upon the understanding that a basic order exists in the universe to which all things are connected. The order fluctuates with the flow of energy among systems (Friedemann, 1995). Congruence is a state of being in which systems are in harmony, allowing for the free flow of energy within and between systems (Friedemann, 1995). If the flow of energy is blocked or a system is no longer in accordance with an individual’s morals and principles, a state of incongruence occurs (Friedemann, 1995). Using the previous example, if the mother with SCI was not accepting of the fact that her role within the family unit had changed, she would experience incongruence, as would any of the other family members, due to the disharmony and disunity created by the mother’s inability to accept a new reality.

**The process dimensions.** In order to further understand Friedemann’s (1995) framework, the process dimensions of system maintenance, system change, coherence, and individuation need to be considered. Through these processes, people, e.g., family caregivers and care recipients, can strive for and may obtain well-being or congruence and/or curb anxiety or incongruence.

**System maintenance.** Friedemann (1995) relates that persons have flexibility, the ability to explore different options, a regard for diversity, and the aptitude to change patterns and ways of being. If these changes do not cause pain and struggle they contribute to system maintenance, actions that help to maintain physical, emotional, and social needs and reduce the threat of change (Friedemann, 1995). An exemplar: a person
who has sustained a stroke may be aware of abilities to articulate words correctly yet fully understands what he needs to communicate. He decides to use paper and pencil to do so, maintaining his ability to communicate effectively with those around him. Perhaps it is the family caregiver that suggests this new form of communication, contributing to the stroke person's system maintenance.

**System change.** System change occurs when pressure from within oneself or from the environment forces testing of values and the setting of new priorities and adjustment (Friedemann, 1995). For instance, when an athletically minded person suffers a SCI and she is faced with the inability to create purposeful movement, she may choose to focus on the abilities lost and reject change. Alternatively, she may contemplate if there is more to life than physical functioning, choose to change former values of athletic abilities, and rejoice in the ability to give and receive affection, thereby changing former values and embracing new ones. If her family caregiver has encouraged her acceptance of a different way of living, she or he has assisted in system change for this person.

**Coherence.** Friedemann (1995) portrays coherence as behaviors needed for unity, reaching out to others for support, bonding and displaying togetherness, being committed to family members. Coherence entails the physical body as well as psycho-social aspects such as body image, self-confidence, and personal identity (Friedemann, 1995). A person who has recently experienced a TBI may be cognizant of some memory deficits but unsure of how to cope with them, while a person with TBI from many years ago may choose to use smart phone alarms and reminders to help trigger him to remember to
complete tasks. This person has chosen to accept his limitations and find different ways of achieving goals, redefining his self-confidence and maintaining his identity. The recent TBI person may need a family caregiver to arrange for these task alerts to begin the process of reaching goals through an unanticipated pathway, allowing for coherence.

*Individuation.* Friedemann (1995) describes individuation as activities focused on self-development and learning new information. Individuation is represented by a person with SCI choosing to attend and participate in a SCI support group, learning how others with paralysis have adjusted to their reality, and adapting to one’s own new reality. Activities as varied as self-catherization to empty one’s bladder to participating in wheelchair athletic events to counseling the person with newly sustained SCI could all contribute to individuation and may be influenced or initiated by the family caregiver.

**Synthesis of the Framework**

The conceptual map presents Friedemann’s (1995, 2016) concepts applied to the care recipient, a person with a neurological insult (Figure 1). Friedemann’s (1995, 2016) Framework of Systemic Organization is an appropriate guide for this research study to examine actions that family caregivers of persons with neurological insult take to prevent hospital readmissions and, if there are such actions, the reasons those actions were chosen. The family caregiver and care recipient are each parts of a family structure, individual members “who feel emotionally bonded by a sense of belonging” (Friedemann, 1995, p. 60). According to Friedemann, the family needs to “endure and
adjust in the midst of change and maintain congruence with its environment” (1995, p.18). This study aims to determine if family caregivers are taking actions to prevent readmissions to hospitals, thereby assisting the care recipient toward well-being/congruence, and if actions are chosen, what the reasons are. The care recipient and family caregiver must adjust to each other’s role changes within the family “by seeking within that person the pattern of wholeness that reflects universal order” (Friedemann, 1995, p. 63). The actions of the family caregiver influence all four process dimensions of Friedemann’s (1995, 2016) Framework of Systemic Organization, thereby affecting the care recipient’s journey toward health/well-being or congruence.

![Diagram](image-url)

**Figure 1.** Conceptual map based on Friedemann’s Framework of Systemic Organization and care recipient with a neurological insult (1995, 2016).
Review of Research Literature

The research literature related to the topic of actions that caregivers might take to prevent readmissions in the neurological insult population is sparse, certainly indicating a need for further research. The literature reviewed in this section includes three studies regarding caregiver interventions that potentially reduce readmissions, four studies involving stroke caregiver interventions and their potential effects on the care recipient/stroke survivor, and one study that dealt with brain injury caregiver interventions and outcomes for the care recipient. There were no studies uncovered that focused on spinal cord injury caregiver interventions and the effects on their care recipient.

Interventions to Reduce Readmissions

Coleman et al. (2006) conducted a randomized controlled trial that tested their Care Transitions Intervention in a large population of patients with “complex care needs who require care across different health care settings” (p. 1822). The Care Transitions Intervention provided a patient care record and encouraged patient and/or caregiver management of their own healthcare management (N=750). The intervention was built upon four pillars including medication self-management, patient-centered record, follow-up, and red flags. Goals for each pillar were delineated. A transitions coach met with each patient, and caregiver if applicable, while still in the hospital and discussed the goals. The coach then made a home visit in which the goals were reiterated and questions were answered. Three follow-up telephone contacts were made over the next
month to assess and discuss progress toward goals. The 2-sample comparison data were analyzed using the Wilcoxon rank sum test and Fisher exact test, with the $\chi^2$ test to determine statistical difference of outcomes between the study and control groups. The Care Transitions Intervention group was found to have lower hospital readmission rates at 30-, 90-, and 180-days post discharge in this study. Limitations of this study were that it was conducted in one healthcare system in one western U. S. state, post-hospital care was provided by a hospital-based physician, assuring access to hospitalization records, and study participants were all aged 65 and over (Coleman, et al., 2006).

Pierce, Steiner, Khuder, Govoni, and Horn (2009) compared the use of a Web-based intervention for stroke survivor caregivers (N=36) versus no caregiver intervention (N=37) on several aspects of healthcare service use, including the care recipient’s readmission and/or emergency room visits. This one year, randomized, repeated measures study was conducted with an intervention and control group of caregivers. The intervention, or Web-user, group was provided stroke-focused education and support through a Web site that had been piloted in prior studies. The elements of the intervention site consisted of four correlated segments: links to other relevant stroke and caregiving Web sites; educational information and suggestions specifically for caregivers of stroke survivors; a private email discussion area to correspond with a nurse or multi-disciplinary rehabilitation team; and a non-private email discussion area for caregivers to correspond with each other that was facilitated by a nurse. Telephone interviewers assessed all participants about their well-being and the stroke survivors’ use of healthcare services. Data were characterized using descriptive statistics, and comparison between
groups was calculated using chi-square and t-tests. Mixed model analyses were conducted for differences over time and two-way ANOVA was used to compare differences between the two groups. While the study ultimately found no differences in well-being among the two groups of caregivers, they did find lower readmission rates and less emergency room visits for the stroke survivors in the Web-user group. These results indicate that assisting caregivers in obtaining information may influence their decision making, thereby reducing healthcare service use. Limitations for this study include the inability to generalize the findings due to its small geographic area in two Midwestern states and the homogeneity of participants, as well as relying on the caregivers’ perception of the care recipients’ use of healthcare services (Pierce, et al., 2009).

White et al. (2015) conducted a qualitative descriptive study to enhance comprehension of stroke caregivers’ and care recipients’ viewpoints on readmissions. Participants were older stroke survivors who had been readmitted to the hospital within six months after the initial stroke event and/or their caregivers (N=20). They were interviewed by phone about two weeks following their discharge from the readmission. Data analysis methods are not described in this study, but the authors did state that the study produced five themes related to the stroke survivors’ and caregivers’ needs and concerns: preparation for discharge; home expectations; medication management intricacies; self-care support at home; and the influence of social aspects. This study provides an insight into the specific needs of stroke survivors and their caregivers, from their unique point of view. It offers focus-areas for future discharge planning and
potential nursing interventions. Limitations of this study include small sample size and readmissions that were only from home (White, et al., 2015).

**Stroke Caregiver Interventions**

Lincoln, Francis, Lilley, Sharma, and Summerfield (2003) performed a randomized controlled study in the United Kingdom to determine the effects of a Family Support Organizer (FSO) service on caregivers’ and stroke survivors’ moods, activities of daily living (ADL) independence, and stroke knowledge. Participants (N=212) were randomized into an FSO service or standard care. Those in the FSO group received contact by the organizer within two weeks of agreeing to participate, were provided information about stroke, and were queried as to their particular needs. For up to nine months in the study, the organizer assisted with discharge planning, made home visits, provided emotional support, and offered guidance to secure necessary services. Data were analyzed using the Mann-Whitney U test to gauge differences between groups. Ultimately the study determined there was no difference in mood or independence among the two groups, however, the FSO group participants were much more knowledgeable concerning stroke risk reduction, available services in the community, and who to connect with for further stroke information. This study is limited based on the use of one FSO, which may not be representative of all FSOS, and the small sample size of this heterogenous population (Lincoln, 2003).
Another United Kingdom study completed by Kalra et al. (2004) looked at the outcomes of a caregiver training program on the stroke survivors. This particular study recruited caregiver participants (N=300) to either receive training during the stroke survivor’s rehabilitation stay or receive conventional support. The caregiver training group included professional instruction about usual stroke-related difficulties and their prevention, such as gait abnormalities, pressure sores and proper positioning, optimal nutrition, and counselling about benefits and community services. The training group also received hands-on instruction in ideal lifting, transferring, ADL assistance, and communication techniques for their individual stroke survivor. Outcomes data were evaluated using modified Rankin scale, Barthel index, Frenchay activities index, and EuroQol scale, with the Mann-Whitney and $\chi^2$ tests used to determine differences in the groups. This study found that stroke survivor mortality, hospitalization or other inpatient care, and disability were not affected by the caregiver training, although stroke survivor depression, anxiety and quality of life were positively influenced. Limitations of this study include the inability to fully blind observers, the potential for observer bias, missing data on some assessments attributed to encouraging the participants to complete assessments independently, and the inability to generalize findings as the participants were from one middle-class suburban area (Kalra, et al., 2004).

In a United Kingdom cluster randomized controlled trial study by Forster et al. (2013) of 928 stroke-caregiver dyads from multiple rehabilitation units, the effects of the London Stroke Centers Training Course (LSCTC) were assessed on both physical and psychological effects. Although the LSCTC had promising results in its initial, small
trial, those results were not replicated in this larger study. A caregiver training record was used to assess each stroke unit’s conformance with LSCTC provisions and adjustments for stroke severity were made based on the Edinburgh stroke case mix adjuster. Primary outcome data, ADL independence, from the two groups was compared using a two-level hierarchal model between study or control stroke units. This particular study concluded that the LSCTC group showed no significant differences in stroke survivor ADLs nor in the caregiver burden scale at six months post-stroke. Additionally, the study found patient and caregiver costs were not statistically different between the two groups in that time frame. The researchers determined that this study was robust and generalizable to UK stroke survivors and their family caregivers (Forster, et al., 2013).

A promising recent study carried out by Ostwald et al. (2013) in the United States investigated the effects of in-home psychoeducational support versus mailed information in stroke-caregiver dyads. The randomized trial assessed overall health, depression, stress, burden, coping, support, and function on each dyad and repeated these assessments to determine change over time. After obtaining IRB approval, this study recruited 159 dyads for participation, with 134 completing the study. All participants were mailed stroke information on stress reduction, diet and exercise, support and advocacy group contact information, signs and symptoms of stroke, and stroke risk reduction strategies. The in-home group was also provided with home visits by advanced practice nurses, occupational therapists, and physical therapists who delivered further education, support, counselling and skill training. Data were analyzed using descriptive statistics for demographic variables, $t$-test for independent samples, Wilcoxon rank sum test for
ordinal variables, and the chi-test or Fisher’s exact test for categorical assessment. After six months and twelve months, the in-home group of caregivers exhibited perceived better health and utilized a support system versus the mailed information group. Additionally, the care recipients displayed better perceived health and improved cognition at six and twelve months, though no significant difference was found in depression or stress. This study reveals that multi-faceted interventions may be effective at improving stroke survivors’ and caregivers’ perceived health. However, the limitations of this study were that, though the participants were diverse, it was conducted in one metropolitan area and the sample size is not large enough to analyze by race or ethnicity. Another limitation was the inclusion criterion of the stroke survivor being over the age of 50 years old, thus the results cannot be applied to younger stroke survivors (Ostwald, et al., 2013).

**Traumatic Brain Injury Caregiver Interventions**

A study of 90 severe brain injury survivors and their families was undertaken in India by Reddy and Vranda (2012). The study investigated the effectiveness of the Family Intervention Package (FIP), an intervention consisting of eight specific educational training sessions for the family members as well as follow-up visits and return to work mediation for the TBI survivor. Data collection and analysis methods are not discussed in the publication. The authors deemed that the study group demonstrated increased functioning and family interaction at the six month conclusion of the study as compared to the control group. This study was relatively small and limited to patients in
one institution’s neurosurgery department, but highlights the importance of educating the caregivers in improving the well-being of the TBI survivor (Reddy & Vranda, 2012).

**Synthesis of Research Literature**

In general, reducing readmission rates in the neurological insult population through caregiver interventions is a subject just beginning to be researched. This literature is still very limited with no studies uncovered in the SCI population and is showing mixed results in the few studies that have been undertaken in the stroke and TBI populations. The promising results show that including the caregiver in educational and support features may be helpful in increasing the neurological insult person’s health/well-being related to stroke and TBI (Ostwld et al., 2013; Pierce et al., 2009; Reddy & Vranda, 2012; White et al., 2015). Thus, very little data is available demonstrating the effects of the caregiver’s actions on hospital readmissions.

**Summary**

In this chapter Friedemann’s (1995, 2016) framework of systemic organization was described and applied to this study, including a conceptual map. As the conceptual map shows (Figure 1), the neurological insult suffered by the care recipient nudges him or her away from congruence/well-being. The actions of the family caregiver have effect
not directly on congruence, but on the four process dimensions of the care recipient: system change; coherence; individuation; and system maintenance, which directly impact the care recipient’s attainment of congruence/well-being. Balance among and between these process dimensions is the optimal goal of the care recipient, striving toward a state of congruence/well-being (Friedemann, 1995, 2016).

While some studies have been done that examine the effects of certain interventions on care recipient and family caregiver quality of life issues, such as decreased depression and anxiety (Kalra et al., 2004), others have shown no effect on those areas (Lincoln et al., 2003; Ostwald et al., 2013). No studies were found that examined actions that family caregivers of persons with neurological insult might take to prevent hospital readmissions or the reasons for taking those actions. The current study seeks to determine if these family caregivers do indeed take particular actions in an attempt to reduce readmissions and, if so, why those actions are chosen. The methods, data collection and analysis procedures for this study, are presented in the next chapter.
Chapter 3

Method

The rationale for studying family caregivers’ actions taken to prevent hospital readmissions for neurological insult persons was presented in Chapter 1. The theoretical framework and research literature review were presented in Chapter 2. This research study’s design, sample, materials used, data collection, and data analysis are discussed in this chapter.

Design

This study used a qualitative descriptive design to explore what actions, if any, family caregivers of neurological insult persons took to prevent hospital readmissions.

Setting and Sample

With the University of Toledo Institutional Review Board approval, family caregivers of neurological insult persons who had been discharged from the Coghlin Rehabilitation Hospital at the University of Toledo were recruited for this study. It was anticipated that at least fifteen caregivers would need to be contacted in order to find twelve caregivers who would agree to be interviewed. A sample size of twelve is appropriate for a qualitative study as determined by Guest, Bunce, and Johnson (2006)
who found that ninety-seven percent data saturation was achieved after analysis of data from just twelve interviews.

Inclusion Criteria

The potential participants were family caregivers of neurological insult (stroke, SCI, TBI) persons who were six to twelve months post discharge. Participants recruited were over twenty-one years of age and English speaking, to facilitate the interview process. It was anticipated that the racial/ethnic background of the participants would reflect that of the population within the rehabilitation hospital’s service area of Lucas County, Ohio: 74 percent Caucasian; 19 percent African American; six percent Latino; and one percent of other racial/ethnic groups (Toledo-Lucas County Commission on Minority Health, 2011). No racial/ethnic groups were excluded.

Exclusion Criteria

To facilitate recruitment, potential participants who did not have a telephone or did not speak fluent English were excluded from the study.
Material

Participants were asked questions in a face-to-face structured interview designed for the study by the research team - the student researcher and three doctorally prepared researchers. The structured interview questions were chosen, discussed, and agreed upon by the research team based on the literature and their professional experience in order to achieve the aims of the study (see Appendix A; Guided Interview Form). The interviews began by asking the participant for demographic information about him/her-self and the care recipient. The questions included: age, gender, race/ethnicity, schooling, employment status, and overall health of the family caregiver; and race/ethnicity, age, relationship to the family caregiver, gender, living arrangements, neurological insult diagnosis, other chronic conditions, overall health, and length of time since hospital discharge of the care recipient. The interviewer then asked the family caregiver to think about times when he/she thought the care recipient would have been hospitalized if he/she did not take action. The caregiver was asked to tell those stories and describe those situations. If the family caregiver was not able to identify any actions, interview prompts were used to help him/her recall any actions that he/she might have taken, such as calling a healthcare provider, giving a medication, asking a friend for advice, or conducting an Internet search. If the family caregiver did not indicate in his/her description why the actions taken were chosen, he/she was specifically asked. Finally, the family caregiver was asked if his/her care recipient had been readmitted to a hospital since the care recipient’s discharge from the rehabilitation hospital and, if so, for what reason. The
interview concluded with asking the family caregiver if there was any other information he/she would like to add and thanking him/her for his/her participation.

Data Collection

Sampling

Purposive sampling was used in this study because only caregivers of neurological insult persons could answer these questions. Family caregivers who were identified by the rehabilitation hospital staff as potential participants were called on the telephone by the staff to determine if they would be willing to have a student researcher call them and explain this study to them. If a family caregiver was willing, the staff documented his or her first name and telephone number on a subject recruitment form (see Appendix B; Subject Recruitment Form) which was provided to the student researcher in a sealed envelope. The student researcher then called the caregiver to explain the study and consent form, as well as answer any questions he or she had about the research. If the family caregiver was willing to participate, a meeting was arranged at a convenient location, such as the caregiver’s home or a public library. At the meeting, the student researcher obtained informed consent (see Appendix C; Informed Consent Form) and then conducted the face-to-face structured interview. If the caregiver-participant so chose, they were welcome to take the consent form home and schedule the
interview for a later date, thus providing time for their further consideration prior to the interview.

Protection of Human Rights

The university Institutional Review Board (IRB) approval (see Appendix D; IRB Approval) for this study implies protection of human rights. There was minimal risk to the participants, but the participants were assured that should they become uncomfortable with the discussion or answering interview question(s), they were able to refuse to answer or completely stop the interview at any time. Confidentiality was protected by assigning identification numbers and assuring the participant’s name would not appear on any portion of the data analysis or results. All data were stored on a secure server at the university to minimize the risk of loss of confidentiality. Further, all participants were informed that study results may be shared with a professional journal and its readership in aggregate and no actual names would be associated with any of these data.

Data Collection and Recording

A structured interview lasting approximately one hour was conducted to explore if family caregivers took actions, if any, and reasons to try to prevent hospital readmissions for their care recipients. Answers to the demographic questions were documented on a hard copy of the interview guide. Qualitative answers were noted on a hard copy of the interview guide and also electronically audio recorded and later
transcribed by the student researcher in their entirety into a Microsoft Word document. The notes taken on the structured interview guide were only used to maintain focus on the interview as it progressed and were not analyzed. To maintain confidentiality, only participant identification numbers were used with the interview data.

Validity

Face validity is defined by Grove, Burns, and Gray as verification “that the instrument ... gave the appearance of measuring the construct it was supposed to measure” (2013, p. 394). To ensure validity, the structured interview questions were developed by the research team based upon the literature review and their research and nursing experiences.

Assumptions and Limitations

Assumptions are statements believed to be true though they have not been scientifically proven (Grove, et al., 2013). Assumptions in this study include that the family caregiver participants were able to take actions to prevent hospital readmissions for their care recipients with neurological insult. Other assumptions included that participants were truthful in discussing any actions they took to prevent hospital readmission, whether they believed their actions prevented readmissions, and why or the reasons for those actions were chosen.
On the contrary, transferability was one of the limitations of this study due to the purposive sampling and the setting of one Midwest City. While the participants may have been representative of this one hospital’s patient and family caregiver population, they may not be representative of all family caregivers of neurological insult persons in the Midwest, the United States, or globally.

Data Analysis

Demographic data were obtained from the family caregivers and analyzed using descriptive statistics. Data on hospital readmissions were also analyzed using descriptive statistics. Qualitative interview data or the stories family caregivers provided related to actions taken to prevent readmissions were transcribed into Microsoft Word verbatim from electronic audio recordings. The transcribed narrative data were then analyzed for common themes using Colaizzi’s (1978) rigorous method of content analysis. The following steps are included in Colaizzi’s method of content analysis (1978):

- Read the entire descriptions to obtain a sense for the whole.
- Extract significant statements and phrases pertaining directly to the phenomenon, in this case, what actions, if any, family caregivers of neurological insult persons took to prevent hospital readmissions. If family caregivers took actions, why were those actions chosen (reasons) and did they believe those actions prevented readmissions.
- Formulate meanings from the significant statements and phrases.
• Cluster meanings into themes.

• Integrate results into an exhaustive description of the phenomenon.

The student researcher and the other investigators on the research team then collaborated and discussed differences in coding and categorizing the data throughout this process until a final agreement was reached. Only then were the results integrated into a description of the phenomenon using the process dimensions of Friedemann’s (1995, 2016) Framework of Systemic Organization.

Summary

This qualitative descriptive design was used to determine what particular actions, if any, family caregivers of neurological insult persons may take to prevent hospital readmissions and explore the reasons for or why those actions were chosen. After obtaining university IRB approval, family caregivers of neurological insult persons that had been discharged from the rehabilitation hospital were contacted by hospital staff to ascertain if they might be willing to learn more about this research. If they were willing, the hospital staff provided their first name and phone number to the student researcher. The student researcher contacted the potential participant to explain the research and informed consent, and then arranged a meeting time and place convenient for the caregiver if he or she were interested in participating. At the meeting, informed consent was obtained, and one face-to-face interview was conducted. Demographic information was recorded on the guided interview form and the qualitative data were electronically audio recorded. Participants’ demographic and hospital readmissions data were analyzed.
using descriptive statistics. Narrative responses were transcribed into a Word document and then analyzed using Colaizzi’s (1978) method.

Friedemann’s (1995, 2016) Framework of Systemic Organization was applied to the results to gain an understanding of the impact of these actions and reasons for those actions on the health/well-being/congruence of the care recipients with neurological insult. The results are presented in the following chapter with data analysis details and selected participants’ remarks.
Chapter 4

Results

In the previous chapter, the research design, data collection procedures, and data analysis processes were described. The results of these analyses are presented in this chapter. Included in this section are: 1) a demographic profile of the caregiver participants, as well as their care recipients, and 2) the findings of the study indicating what caregiver actions were taken to prevent readmissions to the hospital and why those particular actions were chosen. This chapter concludes with a summary.

Sample: Profile of Caregivers and Care Recipients

Caregivers of neurological insult patients who met inclusion criteria were identified by the hospital staff (N=11). One caregiver declined to participate when contacted by the staff and five declined when contacted by the researcher. Five caregivers agreed to participate in the research study. One potential participant, however, was determined to have not met inclusion criteria as her care recipient was discharged from the rehabilitative care unit less than six months ago. Ultimately, four caregivers of persons with stroke signed the informed consent form and participated in the study. There were no caregivers of SCI persons or TBI persons that agreed to participate in the study.
The caregivers’ ages ranged from 35 to 62 years. The majority of these four caregivers were female and white, not of Hispanic origin (75%); half were employed full-time; and all had completed at least a high school education. These caregivers all perceived themselves to be in good to very good health; most were providing care for a relative (75%); and most had been providing care for nine months or more (75%). See Table 1 for a complete demographic profile of these caregivers.

The care recipients were aged 44 to 70 years. They were evenly divided between male and female; and most were white, not of Hispanic origin (75%). The majority of caregivers perceived their care recipients to be in good health (75%) and half of the care recipients lived with their caregiver. Additionally, all the care recipients had one or more other chronic medical condition. They all had a diagnosis of hypertension, two had hypercholesterolemia, two had heart disease, one had diabetes, and one had an anticoagulating disorder. A complete demographic profile of the care recipients, as reported by their caregivers, is displayed in Table 2.
Table 1. Demographic profile of caregivers (N=4).

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Table 2. Demographic profile of care recipients (N=4).

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<td>With caregiver</td>
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Findings: Actions and Reasons

Only one care recipient had been readmitted to the hospital after acute rehabilitation discharge. The admission was for a seizure related to the hemorrhagic stroke he had suffered.
Actions Caregivers Took to Prevent Hospital Readmissions

During the interviews, the caregivers discussed actions they took that may have prevented their care recipient from being readmitted to the hospital, including making sure their care recipient continued home exercise programs, took their medications correctly, and received the necessary help to perform activities of daily living, including cooking and cleaning. Among the actions caregivers described, five themes emerged: 1) consulting with healthcare providers; 2) encouraging the care recipient; 3) observing the care recipient closely; 4) assisting the care recipient with activities of daily living (ADLs); and 5) seeking information/education.

Consulting with healthcare providers. Caregivers indicated they consulted with different healthcare providers at different times following discharge from the rehabilitative care unit. Caregivers told of asking questions of nurses, emergency responders, and physicians. Most caregivers asked questions during a healthcare interactions, such as during a therapy session, at a scheduled appointment, or when emergency responders were present. They expressed a need to obtain answers or information specifically from healthcare professionals. Specific quotes connected to this theme are listed in Table 3.
Table 3. Consulting with healthcare providers theme quotes.

<table>
<thead>
<tr>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Restless and agitated, he was almost like out of control type of thing...then (he) just kind of went limp. (I) called 911 quick, not knowing what was happening.”</td>
</tr>
<tr>
<td>“I made sure the doctors and therapists and nurses knew that the foot drop was not related to his stroke.”</td>
</tr>
<tr>
<td>“(I) called the paramedics. By the time they got there she was feeling a little better and they looked her over and checked her blood sugar and it was like low.”</td>
</tr>
<tr>
<td>“We inundated the nurses in rehab with questions about what we should do at home and what Mom should do. They gave us ‘real world’ helpful advice, not just stuff written in some papers that got buried with the multiple other papers we were given.”</td>
</tr>
</tbody>
</table>

Encouraging the care recipient. All of the caregiver participants had a story to tell about motivating and supporting their care recipient. The caregivers urged their care recipients to attend formal therapy sessions and practice therapy lessons when at home. They also supported their care recipients’ best efforts to complete tasks and did not dwell on their disabilities. They celebrated accomplishments and worked with their care recipients to foster their recovery. Table 4 identifies specific quotes from caregivers exemplifying this theme.

Table 4. Encouraging the care recipient theme quotes.

<table>
<thead>
<tr>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I also made sure he went to all of his therapy visits, PT, OT and speech. I made him practice the speech exercises at home too. I even have a couple apps on my phone that the speech therapist suggested...OT had given us things to do at home as well.”</td>
</tr>
<tr>
<td>“You know, the doctor-prescribed rehab where they’ve taught her the home stuff. She doesn’t really want to do that at home like they tell her too. Like the talking and stuff, speech therapy I should say. So we prod her to keep up with that.”</td>
</tr>
<tr>
<td>“I encouraged him to do the home exercises the physical therapists and occupational therapists taught him. That would be another thing that helped keep him at home.”</td>
</tr>
</tbody>
</table>
Observing the care recipient closely. Among the stories that unfolded related to actions caregivers took to prevent hospital readmissions were cautious tales of watching the care recipients. The caregivers felt a need to literally keep their eyes on their care recipients to watch for signs of distress and to keep the care recipients from being home alone. The caregivers were concerned for their care recipients as they tried to maintain their well-being. See Table 5 for quotes from the participants related to this theme.

<table>
<thead>
<tr>
<th>Table 5. Observing the care recipient closely theme quotes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“There was one time she had a fainting spell...normally it wouldn’t be that big of a deal. People get lightheaded all the time but she had just had the stroke and she was scared and she was falling to the ground and I braced her and lowered her to the ground”</td>
</tr>
<tr>
<td>“I watch for any kind of shaking or agitation now. I do get concerned sometimes, it seems about once a month he has a bad headache, maybe like a migraine. I watch him while he sleeps, you know, looking for shaking or even his body to go limp. I guess I’m still pretty concerned that he might have another seizure or another stroke.”</td>
</tr>
<tr>
<td>“I stayed with (him) whenever (his wife) wasn’t home for the first few months. And I want you to know too that he has not had to be admitted to the hospital again. He’s still at home.”</td>
</tr>
</tbody>
</table>

Assisting the care recipient with activities of daily living. All caregivers provided accounts of helping their care recipients get through ordinary days and perform routine tasks. These caregivers offered varied accounts of assisting with physical activities of daily living such as bathing and dressing, as well as instrumental activities of daily living such as cooking and making sure that medications were taken correctly. Interestingly, all caregivers gave the impression that it was important to support their care recipient but not complete tasks for them. In Table 6 are quotes linked to this theme.
Table 6. Assisting the care recipient with activities of daily living theme quotes.

<table>
<thead>
<tr>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I would walk with her and have her put her bad hand on the vacuum handle and I would stand on that side of her. I tell you what, her carpet was clean! Some days she moved SO slow – no speck of dust stood a chance ‘cause the vacuum was over the same spot of carpet for a long time.”</td>
</tr>
<tr>
<td>“I would come over in the evenings…and help her get showered – washing her hair for her and things like that. Then I’d help her get her pajamas on for the night.”</td>
</tr>
<tr>
<td>“(I) set it up with the (pharmacy) where they deliver her medicines every month and they’re in those nice little packages for each time during the day. I can always see that she has taken her medicines and so can she, in case she forgets or isn’t sure or whatever.”</td>
</tr>
<tr>
<td>“I do make sure that he has his medicines every day. It seemed to take a while to get his magnesium and potassium levels straightened out, but that’s all normal now.”</td>
</tr>
</tbody>
</table>

**Seeking information/education.** The caregivers wanted more knowledge about the caregiving situation. They were looking for specific information about medications, diagnoses, treatment options, and recovery trajectories. The caregivers spoke of needing to know about this new-to-them condition and what they should look for or expect, as well as how they should be providing care and what they should be doing for or with their care recipients. Table 7 includes quotes from the caregivers that are associated with this theme.

Table 7. Seeking information/education theme quotes.

<table>
<thead>
<tr>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I just worked at encouraging her to take charge of what she could. And that was very different for her. I think she was confused and startled, her whole world had just changed too.”</td>
</tr>
<tr>
<td>“I looked up all kinds of information on the Internet. I found the patient information on (a particular web site) to be very helpful. I could understand it. So I really encouraged (her) to look in to that too.”</td>
</tr>
<tr>
<td>“What I did was just help her learn to get information and use it.”</td>
</tr>
</tbody>
</table>
Reasons for Choosing Actions to Prevent Readmissions

Caregivers’ reasons for choosing particular actions to prevent hospital readmissions were not clearly stated, but they were gleaned from the stories that they shared. The reasons for choosing their actions demonstrate the deep concern and commitment these caregivers had for their care recipients. Four themes were discovered that related to reasons for choosing actions: 1) promoting safety; 2) increasing physical function; 3) respecting individuality and dignity; and 4) maintaining roles and relationships. While examining the individual stories and uncovered themes, it was noted that one experience, the example of a friend assisting her care recipient in cleaning the house, spanned all four themes. The caregiver maintained her safety by walking with her; increased her physical function by encouraging her to complete the task; respected her individuality and dignity by allowing the care recipient to determine what tasks were important to her to carry out; and maintained roles and relationships by assisting the care recipient to manage the daily tasks she had previously been, and was determined to remain, responsible for.

Promoting safety. Every caregiver spoke of concern for their care recipient’s well-being and safety. They chose their actions based on a desire to keep their care recipients free from injury, or further injury, during their recovery period. The care recipients conveyed uncertainty about what the care recipient would do on his or her own and worry for their welfare. Table 8 displays caregivers’ quotes connected to this theme.
Table 8. Promoting safety theme quotes.

<table>
<thead>
<tr>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I’m still pretty concerned he might have another seizure or another stroke.”</td>
</tr>
<tr>
<td>“she had a fainting spell…and she was falling to the ground.”</td>
</tr>
<tr>
<td>“I can always see that she has taken her medications and so can she.”</td>
</tr>
<tr>
<td>“He was not real steady walking so being able to be there for him and help him get around the house, I guess that was safer for him.”</td>
</tr>
</tbody>
</table>

**Increasing physical function.** Uncertainty about the decreased physical abilities of their care recipients after the stroke prompted all caregivers to foster functional improvement to the greatest extent possible. This is evidenced by the caregivers who all told of times they encouraged physical, occupational and speech therapies, home exercise, and ambulation. In Table 9 are quotes from participants related to increasing physical function.

Table 9. Increasing physical function theme quotes.

<table>
<thead>
<tr>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I prod her to keep up with the therapy. She doesn’t really want to do that (exercise program) at home like they tell her too.”</td>
</tr>
<tr>
<td>“I would think that helped them plan his treatment or therapy sessions.”</td>
</tr>
<tr>
<td>“(rehab nurses) are the ones who told us about getting handle bars for the shower. That has been really helpful at home (allowing her to bathe herself safely).”</td>
</tr>
<tr>
<td>“I think (continuing) therapy was a big help in keeping (him) out of the hospital.”</td>
</tr>
</tbody>
</table>

**Respecting individuality and dignity.** Two caregivers pointed out that they took actions simply out of respect for their care recipients. One story revolved around how important it is to allow the care recipient to determine what tasks needed to be completed and how much assistance was needed for the care recipient to complete the tasks. Similarly, another report focused on the care recipient’s prior functional status was
known so as not to focus recovery on a pre-existing condition. View Table 10 for these
caregivers’ particular quotes.

<table>
<thead>
<tr>
<th>Table 10. Respecting individuality and dignity theme quotes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...she’s picky, she wouldn’t let her husband help her in the shower. I think their relationship is different than what many of us have, but it works for them.”</td>
</tr>
<tr>
<td>“It was very important to her to feel like she was doing something to help her family.”</td>
</tr>
<tr>
<td>“I would think that helped them plan his treatment or therapy sessions.”</td>
</tr>
</tbody>
</table>

**Maintaining roles and relationships.** Maintaining roles and relationships was a theme exemplified in most of the caregivers’ tales. The caregivers voiced great concern regarding their recipients’ ability to preserve role identity in their relationships. They discussed being present and assisting so the care recipients could continue prior responsibilities such as completing household chores and sustain employment. Table 11 includes the quotes linked to the maintaining roles and relationships theme.

<table>
<thead>
<tr>
<th>Table 11. Maintaining roles and relationships theme quotes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I never really thought of what I did as care giving per se, I was just helping a friend who needed help.”</td>
</tr>
<tr>
<td>“I didn’t want to see either (of them) lose that closeness they had shared because their roles had changed.”</td>
</tr>
<tr>
<td>“I ... just helped out so (she) could still work. So maybe that helped her too. Maybe going to work gave her time to almost re-focus her thoughts.”</td>
</tr>
</tbody>
</table>
Summary

The purpose of this study was to determine if caregivers of neurological insult persons took actions to prevent hospital readmissions and, if so, why (reasons) those particular actions were chosen. Four caregivers of persons with stroke were interviewed and encouraged to tell their stories about potential actions they took to prevent hospital readmissions. In this chapter, caregivers’ recipients’ demographic information were presented and the caregivers’ responses regarding actions taken to prevent readmission to the hospital and the reasons for those actions were described.

The findings revealed that caregivers of persons with stroke described actions taken to prevent hospital readmissions. Five themes emerged from the data: 1) consulting with healthcare providers; 2) encouraging the care recipient; 3) observing the care recipient closely; 4) assisting the care recipient with activities of daily living (ADLs); and 5) seeking information/education. In addition, four themes were uncovered related to why those actions were chosen. These four themes were: 1) promoting safety; 2) increasing physical function; 3) respecting individuality and dignity; and 4) maintaining roles and relationships. The research questions were not answered directly, but gleaned from these caregivers of persons with stroke. However, no other neurological insult caregivers, e.g., spinal cord injury (SCI) or traumatic brain injury (TBI), participated in this study. A discussion of these themes of actions caregivers took and the reasons for those actions is linked to the literature and Friedemann’s (1995, 2016) framework that guided this study in Chapter 5.
Chapter 5

Discussion

The findings of the data analysis were presented in the previous chapter. In this chapter, the findings of this study are compared to those in the research literature. Findings are also considered in relationship to Friedemann’s (1995, 2016) Framework of Systemic Organization. Conclusions and limitations of the study are offered as well. Potential implications for nursing practice and recommendations for additional research conclude this chapter.

Findings Related to the Research Literature

Research Questions

The research questions were: 1) are there actions that family caregivers take to prevent hospital readmissions; and 2) if actions are taken by the caregivers, what are the reasons those actions were chosen? The findings were analyzed and themes emerged from each set of narrative data. Most caregiver participants responded to the actions taken question by saying that they did not see their caregiving as deliberately planned to prevent their care recipient from having a hospital readmission. However, with further questioning and discussion, actions they took that may have prevented hospital readmissions and the reasons for taking those actions were revealed.
Five themes emerged related to research question number one, actions the caregivers took. Those action themes were: 1) consulting with healthcare providers; 2) encouraging the care recipient; 3) observing the care recipient closely; 4) assisting the care recipient with activities of daily living; and 5) seeking information/education. There were also four themes related to research question two, reasons for choosing those actions. Those reason themes were: 1) promoting safety; 2) increasing physical function; 3) respecting individuality and dignity; and 4) maintaining roles and relationships.

**Research Question One: Actions Taken by Family Caregivers.**

**Cognitive actions.** Participants took cognitive actions to fulfill their needs for further information in their new role as caregiver. This supports the results of the studies conducted by Coleman et al. (2006), Pierce et al. (2009), Reddy and Vrnada (2012), Ostwald et al. (2013), and White et al. (2015), which all found that including the caregiver in education processes may be beneficial in promoting the care recipient’s health/well-being. In this current study, the caregivers’ actions to increase their knowledge and understanding are seen in the following themes: consulting with healthcare providers; and seeking information/education.

The importance of educating caregivers is underscored in various research studies. Coleman et al. (2006) found that care recipients with “complex care needs” (p. 1822) that participated in their Care Transitions Intervention, beginning prior to hospital discharge, experienced reduced readmissions as compared to the control group. This
study, however, focused on care recipients with one or more of eleven chronic health conditions, including, but not limited to, stroke. Pierce et al. (2009) determined that the care recipients of new caregivers who used their Web-based stroke intervention to access stroke information and converse with healthcare professionals and each other had lower emergency department visits and lower hospital readmissions than the non-intervention group. Reddy and Vranda (2012) concluded that a multi-faceted family intervention involving TBI caregivers resulted in enhanced functioning of the care recipient as compared to the control group. The research conducted by Ostwald et al. (2013) revealed that a home-based intervention providing information/education and support to the caregiver-care recipient dyads in their study lead to improvements in cognitive functioning of the care recipient. Further, the White et al. (2015) study, of caregivers and their stroke care recipients that were readmitted to the hospital within six months of initial discharge, identified the need for superior discharge planning. These study participants acknowledged deficits in preparing to bring their care recipients home, what to expect once discharged, how to manage complex medication regimens, and how to access community supports, all of which indicate educational needs.

Several United Kingdom studies of stroke caregiver-care recipient dyads contest the benefits of educational processes and provide conflicting conclusions. Lincoln et al. (2003) uncovered no difference in mood or independence of care recipients after working with their support organizer for up to nine months. Kalra et al. (2004) determined that care recipient mortality, hospitalization and disability were unaffected by their training intervention, though their care recipients did show improvement in depression, anxiety
and quality of life. The Forster et al. (2013) study concluded that their investigatory training process had no significant effect on care recipient ADLs nor caregiver burden. These studies refute the need for further education in the stroke population.

**Physical actions.** No research literature was uncovered regarding physical actions caregivers take with or for their care recipients. However, themes involving physical action that emerged from this study were encouraging the care recipient, observing the care recipient closely, and assisting the care recipient with ADLs. The care recipients all shared accounts of ways in which they accomplished tasks related to these themes, from directing practice therapy sessions at home to watching their care recipient sleep to helping their care recipient bathe.

**Research Question Two: Reasons Family Caregivers Chose Actions.**

The caregivers in this current study indicated their reasons for choosing particular actions on their care recipients’ behalf and these were categorized into four themes: promoting safety; increasing physical function; respecting individuality and dignity; and maintaining roles and relationships. There was no research literature discovered concerning the reasons caregivers took actions. That said, White et al. (2015) did study stroke caregiver-care recipient perspectives, but this research team only assessed their needs and concerns, not their reasoning.
Findings Linked to the Theoretical Framework

As a review, Friedemann’s (1995) theory is based on the assumption that individuals are their own system and part of social systems and environmental systems, and that all of these systems interact to produce a state of congruence or incongruence. Congruence, or health, according to Friedemann (1995), is a state when an ideal flow of energy between all systems is achieved, creating a balance among the process dimensions. Particular to this study, it is assumed the family caregiver and care recipient are in a state of incongruence, lack of well-being or health, due to the result of the neurological insult. The framework implies that pursuit of congruence, as a part of their family system may be achieved, by moving toward congruence in adapting to their situation.

The actions and reasons for taking those actions themes are discussed in relation to Friedemann’s (1995, 2016) Framework of Systemic Organization process dimensions of system maintenance, coherence, and individuation. Since the process dimensions are all inter-related, there are some themes that relate to more than one dimension. Of note, the process dimension of system change was not realized in this study as system change involves an extended process of testing values, setting new priorities, and accommodating to a significant life alteration. This study focused on stroke caregivers and care recipients six to twelve months after initial hospitalization. Thus, it is hypothesized that not enough time had elapsed to appreciate system change. See Table 12 for the relationship of the themes to Friedemann’s (1995, 2016) process dimensions.
Table 12. Relation of caregivers’ action and reason themes to Friedemann’s (1995, 2016) process dimensions.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Related Process Dimension</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Actions caregivers took</strong></td>
<td></td>
</tr>
<tr>
<td>Consulting with healthcare providers</td>
<td>System Maintenance/Individuation</td>
</tr>
<tr>
<td>Encouraging the care recipient</td>
<td>Individuation/Coherence</td>
</tr>
<tr>
<td>Observing the care recipient closely</td>
<td>System Maintenance</td>
</tr>
<tr>
<td>Assisting the care recipient with ADLs</td>
<td>System Maintenance/Coherence</td>
</tr>
<tr>
<td>Seeking information/education</td>
<td>System Maintenance/Individuation</td>
</tr>
<tr>
<td><strong>Reasons for choosing actions</strong></td>
<td></td>
</tr>
<tr>
<td>Promoting safety</td>
<td>System Maintenance</td>
</tr>
<tr>
<td>Increasing physical function</td>
<td>Individuation</td>
</tr>
<tr>
<td>Respecting individuality and dignity</td>
<td>System Maintenance/Individuation</td>
</tr>
<tr>
<td>Maintaining roles and relationships</td>
<td>Coherence</td>
</tr>
</tbody>
</table>

**System Maintenance**

Four action themes and two reason themes relate to Friedemann’s (1995, 2016) system maintenance process dimension. System maintenance consists of actions which maintain physical, emotional, and social needs. Maintaining one’s system, or basic order, fosters health/well-being, or congruence in Friedemann’s (1995, 2016) theory.

Consulting with healthcare providers, observing the care recipient closely, assisting the care recipient with ADLs, seeking information/education, promoting safety, and respecting individuality and dignity related to system maintenance. These themes all concern ways in which the caregivers acted, or thought to act, in a manner to preserve the needs of their care recipients. Caregivers spoke with or phoned healthcare providers to find out how they should assist their care recipients. They apprehensively watched their care recipients so they could intervene quickly, if their care recipients appeared somehow out of the ordinary or physically or emotionally different.
Caregivers also aided their care recipients with daily tasks such as bathing and dressing, though they clarified that they did not perform these tasks on their care recipients’ behalf but in unison with them. These actions were taken in an attempt to promote the safety of the care recipients. The caregivers related they felt it was important to get answers from healthcare providers so they could assure that they and their care recipients were doing the right things and taking medications correctly. The caregivers took these healthcare provider answers and advice as a requirement to stand guard over their care recipients and report any problematic signs. Caregivers in this study also voiced that their assistance with ADLs was to encourage the care recipients to do as much for themselves as they were able, yet assure that they were clean, dressed, fed, and toileted – promoting safety. Caregivers’ actions indicated a clear demonstration of respecting their care recipients’ individuality and dignity by allowing them to complete what they could without judgement and directing what assistance was acceptable from the caregiver.

Coherence

Activities that are necessary to achieve unity, such as connecting with others for support, bonding with people, exhibiting intimacy, and remaining loyal to family members are the hallmarks of Friedemann’s (1995, 2016) coherence process dimension. Two action themes and one reason theme relate to coherence.

Encouraging the care recipient, assisting the care recipient with ADLs, and maintaining roles and relationships related to coherence. All of the caregiver
participants told of promoting their care recipient’s activity to the extent of their abilities. This encouragement of care recipients reveals a strong sense of loyalty, a hallmark of Friedemann’s (1995, 2016) coherence process dimension. The caregivers in this study also helped their care recipients to complete everyday self-responsibilities out of their sense of devotion to the care recipient. Providing assistance in a way the care recipient felt most comfortable aligns with Friedemann’s (1995, 2016) depiction of coherence. The caregivers were cognizant of their care recipients’ need to complete tasks as independently as possible as a means of continuing their contribution to their family processes. The caregivers encouraged this independence, yet demonstrated their own commitment by readily aiding the care recipients when necessary. These themes promote coherence or togetherness between/among family members, which contributes to congruence or health, when balanced with the other process dimensions.

**Individuation**

Friedemann’s (1995, 2016) process dimension of individuation exemplifies self-development and new learning. There were four themes exposed in this study that align with individuation: action themes of consulting with healthcare providers, encouraging the care recipient, and increasing physical function; and the reason theme of respecting individuality and dignity. Persons are in a constant state of motion, waxing and waning in an attempt to achieve congruence, or health/well-being (Friedemann, 1995, 2016). Modifications in the way one views and accomplishes responsibilities through the incorporation of innovative knowledge assists persons to consider new view points and
adapt to alterations within themselves, such as the loss of use of one side of the body so often seen in stroke persons. This self-development eases one towards health, well-being or congruence.

Consulting with healthcare providers, encouraging the care recipient, seeking information/education, increasing physical function, and respecting individuality and dignity related to individuation. Caregivers explained instances of consultation with healthcare providers, including first responders, nurses, therapists, and physicians, as a means to acquire information they were lacking. These new facts were then put into use by the caregivers on behalf of the care recipients, such as assuring a medication was taken because its importance was now understood. All caregiver participants in this study chronicled ways in which they encouraged their care recipient. Using newly acquired information, nearly everyone told of at least one instance in which they helped with a therapeutic exercise or cajoled their care recipient into completing home therapies on their own. Similarly, caregivers in this study sought out information they felt was necessary to allow them to provide care. The caregivers determined that they needed more information and found ways to acquire it. They searched the Internet and asked others around them questions.

Persons, in this case the care recipients, are pushed into a state of incongruence when they suffer a stroke. This study found that caregivers of these persons can exert influence on three of Friedemann’s process dimensions - coherence, system maintenance,
and individuation. Therefore, the caregiver may affect the care recipient’s journey to congruence or well-being. This dynamic is illustrated in Figure 2.

Figure 2. Conceptual map based on Friedeman’s (1995, 2016) Framework of Systemic Organization and study results.

Conclusions

Hospital readmissions are costly and healthcare costs can be lessened by reducing them (Moy, et al., 2013). Family caregivers provide billions of dollars’ worth of care (Feinberg, et al., 2011) that would increase overall costs if their services were to be compensated. The purpose of this study was to determine if caregivers might take
actions that reduce hospital readmissions, specifically among the neurological insult population, and queried about reasons behind those actions. By interviewing family caregivers of persons with stroke, more was learned about the actions taken and the reasons those actions were chosen. Of the participants in this study, only one care recipient had been readmitted to the hospital for seizure, related to his hemorrhagic stroke. This study has revealed that caregivers do take some actions that may prevent hospital readmissions: 1) they assured that their care recipients took ordered medications as prescribed; and 2) they helped their care recipients stay physically active. These actions that were taken both reduce the risk of re-stroke which would result in hospital readmission and the caregivers identified their reasoning for these actions as promoting the care recipients’ safety and increasing their physical function. The actions and reasons relate to Friedemann’s (1995, 2016) Framework of Systemic Organization, influencing the family caregivers and care recipient’s journey toward congruence/well-being.

On the other hand, these family caregivers did not take a lot of actions or fully realize that their actions may have prevented hospital readmissions. This lack of understanding, particularly about medications’ importance and the possibility of seizures occurring in a hemorrhagic stroke survivor, reveals a prime opportunity for nurses to intercede and properly educate the family caregiver of stroke survivors.
Limitations

Transferability of findings is a chief limitation of this study due to the homogeneity of the study participants in both demographic characteristics and geographic location. The sample size was small, consisting of only four caregivers, three of whom were white women, and data saturation was not achieved. The study was restricted to caregivers of patients from only one university-affiliated rehabilitation hospital in the Midwest. Additionally, only caregivers of stroke survivors participated, thus the findings cannot be transferred to all neurological insult persons, even within this particular hospital or Midwest region.

Another limitation of this study may lie in the caregiver participants’ ability to clearly express their thoughts or feelings. The caregivers may have felt awkward discussing their stories with the interviewer or uncomfortable having the interview electronically recorded. It is also possible that caregivers may not have remembered all the actions they took since their care recipient’s discharge from the rehabilitation hospital. It is conceivable that more actions were taken than were relayed to the interviewer, since at least six months had passed since discharge. Stories of actions taken while caring for that person may have been forgotten along the way, or not brought up because the caregiver did not think it was an important action.
Implications for Nursing

Registered nurses are known as frontline healthcare professionals, as they directly interact with the patient, the patient’s family caregiver, and the entire realm of multidisciplinary healthcare providers. Rehabilitation nurses routinely work with rehabilitation aids, physiatrists, physical therapists, occupational therapists, speech and language pathologists, social workers, phlebotomists, respiratory therapists, radiology technicians, and other specialty providers. The nurses are skilled at inter-professional communication. Since the results of this study indicate that family caregivers take actions that might prevent hospital readmissions, nurses are in a unique position to influence those actions. Nurses should advocate for family caregiver inclusion in the discharge process by making needs known to the appropriate discipline as soon as discovered and collaborate with the indicated healthcare discipline to assure those needs are met.

Knowing what actions caregivers take and why (reasons) they take those actions can help rehabilitation nurses, including advanced practice registered nurses, prepare family caregivers of persons with stroke for the transition to home. Nurses can use the information gleaned from this study to design interventions to educate caregivers in their attempt to provide safe and effective care to the person affected by the neurological insult of a stroke. A variety of ways to meet educational needs exist. For example, all family caregivers in this study encouraged physical activity for their care recipients. Rehab nurses can assure that family caregivers are aware of and able to demonstrate safe
ambulation and transfer techniques prior to hospital discharge by observing their interaction with therapists and aides as well as by teaching them and having them perform the task under the nurse’s observation.

This study also indicated that family caregivers have a need to know about community resources available to them and/or their care recipient. Nurses are often aware of these resources and can be instrumental in directing caregivers toward the appropriate services for them. Many community resources are hidden gems, meaning the general public does not know that they exist until someone points them in the correct direction. Nurses are in an idyllic position to do this. An exemplar is: Nurses should assess the family caregivers’ need, such as convenient medication packaging, and refer them to resources, such as particular pharmacies in their communities who are able to meet those needs.

It is hoped that if family caregivers have the knowledge needed to provide optimal care perhaps the number of hospital readmissions can be reduced. Nurses can convey suitable strategies to these family caregivers to assist them in providing optimal care after discharge. As with patient care, caregiver interventions must be individualized and based upon the individual caregiver’s needs and health literacy level. Further, using a method like teach back for a technique assures the nurse that the family caregiver has a clear understanding what is being taught and how to safely assist the care recipient. The teach back method involves educating about what the technique is and why it is
important, and demonstrating how to perform it properly. The method concludes when
the caregiver is able to demonstrate proper performance of the technique.

Advocacy

Advocating for persons with chronic conditions such as stroke has long been a
mainstay of nursing care and nurses are proficient at making sure that these persons’
needs are met. Since many neurological insult persons, like stroke survivors, require a
family caregiver after discharge from the rehabilitation hospital, nurses need to broaden
their advocacy perspective and promote the inclusion of family caregivers in the
discharge process. Nurses can interact with these caregivers during their own provision
of care and assist them in identifying the needs of the care recipient. The nurse can then
work with the family caregiver to assess their strengths and weaknesses and make that
assessment known to the multi-disciplinary teams involved in the discharge process. For
example, stroke patients often have difficulty swallowing after suffering their
neurological insult and are often allowed only water by mouth. The nurse should assure
that the speech therapist is including the family caregiver in observing swallowing
exercises and understanding the potential adverse effects if other substances are aspirated
into the lung.

Some stroke survivors have severe limitations or comorbid conditions that
increase the caring burden. When the nurse observes that necessary caring appears to be
beyond the capabilities of the family caregiver, the nurse should make those concerns
known to the physician and social worker and support the inclusion of home health care upon discharge. For example, a stroke survivor may progress beyond the need for around-the-clock nursing care and be discharged to home with a caregiver, yet still require very close monitoring of medications, diet, or other conditions not directly linked to the stroke deficits. The nurse should request home health care whenever she has learned that a caregiver-care recipient team may have a need for additional nursing care. As noted in one of the caregiver stories, one care recipient passed out due to a very low blood sugar. The caregiver assumed she was experiencing another stroke and did not check her blood sugar level. A home health nurse may have been instrumental in encouraging adequate blood sugar monitoring at home so the low level was observed and treated prior to becoming so low as to cause decreased consciousness.

Families—not institutions or agencies—provide the majority of care to survivors of stroke. These families know the enormity of the burden in caring for someone and they also know the challenges in locating appropriate advice, services, and respite. Personal experience with community agencies, round-the-clock care, and financial hardships mean families know what the important issues are. This puts family caregivers in a unique position to act as advocates with professional nurses. Together, nurses and caregivers, can educate elected officials charged with development of public policy and funding priorities. Nurses can teach caregivers how to be an advocate.

The following are suggested ways for advocacy at local, state, and national levels of governments. Writing or emailing letters to their elected officials is an effective
means of contact. In addition, when time is of the essence, a phone call can be a practical way to express their concern to an elected representative. The most effective calls are to the state or capitol offices, particularly when a vote is imminent. Visits to elected officials are also important ways to advocate for important issues. Meeting face-to-face with a legislator or designated staff member by nurses or caregivers is an excellent way to establish a relationship and convey the point of view. In this study, one caregiver indicated her frustration with her care recipient not being able to continue speech therapy. His stroke left him with a significant speech and swallowing deficits, but Medicare limits the number of out-patient speech therapy sessions in any one calendar year, regardless of need or the progress being made. This caregiver would be an excellent candidate to relate her story to a local legislator, or a group of policy makers, to push for better coverage when warranted. The nurse should encourage such political activity in an effort to ensure the care recipient receives the full services he or she may need. Unfortunately, this care recipient was left to practice techniques at home for at least four months before he would again qualify for coverage of speech therapy sessions.

Other ways for advocacy that nurses and caregivers can implement include:

- Stay informed by keeping contact with a number of organizations which monitor legislative activities at either the state or the federal levels.

Newsletters and other publications can keep provide up-to-date information. The National Stroke Association offers a monthly electronic newsletter, including a policy arena called Stroke Advocacy Network encouraging contact with policy makers (216).
• Contribute ideas and energy by joining a committee, taskforce, or campaign. Such groups may work on a single issue or a variety of issues. Tasks might include organizing a public event or drafting policy recommendations. Even if you do not attend committee meetings you can still lend your support to a letter writing campaign or telephone tree. For instance, caregivers often find like-caregivers while waiting at therapy appointments. Perhaps several caregivers would be interested in starting a committee to encourage better therapy coverage after a stroke and the nurse could encourage these caregivers to get involved and be heard, instead of lamenting the lack of coverage.

• Write a letter to the editor or opinion editorial op-ed piece stating views that can be published in the local newspaper. This is an excellent sounding board to help educate the public about a cause. It is highly likely that the majority of Medicare beneficiaries do not know that they would have a limited number of therapy visits after suffering a stroke. Nurses should encourage caregivers to make their stories known through these venues.

• Testify at a legislative or congressional hearing to offer opinions/gather support when legislation is being drafted. Nurses and family caregivers can provide compelling stories of their daily struggles in caring for a loved one. Again, the nurse should encourage the caregiver in the examples above to offer her testimony. Change cannot be accomplished if no one understands the need.
• All federal bills can be searched and downloaded at
  https://www.congress.gov/. Copies of bills can also be requested from local,
  state and federal representatives.

Education

It is clear from this current study that caregiver education is a priority. As
highlighted in the previous study conducted by Burke, et al., "educating patients to
promote self-management" was linked to a reduction in hospital readmissions (2014, p.
6). This current study indicates that family caregivers need to know how to help manage
their care recipient, what potential problems to look for, what signs would indicate that a
problem exists, and how the recovery is expected to progress before their care recipient is
discharged to home. Family caregivers in this study indicated that they asked questions
of healthcare professionals and searched Internet sites for the information they desired.
Nurses can provide one-to-one teaching of hands on skills to the family caregiver, such as
how to properly position the body and use a gait belt to assist the care recipient in
transferring or ambulation. The nurse should always then observe the family caregiver in
applying the gait belt and safely transferring and/or ambulating with the care recipient.
This time for the caregiver to teach back the skill they learned allows the nurse to
ascertain the level of understanding and any additional teaching that may be required.

Nurses can also develop and provide written education materials to the family
caregiver and care recipient regarding the diagnosis, what functional or neurological
changes to watch for, and what to do if those changes are observed. Family caregivers learn in many different ways, so it is important to include words and pictures in the materials, as well as verbal reinforcement and physical demonstration. As indicated by one of this study’s participants, family caregivers of stroke care recipients need to know if there is a risk for seizure and what to do if one should occur. It cannot be assumed that family caregivers understand what a seizure is or why it may transpire in their care recipient, but a nurse can ease the caregiver’s anxiety by explaining in lay terms what may be observed. For example, a hemorrhagic stroke is caused by blood leaking into the brain. Caregivers may know this, but they may not know that blood is an irritant to neural/brain tissue and that the irritation can cause the nerve cells to over react, triggering a seizure. A seizure may look like someone shaking uncontrollably or as if the person is in a trance-like state. There are medications that significantly lessen the chance of suffering a seizure and they are generally prescribed for several months following a hemorrhagic stroke. Both caregivers and care recipients need to be taught these facts. In this case, the discussion can also serve as segue into a discussion of medications and the importance of the anti-convulsant treatments for persons who suffered a hemorrhagic stroke.

Community Resources

Nurses should refer stroke survivors and their caregivers to potentially useful resources within the community. For example, if drug management is an issue, there are local pharmacies that package multiple medications according to the times of the day that
drugs need to be taken. This pre-packaging can help to relieve caregiver stress by completing this task for the stroke survivor and provides assurance at a glance that medications were taken as directed. There are also local and mail-order pharmacies that will automatically provide refills when they are due and/or contact the care recipient’s prescriber for new medication orders when needed. Having this service can alleviate caregiver stress by assuring that medications are ready for the care recipient when needed without the caregiver having to intervene.

Additionally, some larger cities, including Toledo, Ohio, have an Area Office on Aging, or similar program for older adults, in their community. An Area Office on Aging can answer questions about qualifications for home health care, connect families with support groups, assist with advanced care planning, and provide invaluable information on a host of other issues affecting older adults (Area Office on Aging, 2016). Also, most cities have local support groups based through national organizations, such the American Stroke Association. In Toledo, The Ability Center of Greater Toledo (ACT) aids those persons with disabilities, including many stroke survivors (ACT, 2016). The ACT offers assistance dog training and placement, a huge resource of educational materials for myriad disabilities, and makes available education regarding the value of independent living (i.e. being able to stay in one’s own home). The ACT also connects persons with support groups. These groups connect like-diagnosed persons and their caregivers with a larger network of persons facing the same struggles and may help both the stroke survivor and the family caregiver discover there are many people struggling with like difficulties and finding ways to overcome these stroke-related challenges.
Additional resources may be available in different communities. Nurses should be aware of the services available in their locations and provide this information to their patients and the patients' family members. If nurses are not aware of services for stroke survivors they can contact local neurology practices, as these practices are often aware of a large variety of services and programs regionally available. Networking with these providers can enhance nurses' provision of care, as well as the health of their patients.

**Recommendations for Further Research**

Further research is needed. The small sample size and stroke-only diagnosis are limitations of this study and clearly point to further study of the actions family caregivers take to prevent hospital readmission being necessary among persons with neurological insult. No other studies were found about the actions these particular family caregivers may take, pointing to a gap in both the research literature and the healthcare community's understanding of the impact on outcomes based on actions that caregivers may take. Larger studies in multiple areas across the United States need to be conducted to ascertain caregiver of neurological insult persons' actions, and the reasons for those actions as a basis for rehabilitation nurses to design and implement exemplary patient and caregiver interventions. Comparison studies should then be conducted, to determine the most effective interventions and how to best incorporate those interventions into the plan of care, to produce evidence based recommendations.
Summary

Potentially avoidable hospitalizations are of growing concern in the United States, as hospitalizations increase healthcare expenditures (Moy, et al., 2013). This study demonstrates that family caregivers of stroke survivors take actions that may prevent hospital readmissions. For instance, these caregivers took action to help prevent care recipients’ falls and enlisted professional help for care recipients experiencing altered mental status and seizure. These three items related to falls, cognition and seizures are included in the Center for Medicare and Medicaid Service’s potentially avoidable hospital admissions list and in 2005 resulted in a cost of $176,820,327 just in Ohio for those eligible for both Medicare and Medicaid (Walsh, Freiman, Haber, Bragg, Ouslander & Wiener, 2010). Thus, it can be argued that caregivers can be instrumental in reducing potentially avoidable hospital admissions.

Furthermore, family caregivers’ actions have a direct influence on a care recipient’s congruence (well-being/health) or incongruence by affecting the process dimensions that interact to achieve such a state (Friedemann, 1995, 2016). Family caregivers should be included in hospital discharge and follow-up care of the care recipient.

This study has clinical relevance for all professional nurses. Understanding what actions stroke family caregivers take and the reasons for those actions, enables these nurses to provide targeted education and suggest community resources to potentially
reduce hospital readmissions. Nurses can also advocate/intercede with local, state, and federal legislatures, as well as insurance companies, on their behalf.
References


Senior Care Management (2004). Family caregivers play a key role in reducing readmissions for seniors. *Senior Care Management, 7*(5), 49-51.


Appendix A

Guided Interview Form

DO NOT RECORD. First, I am going to ask you some questions about yourself.

1) What is your age? ________ YEARS OLD

2) ONLY ASK IF UNKNOWN: What is your gender? MALE FEMALE
   1 2

3) What is your ethnic background?
   1 AMERICAN INDIAN OR ALASKA NATIVE
   2 ASIAN OR PACIFIC ISLANDER
   3 BLACK, NOT OF HISPANIC ORIGIN
   4 HISPANIC ORIGIN
   5 WHITE, NOT OF HISPANIC ORIGIN
   8 OTHER OR UNKNOWN

4) How many years of schooling have you completed? ________ YEARS (INCLUDING COLLEGE)

5) Are you currently employed?
   Full-time Part-time Medical leave Not employed
   3 2 1 0

   a) What is/was your (paid) occupation? ___________________________

6) In general, would you say your health is?
   Poor Fair Good Very Good Excellent
   0 1 2 3 4

Next, I am going to ask you some questions about the person you are caring for with neurological insult.

1) What is his/her neurological insult diagnosis, that is, did he/she have a stroke, spinal cord injury or traumatic brain injury?
   CVA SCI TBI
   1 2 3 (IF ANOTHER DIAGNOSIS, CAREGIVER IS NOT ELIGIBLE.)

2) What is your relationship to the person for whom you provide care? Your care recipient is your...
   1 HUSBAND
   2 WIFE
   3 MOTHER
   4 FATHER

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APPROVED BY
UNIVERSITY OF TOLEDO IRB
Appendix A
Guided Interview Form

IRB#: 200655

5 OTHER RELATIVE, SPECIFY: ____________________________________________

4 FRIEND

3) When was your [care recipient] discharged from the Coughlin Rehabilitation Hospital?
   ________________________ MONTH/YEAR (IF < 6 MONTHS AGO, CAREGIVER IS NOT ELIGIBLE.)

4) How long have you been providing care for your [care recipient]? ________ MONTHS

5) What is his/her age? ________ YEARS OLD

6) What is your [care recipient’s] ethnic background?
   1 AMERICAN INDIAN OR ALASKA NATIVE
   2 ASIAN OR PACIFIC ISLANDER
   3 BLACK, NOT OF HISPANIC ORIGIN
   5 HISPANIC ORIGIN
   6 WHITE, NOT OF HISPANIC ORIGIN
   8 OTHER OR UNKNOWN

7) ONLY ASK IF UNKNOWN: What is his/her gender? MALE 1 FEMALE 2

8) Where does your [care recipient] live?
   1 ALONE IN HIS/HER OWN HOUSE OR APARTMENT
   2 WITH OTHERS IN A HOME OR APARTMENT
   3 WITH ME (CAREGIVER)
   4 ASSISTED LIVING FACILITY
   5 LONG TERM CARE FACILITY
   6 OTHER, SPECIFY: ___________________________________________________

9) In general, would you say the health of your [care recipient] is?
   Poor 0  Fair 1  Good 2  Very Good 3  Excellent 4

10) In addition to the [neurological insult], does he/she have other chronic medical conditions (e.g. diabetes, heart disease)?
    NO 0
    YES 1
   a) IF YES, What are they? ___________________________________________________

Assigned Version Date: 04/16/2015

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APPROVED BY
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TURN ON RECORDER. Now I am going to ask you some questions about how your [care recipient] has been doing since being discharged from the Coughlin Rehabilitation Hospital, that is since [MONTH/YEAR].

1) I want you to think back to whether there have been times since your [care recipient’s] discharge that you’ve thought that if you did not take action he/she would need to go back to the hospital.

Tell me your story of what happened during that time / those times.

IF THE CAREGIVER SAYS HE OR SHE CANNOT THINK OF A TIME, USE THE FOLLOWING PROMPTS:

For example, did you call a healthcare provider, give a medication to your [care recipient], ask a friend for advice, or search the internet for health information.

IF HIS OR HER "STORY" DOES NOT INCLUDE ALL THE INFORMATION WANTED, THEN ASK:

What actions did you take to try to prevent your [care recipient] from being readmitted to the hospital?

Why did you choose that action? OR Why did you think that would help?

Did your [care recipient] end up going to the hospital?

**--------------------------------****

NOTES:

a) Action:

b) Reason:

a) Action:

b) Reasons:

a) Action:

b) Reasons:

Assigned Version Date: 04/16/2015

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APPROVED BY
UNIVERSITY OF TOLEDO
Appendix A
Guided Interview Form

IRB#: 200655
ID NUMBER: __________________

2) Has your [care recipient] been readmitted to any hospital since his/her discharge from the Coghlin Rehabilitation Hospital?

NO YES

a) If YES, how many times? __________

FOR EACH VISIT, ASK . . .

i) What was the reason?

ii) What was the reason?

iii) What was the reason?

3) Is there anything else you would like to add?

Thank you very much for your help.
Subject Recruitment Form

STAFF: CONTACT FAMILY CAREGIVERS > 21 YEARS OLD OF PERSONS WITH NEURO INSULT (CVA, SCI, OR TBI) WHO WERE DISCHARGED 6 – 12 MONTHS AGO.

Ask the caregiver if he or she is willing to be contacted by Amy Yates, nurse and graduate student at the University of Toledo, to learn about a research study focused on how the caregiver and his or her care recipient have been doing since discharge from the Coghlin Rehabilitation Hospital.

Caregiver Name (first name only): ________________________________

Is the caregiver willing to be contacted? NO YES

IF YES:

Telephone Number (with area code): ______________________________

Best time/day to be contacted: ______________________________

*PLEASE RETURN ALL FORMS TO AMY YATES

TO BE COMPLETED BY RESEARCHER

Date caregiver contacted: ______________________________

Verbally consented: YES NO

ID# __________________

Assigned Version Date: 04/16/2015

APPROVED BY UNIVERSITY OF TOLEDO IRB
ADULT RESEARCH SUBJECT INFORMATION AND CONSENT FORM and
AUTHORIZATION FOR USE AND DISCLOSURE OF PROTECTED HEALTH INFORMATION

Actions caregivers of neurological insult persons take to prevent hospital readmissions

Principal Investigator: Linda Pierce, PhD, RN, CNS, CRRN, FAHA, FAAN
Other Staff (Identified by role): Amy Yates, RN, BSN, CRRN, Graduate Student Investigator
Victoria Steiner, PhD, co-Investigator
Cheryl Gies, DNP, CRNP, co-investigator

Contact Phone number(s): (419) 383-5852 Dr. Linda Pierce
(419) 383-6382 Amy Yates

What you should know about this research study:

- We give you this consent/authorization form so that you may read about the purpose, risks, and benefits of this research study. All information in this form will be communicated to you verbally by the research staff as well.
- Routine clinical care is based upon the best-known treatment and is provided with the main goal of helping the individual patient. The main goal of research studies is to gain knowledge that may help future patients.
- We cannot promise that this research will benefit you. Just like routine care, this research can have side effects that can be serious or minor.
- You have the right to refuse to take part in this research, or agree to take part now and change your mind later.
- If you decide to take part in this research or not, or if you decide to take part now but change your mind later, your decision will not affect your routine care.
- Please review this form carefully. Ask any questions before you make a decision about whether or not you want to take part in this research. If you decide to take part in this research, you may ask any additional questions at any time.
- Your participation in this research is voluntary.

PURPOSE (WHY THIS RESEARCH IS BEING DONE)
You are being asked to take part in a research study exploring the actions caregivers of neurological insult persons take to prevent hospital readmissions. The purpose of the study is to determine if you, the caregiver of neurological insult person, take actions to prevent hospital readmissions and, if so, what those actions are and why those particular actions were chosen.
Appendix C
Informed Consent Form

You were selected as someone who may want to take part in this study because you were identified by the Coggin Rehabilitation Hospital as being the caregiver of a stroke, spinal cord injury, or traumatic brain injury person discharged from their facility in the past six to twelve months. The research will include up to fifteen caregiver participants.

DESCRIPTION OF THE RESEARCH PROCEDURES AND DURATION OF YOUR INVOLVEMENT
If you decide to take part in this study, you will be asked to meet with a member of the research team for a one-time only interview at a location of your choosing which will last approximately one hour. You will be asked some questions about yourself and your care recipient, including whether he or she has been readmitted to a hospital.

You will also be asked to discuss if you have taken any actions since discharge from the rehabilitation hospital to prevent a hospital readmission of your care recipient and why you chose those particular actions. This portion of the interview will be electronically audio recorded to ensure completeness of the information gathered. Once these recordings are transcribed into a Word document, they will be erased.

RISKS AND DISCOMFORTS YOU MAY EXPERIENCE IF YOU TAKE PART IN THIS RESEARCH
There is a slight risk of loss of confidentiality. This risk will be minimized by the researcher storing the data in a locked cabinet in a locked office at the university. Additionally, if you feel uncomfortable answering any question you may choose not to answer and you may end the interview or your participation in the study at any time.

POSSIBLE BENEFIT TO YOU IF YOU DECIDE TO TAKE PART IN THIS RESEARCH
We cannot and do not guarantee or promise that you will receive any benefits from this research.

COST TO YOU FOR TAKING PART IN THIS STUDY
There is no cost to you for participating in this study, other than the time spent completing the interview.

CONFIDENTIALITY - (USE AND DISCLOSURE OF YOUR PROTECTED HEALTH INFORMATION)
By agreeing to take part in this research study, you give to The University of Toledo (UT), the Principal Investigator and all personnel associated with this research study your permission to use or disclose health information that can be identified with you that we obtain in connection with this study. We will use this information to recruit subjects into the study and determine eligibility for participation.

The information that we will use or disclose includes your first name and your telephone number obtained from your care recipient's medical record, and the month and year that you report your care recipient was discharged from the rehabilitation hospital.

Under some circumstances, the Institutional Review Board, or the Research and Sponsored Programs of the University of Toledo may review your information for compliance audits. We may also disclose your protected health information when required by law, such as in response to judicial orders.

The University of Toledo is required by law to protect the privacy of your health information, and to use or disclose the information we obtain about you in connection with this research study only as authorized by you in this form. There is a possibility that the information we disclose may be re-disclosed by the persons we give it to, and no longer protected. However, we will encourage any person who receives your information from us to continue to protect and not re-disclose the information.
Appendix C
Informed Consent Form

Your permission for us to use or disclose your protected health information as described in this section is voluntary. However, you will not be allowed to participate in the research study unless you give us your permission to use or disclose your protected health information by signing this document.

You have the right to revoke (cancel) the permission you have given to us to use or disclose your protected health information at any time by giving written notice to Dr. Linda Pierce at 3000 Arlington Av, MS 1026, Toledo, OH 43614. However, a cancellation will not apply if we have acted on your permission, for example, information that already has been used or disclosed prior to the cancellation. Also, a cancellation will not prevent us from continuing to use and disclose information that was obtained prior to the cancellation as necessary to maintain the integrity of the research study.

Except as noted in the above paragraph, your permission for us to use and disclose your protected health information will stop at the end of the research study.

A more complete statement of University of Toledo’s Privacy Practices is set forth in its Joint Notice of Privacy Practices. If you have not already received this Notice, a member of the research team will provide this to you. If you have any further questions concerning privacy, you may contact the University of Toledo’s Privacy Officer at 419-383-6933.

IN THE EVENT OF A RESEARCH RELATED INJURY
In the unlikely event of injury resulting from your taking part in this study, treatment can be obtained at a health care facility of your choice. You should understand that the costs of such treatment will be your own responsibility. Financial compensation is not available through The University of Toledo or The University of Toledo Medical Center.

By signing this form you are not giving up any of your legal rights as a research subject.

In the event of a research-related injury contact:

Dr. Linda Pierce at 440-462-9123.

VOLUNTARY PARTICIPATION
Taking part in this study is voluntary. You may refuse to participate or discontinue participation at any time without penalty or a loss of benefits to which you are otherwise entitled. If you decide not to participate or to discontinue participation, your decision will not affect your future relations with the University of Toledo or The University of Toledo Medical Center.

NEW FINDINGS
You will be notified of new information that might change your decision to be in this study if any becomes available.

Continued on Next Page
OFFER TO ANSWER QUESTIONS
Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over. If you have questions regarding the research at any time before, during or after the study, you may contact Dr. Linda Pierce at 419-383-5852 or Amy Yates at 419-383-6332.
If you have questions beyond those answered by the research team or your rights as a research subject or research-related injuries, please feel free to contact the Chairperson of the University of Toledo Biomedical Institutional Review Board at 419-383-6796.

SIGNATURE SECTION (Please read carefully)
YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THIS RESEARCH STUDY. YOUR SIGNATURE INDICATES THAT YOU HAVE READ THE INFORMATION PROVIDED ABOVE, YOU HAVE HAD ALL YOUR QUESTIONS ANSWERED, AND YOU HAVE DECIDED TO TAKE PART IN THIS RESEARCH.

BY SIGNING THIS DOCUMENT YOU AUTHORIZE US TO USE OR DISCLOSE YOUR PROTECTED HEALTH INFORMATION AS DESCRIBED IN THIS FORM.

The date you sign this document to enroll in this study, that is, today’s date, MUST fall between the dates indicated on the approval stamp affixed to the bottom of each page. These dates indicate that this form is valid when you enroll in the study but do not reflect how long you may participate in the study. Each page of this Consent/Authorization Form is stamped to indicate the form’s validity as approved by the UT Biomedical Institutional Review Board (IRB).

Name of Subject (please print)  
Signature of Subject or Person Authorized to Consent  
Date

Relationship to the Subject (Healthcare Power of Attorney authority or Legal Guardian)  

Name of Person Obtaining Consent (please print)  
Signature of Person Obtaining Consent  
Date

Name of Witness to Consent Process (when required by ICH Guidelines) (please print)  
Signature of Witness to Consent Process (when required by ICH Guidelines)  
Date

YOU WILL BE GIVEN A SIGNED COPY OF THIS FORM TO KEEP.
Appendix D
IRB Approvals - Initial

The University of Toledo
Department for Human Research Protections
Biomedical Institutional Review Board
Center for Creative Education Building – Room 0106
3025 Arlington Avenue, Toledo, Ohio 43614-2570
Phone: 419-383-6796 Fax: 419-383-3258
(FWA0001086)

TO: Linda Pierce, Ph.D., R.N., CNS., CRRN, FAHA, FAAN
    UT College of Nursing

FROM: Roland Skeel, M.D., Chair
       Boyd Koffman, M.D., Ph.D., Vice Chair
       Susan Pocottie, Ph.D., Vice Chair
       Steven Pesek, Ph.D., Vice Chair
       Rachel Kamin, PharmD, Chair Designee
       UT Biomedical Institutional Review Board

SIGNED: ________ DATE: 3/24/15

SUBJECT: IRB # 200655
Protocol Title: Actions Caregivers of Persons with Neurological Injuries Take to Prevent Hospital Readmissions

The above project was reviewed and approved by the Vice Chair of the University of Toledo Biomedical Institutional Review Board as an expedited review (category #7). A signed and dated Consent and Authorization for Use and Disclosure of Protected Health Information is required from each participant prior to that individual taking part in this research. This action will be reported to the committee at its meeting on 03/21/2015.

Items Available for Review:
- IRB Application Requesting Initial Expedited Review of Research
- Protocol (assigned version date 04/16/2015)
- Consent/Authorization Form (assigned version date 04/16/2015)
- Subject Recruitment Form (assigned version date 04/16/2015)
- Caregiver Guided Interview (assigned version date 04/16/2015)
- Letter of Support from the Coghlin Rehabilitation Center (signed letter dated 01/12/2015)

This research is approved until the expiration date listed below, unless the IRB notifies you otherwise.

Only the most recent IRB approved Consent/Authorization Form listed above may be used when enrolling participants in this research.

APPROVAL DATE: 04/16/2015 EXPIRATION DATE: 04/15/2016

Please read the following attachment detailing Principal Investigator responsibilities.
Appendix D
IRB Approvals - Amendment

TO: Linda Pierce, Ph.D., R.N., CNS., CRRN, FAHA, FAAN
    UT College of Nursing

FROM: Roland Skeel, M.D., Chair
      Boyd Koffman, M.D., Ph.D., Vice Chair
      Susan Pocotte, Ph.D., Vice Chair
      Steven Peseckis, Ph.D., Vice Chair
      Rachel Rarus, PharmD, Chair Designee
      UT Biomedical Institutional Review Board

SIGNED: DATE: 11/12/15

SUBJECT: IRB # 200655
    Protocol Title: Actions Caregivers of Persons with Neurological Insult Take to Prevent Hospital Readmissions

On 11/10/2015, the Amendment listed below was reviewed and approved by the Chair or Vice Chair of the University of Toledo (UT) Biomedical Institutional Review Board (IRB) via the expedited mechanism. The Chair or Vice Chair noted that enrollment continues at this site and that signed and dated Adult Research Subject Information and Consent Form remains required prior to an individual taking part in this research. This action will be reported to the committee at its meeting on 12/17/2015.

**Items Available for Review:**
- IRB Application Requesting Expedited Review of Amendment (UT Reference #A001)
  - Add Diane Salvador as Study Personnel.
  - Remove Cheryl Gies as Study Personnel.
- Current IRB Approved Protocol (assigned version date 04/16/2015)
- Current IRB Approved Consent/Authorization Form (assigned version date 04/16/2015)

The Amendment approval is in effect until the expiration date listed below, unless the IRB notifies you otherwise.

**Only the most recent IRB approved Adult Research Subject Information and Consent Form listed above may be used when enrolling participants into this research.**

**AMENDMENT APPROVAL DATE: 11/10/2015       EXPIRATION DATE: 04/15/2016**

Please read the following attachment detailing Principal Investigator responsibilities.
TO: Linda Piers, Ph.D., R.N., CNS., CCRN. FAHA, FAAN
UT College of Nursing

FROM: Roland Sileo, M.D., Chair
Boyd Kofman, M.D., Ph.D., Vice Chair
Susan Pecotte, Ph.D., Vice Chair
Steven Penev, Ph.D., Vice Chair
Rachel Razum, Pharm.D., Chair Designee
UT Biomedical Institutional Review Board

SIGNED: [Signature] DATE 03/17/2016

SUBJECT: IRB # 200655
Protocol Title: Actions of Caregivers of Persons with Neurological Insult Take to Prevent Hospital Readmissions

The above project was reviewed and re-approved by the Chair or Chair Designee of the University of Toledo Biomedical Institutional Review Board as an expedited review (category B). The Chair or Chair Designee have noted that enrollment continues and a signed and dated Consent and Authorization for Use and Disclosure of Protected Health Information is required from each participant prior to that individual taking part in this research. This action will be reported to the committee at its meeting on 03/17/2016.

Items Available for Review:
- KC Application for Continuing Review of Research (R001)
- Current IRB Approved Protocol (assigned version date 04/16/2015)
- Previous IRB Approved Consent/Authorization Form (assigned version date 04/16/2015)
- Current ICH Approved Consent/Authorization Form (assigned version date 02/29/2016)

This research is approved until the expiration date listed below, unless the IRB notifies you otherwise.

Only the most recent IRB approved Consent/Authorization Form listed above may be used when enrolling participants into this research.

RE-APPROVAL DATE: 02/29/2016 EXPIRATION DATE: 02/28/2017

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