2013

Developing the Rehabilitation Education for Caregivers and Patients (RECAP) Model: Application to Physical Therapy in Stroke Rehabilitation

Megan M. Danzl
University of Kentucky, megandanzl@gmail.com

STUDENT AGREEMENT:

I represent that my thesis or dissertation and abstract are my original work. Proper attribution has been given to all outside sources. I understand that I am solely responsible for obtaining any needed copyright permissions. I have obtained and attached hereto needed written permission statements(s) from the owner(s) of each third-party copyrighted matter to be included in my work, allowing electronic distribution (if such use is not permitted by the fair use doctrine).

I hereby grant to The University of Kentucky and its agents the non-exclusive license to archive and make accessible my work in whole or in part in all forms of media, now or hereafter known. I agree that the document mentioned above may be made available immediately for worldwide access unless a preapproved embargo applies.

I retain all other ownership rights to the copyright of my work. I also retain the right to use in future works (such as articles or books) all or part of my work. I understand that I am free to register the copyright to my work.

REVIEW, APPROVAL AND ACCEPTANCE

The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Director of Graduate Studies (DGS), on behalf of the program; we verify that this is the final, approved version of the student's dissertation including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Megan M. Danzl, Student

Dr. Patrick Kitzman, Major Professor

Dr. Anne Olson, Director of Graduate Studies

DEVELOPING THE REHABILITATION EDUCATION FOR CAREGIVERS AND PATIENTS (RECAP) MODEL: APPLICATION TO PHYSICAL THERAPY IN STROKE REHABILITATION

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Health Sciences
at the University of Kentucky

By
Megan Marie Danzl

Lexington, Kentucky

Co-Directors: Dr. Patrick Kitzman, Associate Professor of Physical Therapy and
Dr. Patrick McKeon, Assistant Professor of Athletic Training

Lexington, Kentucky

2013

ABSTRACT OF DISSERTATION

DEVELOPING THE REHABILITATION EDUCATION
FOR CAREGIVERS AND PATIENTS (RECAP) MODEL:
APPLICATION TO PHYSICAL THERAPY IN STROKE REHABILITATION

Patient and caregiver education is recognized as a critical component of stroke rehabilitation and physical therapy practice yet the informational needs of stroke survivors and caregivers are largely unmet and optimal educational interventions need to be established. The objective of this dissertation was to develop a theory and model of “Rehabilitation Education for Caregivers and Patients” (RECAP) in the context of physical therapy and stroke rehabilitation, grounded in the experiences and perceptions of stroke survivors, their caregivers, and physical therapists.

Qualitative research methods with a novel grounded theory approach were used. Potential constructs of RECAP were identified from existing research. Next, semi-structured interviews were conducted with 13 stroke survivors and 12 caregivers from rural Appalachian Kentucky, a region with high incidence of stroke and lower levels of educational attainment. Lastly, 13 physical therapists, representing inpatient rehabilitation, outpatient, and home health, were recruited and participated in pre-interview reflection activities and interviews. Data analysis involved predetermined and emerging coding and a constant comparative method was employed. Verification strategies included self-reflective memos, analytic memos, peer debriefing, and triangulation.

The theory generated from this dissertation is: physical therapists continually assess the educational needs of stroke survivors and caregivers, to participate in dynamic educational interactions that involve the provision of comprehensive content, at a point in time, delivered through diverse teaching methods and skilled communication. This phenomenon is influenced by characteristics of the physical therapist and receiver (stroke survivor/caregiver) and occurs within the context of the physical therapist’s professional responsibility, the multidisciplinary team, a complex healthcare system, and the

environmental/socio-cultural context. The RECAP theoretical model depicts the relationships between the core and encompassing constructs of the theory.

The RECAP theory and model presents a significant advancement in the study of patient and caregiver education in physical therapy in stroke rehabilitation. This research provides a springboard to inform future research, guide RECAP in stroke physical therapy practice, design optimal educational interventions, develop training tools for entry-level curriculum and practicing clinicians, and to potentially translate to the practice of patient and caregiver education for other rehabilitation professionals and patient populations.

KEYWORDS: Patient Education, Caregiver Education, Stroke, Rehabilitation, Physical Therapy

Megan Marie Danzl
Student's Signature

May 3, 2013
Date

DEVELOPING THE REHABILITATION EDUCATION FOR CAREGIVERS AND PATIENTS (RECAP) MODEL: APPLICATION TO PHYSICAL THERAPY IN STROKE REHABILITATION

By

Megan Marie Danzl

Patrick Kitzman, Ph.D.
Co-Director of Dissertation

Patrick McKeon, Ph.D.
Co-Director of Dissertation

Anne Olson, Ph.D.
Director of Graduate Studies

May 3, 2013

DEDICATION

To my German, Italian, and Irish grandparents, Frank and Mary Ellen Danzl, Joseph and Alice Colosimo; you taught me the importance of family, the value of a dollar and the value of a day off, to appreciate small kindnesses, and to dream big; thank you for your love, encouragement, and the smiles you bring to my life.

– Magpie/Meg

ACKNOWLEDGEMENTS

Benjamin: My handsome wordsmith and egalitarian partner in life; thank you for moving to Lexington, for your steadfast encouragement, and for moments of respite throughout this journey; I love you and could not have done this without you; I'm excited about the rest of our journey to come. –Megan

Mom: You are my unwavering advocate. Thank you for always believing in me and for your encouragement and love. –Maggie May

Dad: To the first Dr. Danzl in the family; you taught me the blueprint for academia long ago – that homework is a lifelong activity; thank you for being my sounding board and the encouragement to dream big. –Bags

Jules: My sibling sidekick; your love of life, big smiles, easy laughter, and dance moves keep my spirit uplifted; thank you for always being there for me. –Maggot

Family: Thank you to my family, by blood or spirit, the village that helped see me through – my husband, parents, sister, grandparents, aunts, uncles, cousins, in-laws, friends, and neighbors – I am blessed to have you in my life.

Participants: Thank you to the resilient stroke survivors, caregivers, and physical therapists for sharing your stories and time; to the PT's, your abiding dedication to making a difference in the lives of those affected by stroke leaves me in awe.

To the Pats, Beth, Anne, and Graham: thank you for being the beacons throughout this journey and helping me to build the foundation for my future academic pursuits; your support and tutelage have left lasting imprints on me.

RHB colleagues – faculty, staff, classmates past and present: I walked in the doors 5 years ago like a deer in headlights and I'm leaving on sure footing as a rehabilitation researcher thanks to your support, encouragement, and challenges to expand my thinking.

KARRN colleagues: Many thanks to the directors, support personnel, community partners, and NAPS team for assistance with the study presented in Section 2; you are an amazing group and it's been a privilege to work with you.

Colleagues at Bellarmine University: I left as a PT graduate 8 years ago and am thrilled to return as a faculty colleague; thank you for welcoming me. Special thanks to Mark – without your persistent encouragement to "go get a PhD" and belief that I could do it, this wouldn't have happened.

Funding acknowledgement: This research was funded by the National Center on Minority Health and Health Disparities (#1RC4MD005760) and by the Kentucky Appalachian Rural Rehabilitation Network.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

SECTION ONE: LAYING THE FOUNDATION

Chapter 1.1: Introduction and Study Overview

The Devastation of Stroke

An estimated 7,000,000 Americans have had a stroke (Roger et al., 2011). Each year, approximately 795,000 individuals in the United States experience a new or recurrent stroke (Roger et al., 2011). Statistics from 2007 indicate that the direct and indirect cost of stroke that year was $40.9 billion and the mean lifetime cost of stroke is $140,048 (Roger et al., 2011). Stroke affects people from every ethnicity and geographical location (Roger et al., 2011), but the incidence is especially high for those in rural areas and for those with low socioeconomic status (Halverson, Barnett, & Casper, 2002; Joubert, et al., 2008; Roger et al., 2011), such as Appalachian Kentucky.

Kentucky is part of the “stroke belt”, a group of 11 southeastern states, which has the highest incidence and mortality rates of stroke in the United States. Appalachian Kentucky could be considered part of the “buckle” of the belt as the Centers for Disease Control and Prevention reports 26 counties in this region have the highest incidence of stroke in the belt (Casper, Nwaise, Croft, & Nilasena, 2008). This is in part attributed to lower socioeconomic status, lower per capita incomes, higher poverty rates, lower educational attainment, reduced medical care access, and higher prevalence of chronic health problems that plague Appalachian Kentucky (Gillum & Mussolino, 2003; Halverson, Barnett, & Casper, 2002; Tickamyer & Duncan, 1990).

While revolutionary medical advances have resulted in a declining mortality rate in the country, the burden of the disease remains high and stroke is a leading cause of long-term disability (Roger et al., 2011). Those affected are confronted with numerous barriers to managing the condition and achieving a positive quality of life (Duncan et al., 2005). This is especially true for individuals in rural areas and Appalachian Kentucky (Alkadry, Wilson, & Nicholas, 2006; Behringer & Friedell, 2006; Halverson, Barnett, & Casper, 2002; Joubert et al., 2008). Barriers to stroke management and positive quality of life for individuals with stroke in rural communities include lack of access to healthcare (Joubert et al., 2008), inability to return to work (Hofgren, Bjorkdahl, Esbjornsson, & Sunnerhagen, 2007), difficulty balancing expectations and physical capacity (Wood, Connelly, & Maly, 2010), and depression (Whyte et al., 2004). Caregivers may experience “lives turned upside-down” (Bulley, Shiels, Wilkie, & Salisbury, 2010) with stress, depression, and reduced quality of life. Improvements in post-acute healthcare and rehabilitation are necessary to reduce disability and stroke-related financial burden (Duncan et al., 2005).

The Hope of Recovery with Rehabilitation

A common theme in the recovery literature is that specific and intensive training induces central nervous system reorganization, a concept formerly thought possible only during the early post-natal period (Dancause et al., 2005; Johansson, 2000; Kopp et al., 1999; Nudo, Plautz, & Frost, 2001). This neuroplastic change is crucial to recovery post-neurological injury, such as stroke. The fact that it is possible to modulate neuroplastic change has

influenced rehabilitation research in supporting the investigation of interventions targeted at enhancing recovery, minimizing disability, and improving quality of life post-stroke. As a result of this growing body of evidence, stroke clinical practice guidelines (Duncan et al., 2005; Gresham et al., 1995; Royal College of Physicians [RCP], 2008) and evidence-based reviews of stroke rehabilitation (Teasell et al., 2011) have been developed to guide practice. In one of the clinical practice guidelines, the use of a coordinated, multidisciplinary rehabilitation team, that includes physical therapists, is suggested to facilitate better outcomes for stroke survivors (Duncan et al., 2005). Continuing to optimize stroke rehabilitation and service provision by multidisciplinary teams, through research and clinical practice efforts, is paramount to facilitating the ability of survivors and caregivers to overcome the disability of stroke. An important component of rehabilitation and service provision is patient and caregiver education.

The Value of Patient and Caregiver Education in Rehabilitation

Patient and caregiver education (PCE) is suggested as a critical component of stroke rehabilitation services (Duncan et al., 2005; Gresham et al., 1995; RCP, 2011; Smith et al., 2008) and physical therapy practice (Rothstein, 2001) to enable stroke survivors and caregivers to overcome barriers and achieve a positive quality of life. According to the *Guide to Physical Therapist Practice* (Rothstein, 2001), PCE is referred to as “patient/client-related instruction” and is “the process of informing, educating, or training patients/clients, families, significant others, and caregivers” (p.102).

Stroke survivors and caregivers are entitled to structured and tailored education and subsequent opportunities for learning in order to interpret and integrate the information provided (Duncan et al., 2005; Gresham et al., 1995; Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011; Rodgers, Bond, & Curless, 2001). PCE is vital to increase stroke knowledge (Vanetzian, 1997), enable coping (Vanetzian, 1997), facilitate goal setting (Laver, Halbert, Stewart, & Crotty, 2010), enhance ability to participate in decision-making (Duncan et al., 2005), improve satisfaction with care (Smith et al., 2008), support a better transition across the care continuum (Cameron & Gignac, 2008), achieve better outcomes in terms of rehabilitation gains, social adjustment and home/community reintegration (Duncan et al., 2005), promote greater compliance with recommendations (Smith et al., 2008), and support health behavioral changes that reduce future stroke risk and secondary complications requiring costly hospital readmissions (Eries & McShane, 1998).

The Problem and the Missing Piece in Physical Therapy Practice

Despite recognition that PCE is a critical component of stroke rehabilitation services (Duncan et al., 2005; Gresham et al., 1995; RCP, 2012; Smith et al., 2008), the informational needs of stroke survivors and caregivers are largely unmet and optimal educational interventions need to be established (Duncan et al., 2005; Garrett & Cowdell, 2005; Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011; Hanger et al., 1998; Rodgers et al., 2001; Smith et al., 2008). Current research demonstrates limited effectiveness of educational interventions to improve perceived health status (Duncan et al.,

2005), quality of life (Duncan et al., 2005), caregiver mood/satisfaction (Smith et al., 2008) and patient independence and participation in social activities (Smith et al., 2008). There is a low level of satisfaction with the PCE provided and perceptions of inadequate communication from healthcare providers (O'Connell, Baker, & Prosser, 2003).

A lack of information, dissatisfaction with PCE, and sub-optimal communication can lead to misconceptions, anxiety and fear in individuals with stroke (O'Connell, Baker, & Prosser, 2003; O'Mahoney et al., 1997; Rodgers, Bond, & Curless, 2001). This contributes to poor health status and emotional problems, such as depression and social isolation (O'Connell, Baker, & Prosser, 2003; O'Mahoney et al., 1997; Rodgers, Bond, & Curless, 2001). In addition, poor dissemination of informational support to caregivers results in an inability to access resources and improve quality of life (Duncan et al., 2005). Ineffective education in stroke rehabilitation may be especially detrimental on the outcomes for individuals in rural areas, such as Appalachian Kentucky, who may have limited knowledge of stroke (Alkadry, Wilson, & Nicholas, 2006) and higher incidence of poor health literacy (Zahnd, Scaite, & Frances, 2009).

Individuals with stroke and caregivers want to be informed and involved but have difficulty obtaining the necessary information (Rodgers, Bond, & Curless, 2001). This is not surprising in light of a study assessing inpatient physical therapy stroke practice, in which PCE was only completed in approximately 7% of >21,000 sessions with 972 patients (Jette et al., 2005). Even if information is provided, as needs change, new questions evolve over

time, and many of these questions remain unanswered far into the chronic phase of stroke (Hanger et al., 1998; Rodgers, Bond, & Curless, 2001). There is a lack of understanding of the basics of stroke (e.g., etiology, risk factors, warning signs), rehabilitation management, and supports available (Smith et al., 2008); highlighting a profound need for improved informational support from providers.

In a Cochrane systematic review of information provision to stroke survivors and caregivers (Smith et al., 2008), many educational interventions are classified as “passive” and inferior to “active” interventions, yet what constitutes “active” educational intervention is poorly described. It remains unclear why contemporary educational interventions, active or passive, are largely ineffective to improve perceived health status (Duncan et al., 2005), quality of life (Duncan et al., 2005), caregiver mood/satisfaction (Smith et al., 2008), and participation in social activities (Smith et al., 2008). Speculations as to the reasons for PCE dissatisfaction and ineffectiveness include poor timing (Cameron & Gignac, 2008; Denby & Harvey, 2003), the perception of providers being unavailable (Hanger et al., 1998; Wellwood, Dennis, & Warlow, 1994), a reluctance to ask questions and missed cues by the provider that further elaboration is needed (Wiles, Pain, Buckland, & McLellan, 1998), complicated or irrelevant PCE (Hanger et al., 1998; Wellwood, Dennis, & Warlow, 1994), deficiencies in provider communication skills and/or knowledge base (Wiles, Pain, Buckland, & McLellan, 1998), provider discomfort in discussing certain PCE topics (Wiles, Pain, Buckland, & McLellan, 1998), and time constraints on providers producing an ‘arms-length approach to teaching’ (Green, Haley, Eliasziew, & Hoyte, 2007) (e.g., pamphlet provision in a

waiting room). Another issue may be a lack of awareness or effort to consider individual factors (e.g., the characteristics and culture of those who live in rural areas, age, gender) and adapt PCE accordingly. These concepts of PCE have not been explored in stroke physical therapy practice.

There is a dearth of research in physical therapy examining PCE given its esteem as a foundational element of physical therapy practice and stroke clinical practice guidelines. In the paucity of studies available, the majority focused on counting and categorizing PCE statements during outpatient sessions (Fruth, Ryan, & Gahimer, 1998; Gahimer & Domholdt, 1996; Sluijs, 1991). While these studies provide valuable insight into the frequency and type of educational statements made by physical therapists, the studies are limited to the outpatient setting and general patient population. Rindflesh (2009) used a grounded theory approach to examine PCE in physical therapy, however, the study was not specific to a diagnosis and none of the patients observed had significant learning barriers, as is found in the stroke population.

Research that builds from the foundational work of the 1990's (Fruth, Ryan, & Gahimer, 1998; Gahimer & Domholdt, 1996; Sluijs, 1991) and expands the work by Rindflesh (2009) in a diagnosis-specific manner is needed. Furthermore, to understand and optimize stroke-related PCE practice and develop effective educational interventions, research that builds a sound theoretical underpinning, grounded in the perceptions and experiences of stroke survivors, caregivers, and physical therapists is necessary. Generation of the theory from the experiences of stroke survivors and caregivers in rural

Appalachian Kentucky would be useful and appropriate as those in this region suffer poorer health, increased risks of negative health outcomes, and higher incidence of stroke disproportionate to the rest of the country (Behringer & Friedell, 2006; Casper, Nwaise, Croft, & Nilasena, 2008; Halverson, Barnett, & Casper, 2002). Individuals in this region typically have lower levels of educational attainment and decreased access to healthcare services (Gillum & Mussolino, 2003; Halverson, Barnett, & Casper, 2002; Tickamyer & Duncan, 1990). The depth and breadth of PCE needs for individuals in this region, therefore, may be extensive enabling individuals from this region to provide key insight into PCE. Additionally, physical therapists who serve individuals in this area will likely be key informants given the high incidence of stroke in the region and potential for extensive educational needs (Halverson, Barnett, & Casper, 2002). The purpose of this dissertation is to develop a theory of "Rehabilitation Education for Caregivers and Patients" (RECAP) by physical therapists in stroke rehabilitation that is grounded in the experiences of stroke survivors, their caregivers, and physical therapists.

Dissertation Overview

Qualitative research methods with a grounded theory approach were used. Potential constructs of RECAP were identified, rooted in previous research examining PCE in stroke rehabilitation. These constructs formed the initial conception of the RECAP theoretical model and are presented in the next chapter of this section. Section 2 describes a qualitative study investigating the experience of stroke survivors and their caregivers from rural Appalachian

Kentucky in receiving education from healthcare providers. The findings presented in this section demonstrate further development of the theory, grounded in the experiences of stroke survivors and caregivers. Section 3 presents the methods and findings of a qualitative study exploring the experience and perceptions of RECAP by physical therapists across the post-acute care stroke rehabilitation spectrum. This study further informed the emerging theory, grounded in the experiences of physical therapists who serve people with stroke and their caregivers. Section 4 integrates the findings from Sections 2 and 3 to present the emergent theory and theoretical model, discusses the findings of this dissertation with respect to previous research, and presents the limitations and suggestions for future inquiries.

Chapter 1.2: RECAP: An Emerging Theoretical Model

Qualitative methods with a grounded theory approach are best suited to broaden the understanding of rehabilitation education for caregivers and patients (RECAP) by physical therapists in stroke rehabilitation. The purpose of grounded theory methodology is to "move beyond description and to generate or discover a theory, an abstract analytical schema of a process" (Creswell, 2007, p.63). The methods used in this study, however, do not adhere strictly to the systematic procedures of Glaser, Strauss, and Corbin (Creswell, 2007). In spirit, this study is more closely aligned with the constructivist grounded theory approach described by Charmaz in that the guidelines of the design are more flexible and theory development "depends on the researcher's view, learning about the experiences within embedded, hidden networks, situations, and relationships" (Creswell, 2007, p.65). Further in line with the perspectives of Charmaz, there is greater "emphasis on the views, values, beliefs, feelings, assumptions, and ideologies of individuals than on the methods of research" (Creswell, 2007, p.65).

One prominent difference in the methods used in this dissertation study, compared to the traditional grounded theory frameworks, is that potential constructs of the theory of RECAP were identified "off the shelf" (Creswell, 2007, p.63), or from existing research, prior to study initiation. Typically, an extensive preliminary literature review is not conducted in traditional grounded theory methods to enable the theory to emerge strictly from the data (Mellion & Tovin, 2002). In contrast, in this dissertation study, I extensively reviewed the existing literature on patient and caregiver education in stroke rehabilitation. Potential

constructs of RECAP were identified and while they would be considered “off the shelf”, the “shelf” was built out of previous research investigating the experiences and perceptions of education for stroke survivors, caregivers, and healthcare providers. In other words, the potential constructs are grounded in the experiences of individuals who have experienced the phenomenon of RECAP in stroke rehabilitation. Of note, even though the preliminary constructs, that will be described next, were used as building blocks for the theory, the data collection and analysis of the dissertation study expanded beyond these.

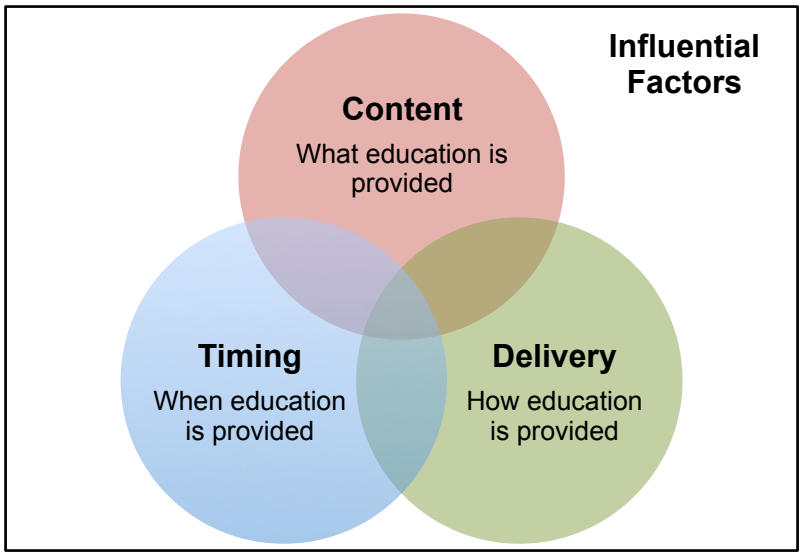
Initial Emerging Constructs of Patient and Caregiver Education

A review of the literature on patient and caregiver education, based on the experiences and perceptions of stroke survivors, caregivers, and healthcare providers, yielded four potential constructs that formed the root of the RECAP theoretical model that was developed in this dissertation. The constructs included: “content”, “timing”, “delivery”, and “influential factors”. A preliminary model of the constructs was developed and is depicted in Figure 1.1.

“Content” refers to what education stroke survivors and caregivers need and/or receive and what education healthcare providers convey to stroke survivors and/or caregivers. The construct emerged based on the findings of studies assessing the perceptions of what information stroke survivors and/or caregivers wanted. For example, in a grounded theory study of the perceived informational needs of stroke patients and caregivers by Garrett and Cowdell (2005), the participants expressed the need for information about diagnosis, prognosis, interventions, prevention, financial matters, recovery process,

Figure 1.1

The Preliminary Theoretical Model of Potential Constructs of Patient and Caregiver Education



sexuality, emotional changes, progress, and events related to the stroke journey. A systematic review by Hafsteinsdottir, Vergunst, Lindeman, and Schuurmans (2011) presents a broad review of potential educational content needs of stroke survivors and caregivers. Examples of content topics and associated references that were identified are provided in Table 1.1.

"Timing" refers to when information is provided or wanted along the continuum of care or time post-stroke. The construct emerged based on the findings of studies assessing the perceptions of when stroke survivors and/or caregivers wanted information. For example, in the grounded theory by Garrett and Cowdell (2005) mentioned previously, stroke patients and caregivers described educational needs at various time points post-stroke. At 2 days post-stroke, caregivers wanted education about diagnosis, prognosis, interventions; at 20 days post-stroke, participants wanted education about longer-term issues such as financial matters; and at 90 days post-stroke, stroke survivors wanted education about what caused the stroke, stroke prevention, recovery process while caregivers wanted education about emotional lability, sexual needs, and recovery of speech (Garrett & Cowdell, 2005). A common theme regarding timing was the desire for repetition and reinforcement of education, to address evolving educational needs over time and to build upon education received (Garrett & Cowdell, 2005; Hanger et al., 1998; O'Connell et al., 2009).

Table 1.1

Examples of Content Needs According to Stroke Survivors and Caregivers Presented in Previous Research

- What is stroke (Garrett & Cowdell, 2005; Keaton, et al., 2004)
- Stroke etiology (Kerr, Hilari, & Litosseliti, 2010; Rodgers, Bond, & Curless, 2001)
- Consequences of stroke (Rodgers, Bond, & Curless, 2001)
- Stroke prevention (Garrett & Cowdell, 2005; Rodgers, Bond, & Curless, 2001; van Veenendaal, Grinspun, & Adriaanse, 1996)
- Prognosis (Avent et al., 2005; Garrett & Cowdell, 2005)
- Interventions (Garrett & Cowdell, 2005)
- Recovery process (Garrett & Cowdell, 2005)
- Progress (Garrett & Cowdell, 2005)
- Depression/emotional reactions to stroke (Garrett & Cowdell, 2005; Kerr, Hilari, & Litosseliti, 2010)
- Need for psychosocial support/counseling (Avent et al., 2005)
- Going out in the community (Kerr, Hilari, & Litosseliti, 2010)
- Aphasia and communication strategies (Avent et al., 2005; Kerr, Hilari, & Litosseliti, 2010)
- Driving (Kerr, Hilari, & Litosseliti, 2010)
- Working after stroke (Kerr, Hilari, & Litosseliti, 2010)
- How to raise public awareness of stroke (Kerr, Hilari, & Litosseliti, 2010)
- Medication management (Keaton, et al., 2004)
- Local community and government services (Kerr, Hilari, & Litosseliti, 2010; Keaton et al, 2004)
- Resources to apply for help (van Veenendaal, Grinspun, & Adriaanse, 1996)
- Discharging home from the hospital (Kerr, Hilari, & Litosseliti, 2010)
- Financial information (Garrett & Cowdell, 2005)
- Coping with stress (van Veenendaal, Grinspun, & Adriaanse, 1996)
- Strategies for mobility and activities of daily living (van Veenendaal, Grinspun, & Adriaanse, 1996)
- Sexual function (Garrett & Cowdell, 2005)
- Retrospective stroke journey (Garrett & Cowdell, 2005)

"Delivery" refers to how education is provided. The construct emerged based on research assessing the perceptions of how stroke survivors and/or caregivers wanted to receive education. For example, in a study by Eames, Hoffmann, Worrall, and Read (2011), the educational delivery preferences of 34 stroke survivors and 18 caregivers were assessed. Stroke survivors preferred a combination of face-to-face, written, and online/audiovisual methods; caregivers preferred face-to-face, written, and telephone methods prior to discharge from the hospital with online, audiovisual, and a telephone hotline to be included post discharge (Eames, Hoffmann, Worrall, & Read, 2011). The sole use of verbal delivery methods was overwhelming according to some participants in the study by Garrett and Cowdell (2005), with the suggestion for 3-dimensional or pictorial formats (e.g., diagnostic imaging) to be included for complex anatomical education. Hoffman, McKenna, Worrall, & Read (2007) noted improved satisfaction with content with computer-generated tailored written materials versus generic written materials.

"Influential factors" referred to any factor that may influence the provision or reception of RECAP. An example of an influential factor would be the learning readiness or abilities of the stroke survivors and caregivers (Vanetzian, 1997). In a qualitative study by O'Halloran, Worrall, & Hickson (2011), the following factors influenced interactions between stroke patients and providers: the knowledge, communication skills, attitudes, and individual characteristics of the providers, the availability of caregivers, the physical environment of the hospital, and hospital policies and procedures. Considerations of reading ability, neglect, health

literacy, and communication/cognitive impairments are also examples of potential influential factors that have been suggested (Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011).

These preliminary constructs of the RECAP model are rooted in the experiences and perceptions of stroke survivors, caregivers, and healthcare providers. To further develop the theory of RECAP in stroke rehabilitation and narrow the focus to physical therapy, two studies were conducted. A study exploring the experiences of receiving education for stroke survivors and caregivers from rural Appalachian Kentucky is described in Section 2. A study exploring the experiences and perceptions of RECAP for physical therapists across the rehabilitation continuum is described in Section 3.

SECTION TWO: THEORY UNDER CONSTRUCTION: EXPERIENCES OF STROKE SURVIVORS AND CAREGIVERS

Chapter 2.1: Methods and Participant Descriptions

This chapter describes the methods used in a study investigating the experience of stroke for rural stroke survivors and their caregivers as they transitioned from stroke onset, through the healthcare continuum, and attempted to return to living post-stroke in their rural communities. A component of this comprehensive study was to investigate their experience of receiving education from healthcare providers. The findings from this embedded component of the overall study are presented in this dissertation. A description of the research design is first presented. Next, the data collection sources, sampling paradigm, and participant recruitment process are reviewed. Then, descriptions of the participants who volunteered to participate are provided. The chapter concludes with an explanation of the data analysis approach and verification strategies used to establish trustworthiness of the findings.

Research Design

A qualitative descriptive research design was used in the overall study due to the nature of the design to provide "a comprehensive summary of an event" (Sandelowski, 2000, p.336), or in this case the experience of stroke, including the experience of receiving education from healthcare providers. Qualitative descriptive designs also involve staying "closer to… the surface of words and events" (Sandelowski, 2000, p.336) in order to accurately describe the sequence of events and the meanings the participants attribute to the events.

A component of the research design was the use of a qualitative research team (Cheek, 2008). A multidisciplinary team is suggested to facilitate rehabilitation post stroke (Duncan et al., 2005). The use of a multidisciplinary team approach in the research design, therefore, is well suited to investigating the experience of stroke for survivors and their caregivers. The team, Kentucky Appalachian Rural Rehabilitation Network affiliates (www.karrn.org), represented the rehabilitation spectrum, with 2 speech-language pathologists, 1 occupational therapist, 1 nurse, and 3 physical therapists. The interprofessional team facilitated holistic development of the interview guide, encouraged the three interviewers to probe outside their area of expertise and personal interests, and added depth to the qualitative analysis and discussion of findings. The institutional review boards for the university and 2 hospital partners approved this study.

Sampling Paradigm and Participant Recruitment

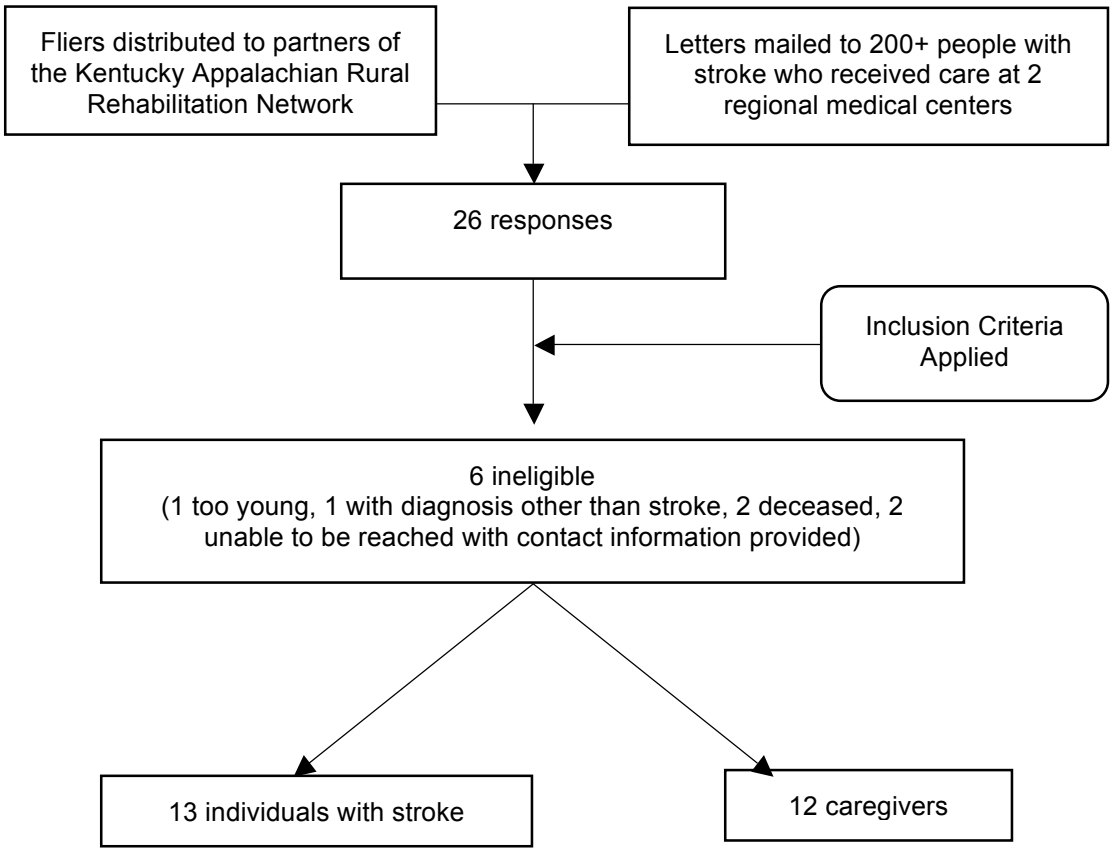
Participants were recruited through purposeful, criterion sampling (Creswell, 2007) to obtain “information-rich” cases (Sandelowski, 2000, p.338), or stroke survivors and caregivers who would best inform an understanding of patient and caregiver education from the perspective of those who receive the education. Participants had to meet the following inclusion criteria: diagnosis of stroke or caregiver of someone diagnosed with stroke, stroke survivor received medical and rehabilitation services, at least 18 years of age, able to participate in a 60-90 minute interview, native language of English, and rural Appalachian Kentucky county resident. While rural demographics and geography were held

constant, we attempted to recruit varied stroke survivors (e.g., range of residual deficits from the stroke, different living situations) and caregivers (e.g., varied types of caregivers such as spouses or children) in order to "explore the common and unique manifestations of a target phenomenon across a broad range of phenomenally… varied cases" (Sandelowski, 2000, p.337-8).

According to the Appalachian Regional Commission, Appalachian Kentucky consists of 54 counties (retrieved December 31, 2012, from http://www.arc.gov/counties), 43 of which are considered economically distressed (retrieved November 20, 2012, from http://www.arc.gov/appalachian_region/CountyEconomicStatusandDistressedAreasinAppalachia.asp). Counties were further identified as rural using the Rural-Urban Continuum Codes, also known as the Beale Codes, yielding a total of 50 out of 54 rural counties in Appalachian Kentucky (retrieved November 28, 2012, from http://www.ers.usda.gov/data-products/rural-urban-continuum-codes.aspx). Fliers were distributed to partners of the Kentucky Appalachian Rural Rehabilitation Network and letters were sent to over 200 people with stroke who received rehabilitation at various sites under the organizational umbrella of 2 large regional medical centers (see Figure 2.1 for a flow diagram of the recruitment process).

Figure 2.1

Flow Diagram of the Participant Recruitment Process



Description of Participants

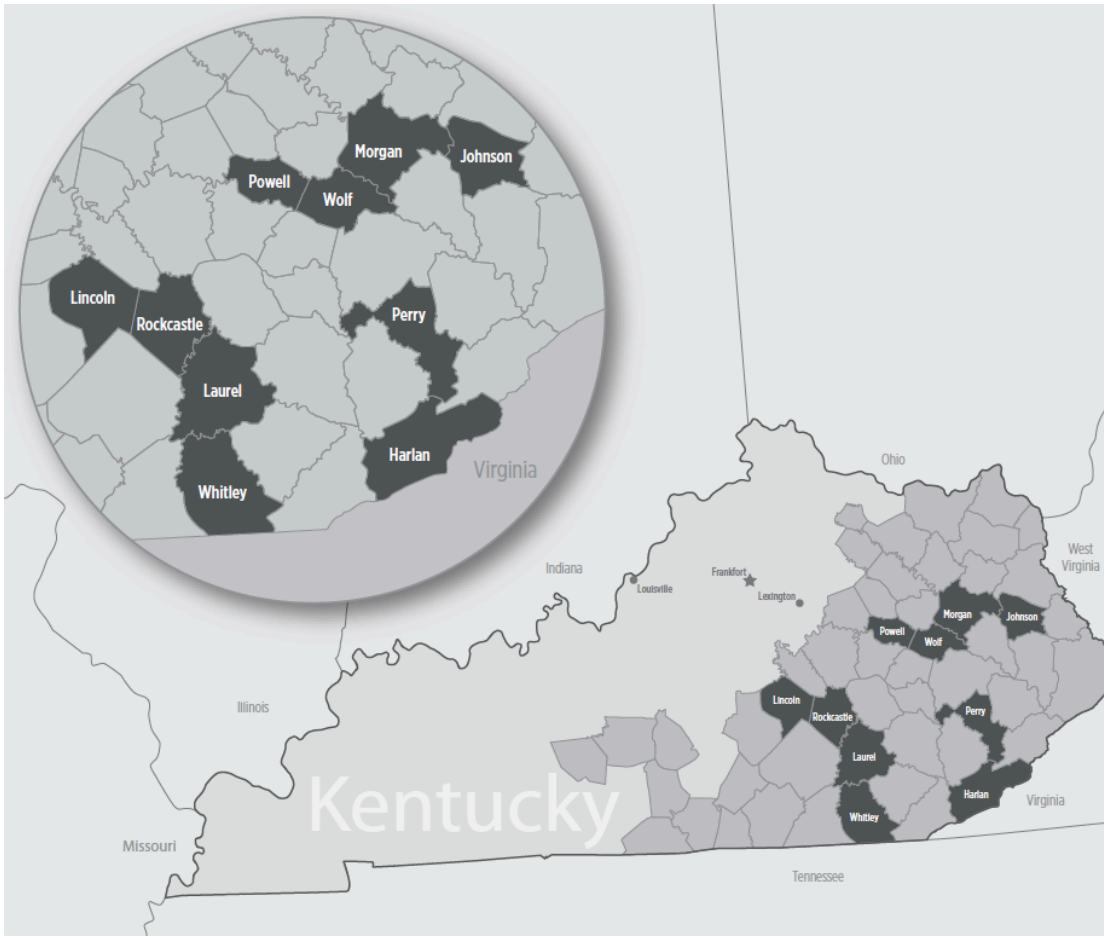
Thirteen individuals with stroke and 12 caregivers who met the inclusion criteria volunteered to participate. Informed consent and permission to audiotape were obtained from each participant. Participants represented 10 rural counties in Appalachian Kentucky (Figure 2.2). County descriptions including population, rural code, economic status, and number of participants are provided in Table 2.1. The average population of the 10 counties was 25,152, and 90% of the counties are classified as distressed.

Socio-demographic data collected included: gender, race, age, years post-stroke, relationship of the caregiver to the stroke survivor, employment status, educational attainment, annual income, marital status, and self-perceived overall rating of recovery on a visual analog scale. These characteristics are described next and an overall summary is provided in Table 2.2. All participants in this study were Caucasian, consistent with the 95.4% Caucasian demographic of Appalachian Kentucky (Pollard & Jacobsen, 2010).

The stroke survivors included nine females (69%) and four males (31%), with an average age of 63.4 years (range, 42-89 years) and an average of 3.6 years post-stroke (range, 1-14 years). None of these participants were employed at the time of the interviews. The majority of stroke survivors (69%) were in households with an annual income of $35,000 or less, while the remaining 31% had an income of $50,000 or more. Marital status included: married (54%), widowed (15%), separated (8%), and divorced (23%). As evidenced by a self-perceived overall rating of recovery (visual analog scale in which “0” indicated no

Figure 2.2

*Rural Appalachian Kentucky Counties Represented in this Study**



*The 10 counties represented in this study included Lincoln, Rockcastle, Laurel, Whitley, Powell, Wolf, Morgan, Johnson, Perry, and Harlan. They are dark shaded and labeled by county name. The remaining medium shaded counties represent additional Appalachian counties in Kentucky.

Table 2.1

*Kentucky Counties Represented in this Study by Population, Rural Code, Economic Status and Number of Participants**

County	Population	Rural-Urban Continuum Codes	Economic Status	N (Individuals with Stroke)	N (Caregivers)
Harlan	29,278	7	Distressed	1	1
Johnson	23,356	7	Distressed	3	2
Laurel	58,849	7	At-Risk	1	1
Lincoln	24,742	7	Distressed	2	2
Morgan	13,923	7	Distressed	2	2
Perry	28,712	7	Distressed	1	1
Powell	12,613	6	Distressed	0	1
Rockcastle	17,056	7	Distressed	1	1
Whitley	35,637	7	Distressed	1	0
Wolfe	7,355	9	Distressed	1	1

*Populations based on U.S. Census Bureau, 2010 census data (retrieved December 3, 2012, from http://2010.census.gov/2010census/popmap/). The "Rural-Urban Continuum Codes", also known as the Beale Codes, classifies metropolitan counties by population size and nonmetropolitan counties by degree of urbanization and adjacency to a metropolitan area on a continuum from 1 (metropolitan area) to 9 (completely rural) (retrieved November 28, 2012, from http://www.ers.usda.gov/data-products/rural-urban-continuum-codes.aspx). Codes represented by counties in this study included 6 (nonmetro county, urban population of 2,500-19,999, adjacent to a metro area), 7 (nonmetro county, urban population of 2,500-19,999, not adjacent to a metro area), and 9 (nonmetro county, completely rural or less than 2,500 urban population, not adjacent to a metro county). "Economic Status" is a classification system reported by the Appalachian Regional Commission; "distressed" indicates counties that are the most economically depressed counties and rank in the worst 10% of all counties in the United States and "at-risk" indicates a county at risk of becoming economically distressed and ranks between the worst 11-25% of all counties in the United States (retrieved November 20, 2012, from http://www.arc.gov/appalachian_region/CountyEconomicStatusandDistressedAreasinAppalachia.asp).

recovery and “100” indicated full recovery), 92% of the stroke survivors perceived residual deficits at the time of the interviews. Self-perceived recovery ranged from 30% to 100%, with an average of 62%. Common secondary complications included falls (11 (85%), with at least one fall post stroke and as high as 7 falls reported for one person) and depression (10 (77%)).

Caregiver participants included seven females (58%) and five males (42%), with an average age of 55.9 years (range, 38-75 years). The 11 caregivers who participated included 6 spouses, 3 daughters, 1 son, and one daughter-in-law. Eleven of the caregivers were married (92%). Levels of educational attainment represented included: elementary education (8%), high school graduate (33%), and higher education (59%). Half of the caregivers were employed, 4 (33%) were retired, and 2 (17%) were unemployed. In contrast to the stroke survivors, the majority of caregivers (67%) reported an annual household income of $50,000 or more, while the remaining 33% reported $35,000 or less.

Data Collection

Semi-structured, open-ended interviews (Dicicco-Bloom & Crabtree, 2006) were conducted with the person with stroke, the caregiver, or both as determined by participant preference. Interviews were selected as the primary means of data collection for the ability to “co-create meaning with interviewees by reconstructing perceptions of events and experiences related to health and healthcare” (Dicicco-Bloom & Crabtree, 2006, p. 316). The interview guide was created and refined by the research team, including myself, during a series of team meetings and pilot

testing. As a result, the finalized interview guide was informed by each team member's unique discipline- and experience-specific point of view. Interview guide questions specific to RECAP are provided in Table 2.2.

Interviews took place at locations determined by participants (homes (9), regional hospital meeting centers (3), and residential nursing facilities (2)). A dyad was not required, but the majority of stroke survivors (85%) did have their caregivers join them in the interview. Additionally, one person living with stroke was not able to participate in the interview due to a decline in medical status, but her caregiver did participate. Interviewer A conducted 5 dyad interviews (*n*=10). Interviewer B conducted 5 interviews including 3 dyads, 1 caregiver only (stroke survivor unable to participate due to medical status decline), and 1 stroke survivor only (*n*=8). Interviewer C conducted 4 interviews including 3 dyads and 1 stroke survivor only (*n*=7). Interviewers recorded reflective memos following each interview (Creswell, 2007), including reactions to the interview, any adjustments needed to the interview guide to share with the team, and any other actions required. Three members of the research team, including myself, served as interviewers and were involved in data collection.

Table 2.2

Participant Demographics

	Individuals with Stroke (N=13)	**Caregivers (N=12)**
Gender		
Female	9 (69%)	7 (58%)
Male	4 (31%)	5 (42%)
Ethnicity		
Caucasian	13 (100%)	12 (100%)
Age in years: Mean (Range)	63.4 (42-89)	55.9 (38-75)
Years post-stroke: Mean (Range)	3.6 (1-14)	N/A
Relationship to person with stroke	N/A	6 (50%)
Spouse		6 (50%)
Child (or child-in-law)		
Current employment status		
Employed (part or full-time)	0 (0%)	6 (50%)
Highest level of education		
1^{st}-8^{th} grade	3 (23%)	1 (8%)
Some high school	1 (8%)	0 (0%)
High school diploma	4 (31%)	4 (33%)
College (some or all)	3 (23%)	7 (59%)
Masters or Doctorate	2 (15%)	0 (0%)
Annual income		
Less than $15,000	3 (23%)	0 (0%)
$15,000-20,000	2 (15%)	2 (17%)
$21,000-35,000	4 (31%)	2 (17%)
$36,000-50,000	0 (0%)	2 (17%)
$51,000-65,000	1 (8%)	2 (16%)
Over $65,000	3 (23%)	4 (33%)
Marital status		
Single	0 (0%)	1 (8%)
Married	7 (54%)	11 (92%)
Widowed	2 (15%)	0 (0%)
Separated	1 (8%)	0 (0%)
Divorced	3 (23%)	0 (0%)

Table 2.3

*Interview Guide Questions with Probes Specific to Patient and Caregiver Education**

Questions and Probes
1. Describe your experience of having the stroke.
How did the healthcare providers explain what was occurring and was it in a way that you could understand?
2. Tell me about any rehabilitation you had.
How did your therapists talk with you during your therapy?
How was your family included in your rehabilitation?
Tell me about anything you did not expect after you had the stroke.
3. Tell me about coming home from the hospital.
How was the discharge process from the hospital?
What challenges did you run into in your first week home?
Who helped your family learn how to help you?
4. Describe any complications you have had since your stroke.
What information did you get about how to prevent future strokes?
5. How do you make decisions about your care and health?
Describe how providers communicate with you.
6. What is the best thing and what is the hardest thing about living in your community in terms of having your stroke?
Access to providers who know stroke?
Access to resources to receive information you need?

*Interview questions were minimally modified when interviewing the caregiver (e.g., “Tell me about any rehabilitation the stroke survivor had”).

Data Analysis

For the findings of the overall study examining the comprehensive experience of stroke, qualitative content analysis (Sandelowski, 2000) was completed concurrently and iteratively with the data collection by the entire 7-person research team. The concept of conducting data collection and analysis simultaneously is also found in traditional grounded theory approaches (Mellion & Tovin, 2002). The audio-recorded interviews were transcribed verbatim and checked for accuracy. All members of the team individually analyzed the first 3 interviews, met to discuss initial findings, and together developed an initial coding scheme derived from the data. As new data emerged from subsequent interviews, the coding scheme was modified and refined by the team.

Three researcher dyads analyzed the remaining interviews using the final coding scheme. Through this dual-coding process, each person in the dyad individually coded the transcripts and then discussed and shared interpretations of the participants' narratives with the other. The back and forth discussion within the dyads produced a single case analysis of the participant, that represented the shared interpretations of the dyad. Each of the three of us who served as interviewers then returned to the cases we conducted interviews for and reanalyzed the data using the final coding scheme to ensure important findings were not overlooked in the initial analysis. I then synthesized the findings from all of the interview analyses. This was followed by team discussion of the final analysis and any subsequent adjustments were made.

To provide a comprehensive summary of the participants' experiences of stroke, participants stories were analyzed and organized by events within a chronological sequence: the onset of the stroke, experience of the healthcare continuum, transition through and between each setting, and attempts to reintegrate into their former lives and rural communities. Data within the "Education and Communication" domain in the coding scheme were used for this dissertation for an in-depth analysis of the participants' perceptions of receiving education during their stroke journey. I analyzed the "Education and Communication" domain, using the initial constructs of the RECAP model as a lens for analysis. In this approach (Diciccio-Bloom & Crabtree, 2006), the RECAP model served as a template in which the constructs of the model served as "predetermined" or "prefigured" codes (Creswell, 2007 and 2009). Emerging codes that did not fit the template but described other dimensions or ideas related to patient and caregiver education were also coded (Creswell, 2007). The theory further evolved from the findings of this study and additional constructs were added to the RECAP model, including identification of educational needs and subsequent educational interaction, sources of education, and receivers of education.

Verification of Findings

Multiple strategies were used in the overall study to verify the findings and establish methodological rigor and trustworthiness. For descriptive validity, every attempt was made to provide an accurate accounting of the events and experiences of the participants as they described them (Sandelowski, 2000). For

interpretive validity, probes and iterative questions to clarify responses and obtain greater depth and richness of data, were used during the interviews to obtain an accurate rendering of the meanings the participants attributed to their experiences (Sandelowski, 2000). Trustworthiness and credibility (Creswell, 2007) were also addressed through the dual-coding process and the use of verbatim quotations, or the use of the voices of the participants to confirm the interpretations of the research team. Member checking was unable to be conducted due to feasibility issues related to the extended time between data collection and analysis of the education and communication data. For verification of my further analysis of the "Education and Communication" domain, peer debriefing (Creswell, 2007) with a second researcher on the team, who was an expert in qualitative research and health literacy, was conducted.

Portions of the methods and participant descriptions in this chapter have been previously published:
Danzl, M., Hunter, E., Campbell, S., Sylvia, V., Kuperstein, J., Maddy, K., & Harrison, A. (2013). "Living with a ball and chain": The experience of stroke for individuals and their caregivers in rural Appalachian Kentucky. *The Journal of Rural Health*, in press.

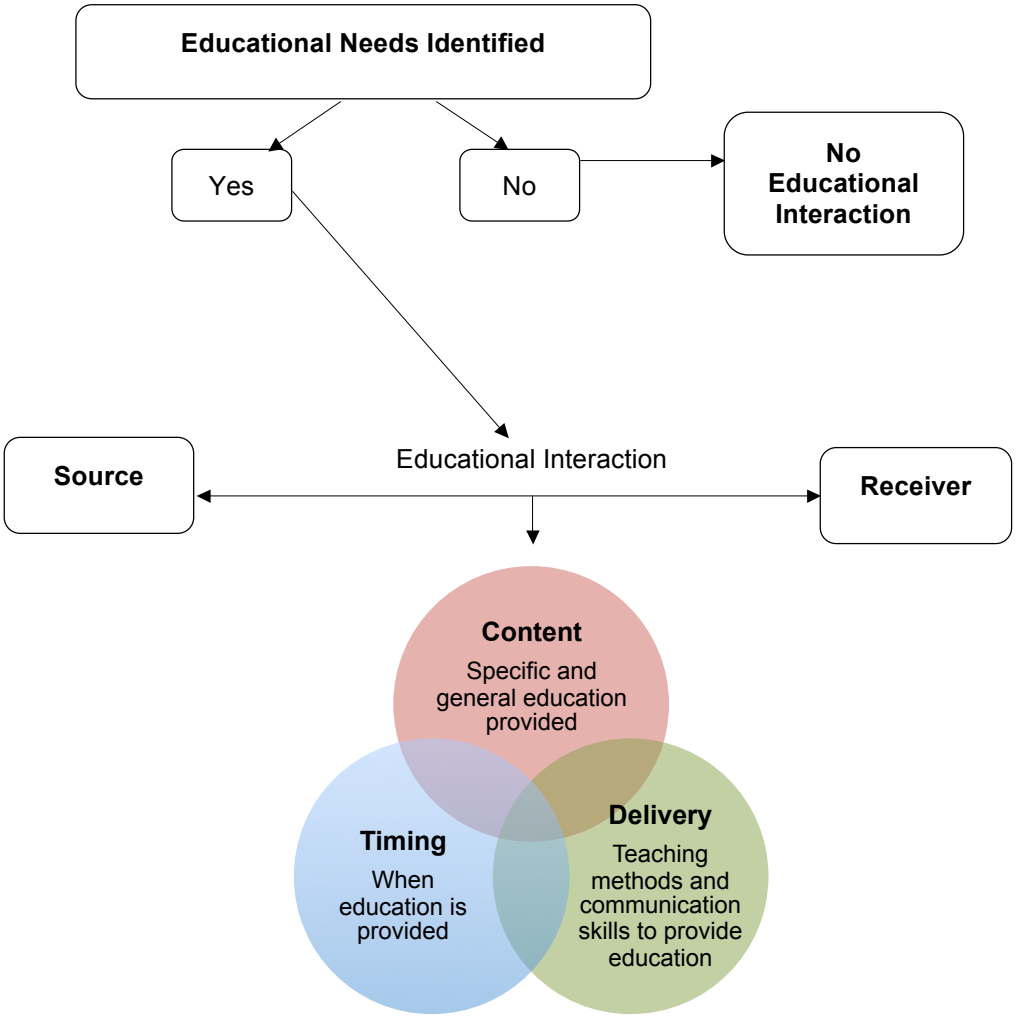
Chapter 2.2: The Experience of Receiving Education

This chapter describes the perceptions of receiving education from healthcare providers for the 25 study participants. Additional constructs, interactions, and relationships within the theory emerged from the data and are depicted in Figure 2.3. The construct “content” evolved to include “specific and general education provided”. The construct “delivery” evolved to specify teaching methods and communication skills used by the provider to deliver education. The concepts of identification of educational needs and an educational interaction between the source (person providing education) and receiver (person receiving education) emerged from the findings and were integrated into the model.

To summarize the evolution of the theory at this point: if educational needs are not identified by the source, then no educational interaction occurs; if educational needs are identified by the source, an educational interaction occurs between the source (e.g., healthcare provider) and the receiver (e.g., stroke survivor and/or caregiver); the educational interaction involves the source delivering content at a point in time. The encompassing construct “influential factors” in the original model was removed at this point because influential factors that emerged related to the constructs and described within each construct of the evolved model. The findings of the study are described in the remainder of this chapter and are structured in the context of the components of the evolved model. Findings presented in this chapter are de-identified using pseudonyms of the participants’ choice.

Figure 2.3

Further Development of the RECAP Theoretical Model



Educational Needs Identified

Participants described how healthcare providers identified their educational needs through two possible methods. In some instances, healthcare providers presumed education was required and preemptively provided the education. Several caregivers described how beneficial it was to receive information without having to ask for it *(they were real good and… every step of the way… communicating with us, telling us what was happenin', why it was happenin' -Patty's husband).* In other instances, stroke survivors and caregivers actively sought out information by asking healthcare providers questions which prompted an educational interaction.

No Educational Interaction

When educational needs were not identified, no educational interaction occurred. For example, in some cases, participants reported that the neurologist and other healthcare providers never described what the stroke was or what caused it. Others reported never receiving information regarding the necessity of interventions. Larry reported feeling unprepared and unsupported when he was discharged directly home from acute care. Once home, home health services were delayed due to insurance issues and Larry and his wife described frustration with the home health providers not recognizing their educational needs:

> *"[The home health agency] didn't do nothin' until the money started rollin'. But it looks like they would've gave us some literature and said, 'This is what you can do in the meantime'." –Larry*

Quite often stroke survivors and caregivers did not seek out information and ask questions because they did not know what to ask. When healthcare

providers did not proactively provide education, therefore, participants felt frustrated and helpless *(they weren't forthcoming with information of things to do… you feel like you don't know what to do… it felt pretty helpless -Samuel's wife).* This was especially applicable to emotional and psychological topics. Participants described reluctance to express educational needs about depression, intervention options, and psychological supports available, possibly due to the sense of pride and independence valued in their rural communities or because they did not know what to ask about. Participants expressed a preference for providers to proactively provide education about these topics so that informational needs could be met.

Source

Participants were largely reliant on healthcare providers as sources of education. In this study, providers included physicians, rehabilitation therapists (physical, occupational, and speech therapies), nurses, and case managers. Few reported accessing other resources (e.g., searching for information online); they either did not have access, computer skills, or an understanding of where to find information. Participants reported that access to sources dramatically decreased upon discharge from inpatient rehabilitation and they were typically left to navigate systems alone. There was an absence of local services, such as local neurologists and an interprofessional rehabilitation team. The unmet need for speech-language pathologists was particularly prevalent. Rural local agencies were described as not being helpful educational sources. For example, Larry and his wife went on to describe their efforts to reach out to the local Medicaid and

disability offices only to perceive that the people working there had no grasp on the devastation of stroke, an unwillingness to help, and an overall lack of compassion.

Access to important information upon discharge from inpatient rehabilitation and throughout the chronic phase of stroke, therefore, typically resulted from coincidentally knowing the right person. This occurred in a haphazard way that required each family to learn about things the hard way.

> *After we already had spent all of her life savings and had no money left… nursing home bill of $7,000, we ended up applying for Medicaid…[a friend] told us to do that…if we had known to begin with... -Rene's daughter*

This reliance on friends and family as educational sources was common and caregivers expressed the need for a contact person within the healthcare system (e.g., health navigator) as an educational source. In addition to greater access to individuals as educational sources, participants described the need for local support groups as potentially ideal venues for sharing and receiving information.

Receiver

The primary receiver of education was typically the stroke survivor. Caregivers advocated for improved inclusion in the educational process and recognition as an important educational receiver, especially during the inpatient phase of rehabilitation. Caregivers described more positive experiences with education when they could physically be present during the rehabilitation. Typically caregivers were separated by large geographic distances between the urban rehabilitation center and the home communities. 85% of the stroke survivors in this study received inpatient rehabilitation care in an urban center potentially 150 miles from their homes. Those who were unable to be present,

largely due to these extensive geographic distances between the hospitals and their rural Appalachian homes, described feeling disconnected, isolated, and distant from the rehabilitation process.

> *I wasn't with him every minute. I didn't know everything they were doin' to him. I didn't get to go [to the hospital]… My point is the fact that I didn't always know what was goin' on with him. A lot of things passed me by. - Columbo's wife*

Overall, participants described the need for providers to recognize the many potential receivers of education, including the stroke survivor, the caregiver, other family members, support networks, and the rural communities. While healthcare providers may not have the opportunity to directly educate all of these receivers, participants expressed the need to receive resources (e.g., educational pamphlets, websites) that they could then provide to their social support and community networks. This was perceived to be important, as a lack of understanding of stroke and disability in these networks led to stigmatization and contributed to emotional and psychological stress.

> *They won't have nothin' to do with you no more. I still have no friends because of the stroke. I've met several people that's had strokes but they're just like me; they just feel like they're just left out in the world. –Larry*

Content

Participants described the content of education they received and the content they wished they received. The broad domains of content, and specific examples within each, are reviewed in the following sections.

Pre-Stroke Knowledge

Participants described the need for education about how to recognize symptoms of stroke and risk factors for stroke, indicating a potential lack of

education from a primary care setting pre-stroke. Alice thought that her symptoms were insignificant and would pass *(it didn't enter my mind [having a stroke]; I thought I just got too hot… a little dizzy… I thought, well it'll pass -Alice).* Caregivers typically felt unprepared to recognize the signs and symptoms of stroke and know what action to take *(I beat myself up for not having known it sooner. Maybe they could have done something sooner -Columbo's wife).* Participants described limited knowledge of how critical time was in seeking intervention to reduce mortality risk and improve prognosis. This caused delays in accessing emergent care, with as long as three days reported.

Residual Deficits

Participants appreciated education about how residual deficits are attributed to the stroke *([the doctor] said with anybody that would have a stroke that size… it would change their personality -Chuck's daughter).* Education regarding rehabilitation and management of residual deficits was important (e.g., how therapeutic activities and exercises could lead to meaningful functional outcomes) *([The speech-language pathologist] taught me ways and means of saying things and the reasons for doing that -Columbo).* Additional topic areas for managing residual deficits included durable medical equipment, adaptive devices, how to obtain equipment, and home modifications. Caregiver education for managing residual deficits included training for how to assist the stroke survivor with functional mobility safely (e.g., use of proper body mechanics and effective communication strategies to use).

Psychological and Emotional Management

Education on management of psychological and emotional issues post-stroke was virtually non-existent. Depression and social isolation participants experienced post-stroke was common (Danzl et al, 2013), while education on how to manage it was uncommon. Participants revealed the need for information about psychological counseling, support groups available, options for anti-depressants, and coping strategies. Information about strategies to resume hobbies, leisure activities, and meaningful roles was lacking. Caregivers specifically needed education regarding respite services available, depression and stress management, and how to balance the caregiver role with other life roles.

Recovery

The concepts of recovery and neuroplasticity were largely absent from participants rehabilitation or the education was not provided in a way that participants understood it. Evelyn's daughter-in-law described being told *"that part of the brain is dead now".* They inferred this description to imply permanency of the brain death. Columbo also shared his perception of the take-home message that the brain is damaged and is unable to recover *('You had brain damage and that won't get any better,' … that was a blow -Columbo).* Typically, participants were eager for information about what they could do to improve their recovery and function. One participant even described an interest in finding out about research studies and clinical trials available for which she could volunteer.

Prevention of Secondary Complications and Future Strokes

Based on participants' descriptions and experiences, education about prevention of secondary complications post-stroke and prevention of future strokes was lacking. Secondary complication information needs included how to reduce falls, risk and management of pressure ulcers, effects of urinary tract infections on physical and cognitive functioning, importance of physical activity (e.g., to prevent deep vein thrombosis, weight management), and how dysphagia can lead to pneumonia. A lack of understanding of what caused the stroke contributed to a lack of understanding of how to prevent another stroke in the future. The extent of stroke prevention education, or risk factor management, that could be recalled, consisted of medication adherence. Participants described minimal understanding of risk factors for stroke. Evelyn described episodes in the months leading up to the stroke that were consistent with transient ischemic attacks but did not know these could be precursors to a larger stroke.

Healthcare System: Settings and Services

Participants expressed the need to better understand the healthcare continuum in terms of what is expected in each setting (e.g., inpatient, outpatient, home health) and what their roles as patient and caregiver are. There was also a need for education about how to navigate the overall healthcare system and for information that would inform decision-making. Larry and his wife didn't want to go to a nursing home from acute care for short-term rehabilitation but they did not realize home health would not be initiated until Medicaid was approved, which

could take weeks to months. They assumed that the home health would be available immediately.

Financial Resources

There was a need for education regarding insurance and other financial support options available (e.g. Medicare, Medicaid, social security, disability, local resources) *(a lot of red tape, and if you've never dealt in it or had anything to do with it… you don't know which way to go… getting his medicine… no kind of benefits. You had to just have cash. And it was kind of hard to come up with that -Larry's wife).* Education needs about establishing living wills, advanced directives, and medical power of attorney was described. Participants also described the need for education about resources to assist with paying for ramp building and equipment (e.g., assistive devices, braces) so that they did not have to rely on friends and family to purchase everything.

Delivery

Teaching Methods

A variety of teaching methods were mentioned by participants including verbal, visual, and written modes of delivery. The primary mode of education was verbal delivery of information. While this seemed to be the favored mode of healthcare providers, it frequently overwhelmed stroke survivors and caregivers. The "Family Teaching Day" concept exemplified this. During inpatient rehabilitation, caregivers were typically invited to visit for a day of "family teaching" in order to receive education and training and feel more prepared to assist the stroke survivor at home. Some caregivers found it to be beneficial

while others perceived it to be overwhelming due to the large amount of information that was verbally provided in a short time span. Verbal delivery that emphasized an “educational pearl”, such as an easy-to-remember tip for doing something, helped participants integrate the information the healthcare provider was trying to teach. For example, Christina remembers “the rock”, a technique her therapist showed her 14 years earlier, to help her stand easier. A valuable verbal delivery method for participants in the inpatient rehabilitation phase was a stroke support group in which education was received through peer interactions and from healthcare provider speakers.

Another common teaching method was through visual means. Demonstrations from therapists or nurses (e.g., performing functional mobility tasks) were typical. After the stroke survivor or caregiver observed the demonstration, they were typically required to provide a return-demonstration. This was followed by education regarding their performance. Visual methods in the form of pictorial resources (e.g., posters, diagrams) and anatomical models were not mentioned. While some participants suggested videos as a potential useful visual educational tool that was needed, one participant described limitations with using this as the primary mode of education. When Juanita was considering a Baclofen pump for spasticity, the dominant method of education she could recall was watching a marketing DVD depicting smiling people walking again, while the potential side effects were overshadowed *(She gave me a DVD to watch… ‘Wow! This’ll be great!’… I should of asked her what the side effects were, but I didn’t. –Juanita).*

Written methods of delivery were described and perceived as useful by some of the participants (e.g., pamphlets, brochures, binders of information). Columbo continued to use the educational binder he received upon discharge from inpatient rehabilitation into the chronic phase of his stroke *(my speech drags on me now… get my paperwork out and practice my words).* Larry found written information beneficial as a method to educate his family and friends regarding stroke *(people were… makin' fun of me, especially my family. [The home health therapist] said, 'they're just showin' their ignorance is all they're doin', they don't understand.'… she gave me a bunch of literature to hand out).*

Overall, participants expressed the need for healthcare providers to use a variety of teaching methods, or multiple modes of delivery, when providing education. Participants described the importance of the use of meaningful tasks and environments to make education meaningful. For example, Evelyn described a sense of self-confidence and perception of recovery when an occupational therapist incorporated laundry tasks with hanging clothes up on a clothesline into therapy, something that Evelyn had to do frequently at home.

Communication Skills

Participants perceived communication from educational sources as a critical component of delivery. Providers' communication skills varied in terms of clarity and effectiveness as perceived by participants. In some instances, the content provided was factually accurate but led to misinterpretations because of wording choice on the healthcare providers part. Both Columbo and Chuck were told they had a "small stroke" and "light stroke". This description led them to

believe the residual deficits would resolve quickly and a full recovery could be expected. Columbo's headaches and concentration deficits, that never resolved, impacted his ability to participate in life roles and this was difficult to come to terms with since he was told he had a "light stroke". Chuck believed that despite his impulsivity and safety awareness deficits, he could return to driving a car and his all-terrain vehicle because he had only had a "small stroke". These descriptions of stroke were frustrating and insulting to their caregivers who perceived providers as downplaying the severity of the stroke and minimizing the event *(I'll tell you, the days that you were bad, it was not anything 'small'… it was scary –Columbo's wife).* Samuel provided another example of semantic misunderstandings: *"I've had certain doctors go, 'oh, well, you're recovering great.' I'm like, well, I'm not really recovering great. I'm compensating great."*

The need for active listening from the providers to optimize educational interactions was described. Samuel described feeling as though he did not have a voice in his rehabilitation *(the most disheartening about the stroke … I don't think I'm being listened to).* As a result, he believed he had many questions that went unanswered and opportunities for education that were missed by providers. Active listening was also important because it conveyed care and concern from the educational source. When participants felt a personal connection with providers, they described greater interest and buy-in to what the providers were educating them about *(I had a speech pathologist… she was just so very outstanding… she reached in to my soul… she taught me ways and means of sayin' things… there was just a personality connection there -Columbo).*

Participants described how the communication style of the educational source impacted educational interactions. For example, Columbo was awakened from a deep sleep by a nurse who immediately began educating him regarding a safety concern: *"She had this military bearing about her… She chewed me up one side and down the other… I didn't realize that I'd done anything that bad… … I wasn't as bad a person as she had laid it out there."* Columbo inferred from her communication style that he was a "bad person". In contrast, participants described providers who communicated with a supporting and encouraging style as a facilitator to educational interactions.

Timing

Participants described experiences of receiving or not receiving content at time points within and across the continuum of care settings. Participants described experiences in acute care and long-term care settings but for the purposes of this dissertation, the data regarding the timing of education in rehabilitation settings will be described.

In the inpatient rehabilitation settings, participants described receiving education about how to start the process of recovery, how to begin coping and adapting post-stroke, and how and what to prepare for in terms of returning home. As described previously, there was a lack of access to educational sources upon discharge from inpatient services and into the chronic phase of stroke. As such, participants described the lack of education provided during these time points. Upon returning home, a time when they were in need of continued education and were often most ready to learn and integrate the

information into their life roles, participants felt they did not have the educational supports needed. It was also challenging for participants to provide education to their support networks and rural communities once home. Larry's wife suggested the need for early access to educational resources (e.g., a class, brochures, videos, websites) to provide or refer their support networks to. Overall, participants described the need for multiple repetitions of education over time, across the continuum of care settings and into the chronic phase of stroke.

Summary

The RECAP theoretical model evolved based on the findings from this study investigating the experiences of receiving education for 13 stroke survivors and 12 caregivers. Further nuances of the constructs of content, timing, and delivery were revealed. In addition, the concepts of identification of educational needs and an educational interaction between a source and receiver emerged. I approached the data collection and analysis in the next study, investigating the experiences and perceptions of stroke-related RECAP by physical therapists, with the evolving theoretical model and constructs in mind. While the evolving model provided a springboard for the next phase, I was open to further evolution of the existing constructs and identification and exploration of new emerging constructs.

Some portions of the findings in this chapter have been previously published:
Danzl, M., Hunter, E., Campbell, S., Sylvia, V., Kuperstein, J., Maddy, K., & Harrison, A. (2013). "Living with a ball and chain": The experience of stroke for individuals and their caregivers in rural Appalachian Kentucky. *The Journal of Rural Health*, in press.

SECTION THREE: ADDITIONAL BUILDING BLOCKS – EXPERIENCES OF PHYSICAL THERAPISTS

Chapter 3.1: Methods and Participant Descriptions

Following the further grounding of the developing RECAP theoretical model in the experiences of stroke survivors and caregivers (described in Section 2), I undertook a second study to ground the theory in the experiences of physical therapists. This chapter describes the methods used in that study investigating physical therapists perceptions and experiences of providing education to stroke survivors and their caregivers. First, a description of the research design is provided. Next, the sampling paradigm and participant selection process is described. Following this, descriptions of the therapists who participated in the study are provided. Then, the data collection sources, procedures, and analysis are reviewed. The chapter concludes with a description of the approaches to the verification of findings.

Research Design

Qualitative methods with a grounded theory approach (Mellion & Tovin, 2002) were used to investigate physical therapists perceptions and experiences of education to stroke survivors and their caregivers, across the post-acute continuum of care. As was previously described, the design did not adhere strictly to the systematic approaches of Glaser, Strauss, and Corbin (Glaser & Strauss, 1967; Strauss & Corbin, 1990). While the design also did not exactly follow the methods described by Charmaz (2006), my point of view does fall more in line with the constructivist grounded theory approach. The intent of

grounded theory is to generate an “explanation (a theory) of a process, action, or interaction” (Creswell, 2007, p.63). Further, the use of a grounded theory approach might yield a theory that helps “explain practice or provide a framework for further research” (Creswell, 2007, p.63) by identifying “the major constructs, or categories of a phenomenon, their relationships, and the context and process” (Mellion & Tovin, 2002). As such, qualitative methods, cast from the grounded theory philosophy, were best suited to achieve the purpose of developing a theory of patient and caregiver education in stroke physical therapy in the hopes of guiding both practice and research.

The design was emergent in that it evolved over time as I entered the field and initiated data collection (e.g., data collection sources required modification) (Creswell, 2007). I approached data collection and analysis with the evolved RECAP theoretical model, that emerged from the study described in Section 2, in mind. I was, however, open to investigating and analyzing any other aspects of patient and caregiver education that emerged in order to further develop the theory. The research questions guiding the study are presented in Table 3.1. The University of Kentucky’s Institutional Review Board approved this study and letters of support were obtained from all participating sites.

Table 3.1

Research Questions Guiding the Study

Central Research Question Guiding the Study
What are the physical therapists' perceptions and experiences of providing patient and caregiver education to stroke survivors and their caregivers?
Sub-Questions Guiding the Study
1. What are physical therapists thoughts, feelings, and attitudes about patient and caregiver education?
2. What reasons do they have for providing education?
3. What value do therapists ascribe to education?
4. How do therapists identify educational needs of stroke survivors and caregivers?
5. What education is provided?
6. How is education provided?
7. When is education provided?
8. What factors influence the provision of education?
9. What barriers exist to providing education?
10. What supports are needed to provide education?

Sampling Paradigm and Participant Recruitment

Sampling Paradigm

This study used a purposeful and criterion sampling paradigm (Creswell, 2007). Physical therapists had to meet the following inclusion criteria to participate: practicing physical therapist, works in an inpatient rehabilitation, sub-acute rehabilitation, home health, or outpatient setting, currently works with stroke survivors and/or their caregivers, and willing to be interviewed. These inclusion criteria were employed to purposefully recruit physical therapists who would best inform theory development as they would have experienced providing RECAP in stroke rehabilitation across the post-acute care continuum. This type of sampling is in accordance with a basic tenet of grounded theory in regards to the expectation that the participants have experienced the phenomenon or process of interest (Creswell, 2007).

Attempts were made to recruit participants with demographic variation (Sandelowski, 1995) (e.g. across the novice-expert spectrum, varied terminal physical therapy degrees, both male and female therapists). Attempts were also made to recruit for phenomenal variation (Sandelowski, 1995), or physical therapists with experience providing education to a variety of stroke survivors and caregivers (e.g., diversity regarding the survivor/caregiver's demographics, geographic backgrounds, and stroke characteristics). These types of variations were included to obtain a breadth of perspectives and "maximize opportunities to discover variations among concepts and to densify categories in terms of their

properties and dimension" (Mellion & Tovin, 2002, p.112) regarding the theory of patient and caregiver education.

Recruitment Site

Participants were recruited from a hospital organization in a southeastern state, in a region with a high incidence of stroke (Halverson, Barnett, & Casper, 2002). This organization was selected for several reasons. The hospital provided physical therapy services to stroke survivors across the post-acute care continuum including inpatient rehabilitation, sub-acute rehabilitation, outpatient, and home health settings. The hospital is a regional organization in which stroke survivors from both the urban city and surrounding rural geographic area seek treatment post-stroke, supporting the likelihood of therapists having experience educating geographically and demographically diverse survivors and caregivers. Additionally, individuals in the region typically have lower levels of educational attainment and decreased access to healthcare services (Gillum & Mussolino, 2003; Halverson, Barnett, & Casper, 2002; Tickamyer & Duncan, 1990). I hypothesized that the depth and breadth of education required for this population of stroke survivors and caregivers would be extensive and that the physical therapists who provided services to this population would be key informants.

The organization was also selected to capitalize on the benefits of "insider research" in which researchers' "conduct studies with populations and communities and identity groups of which they are also members" (Kanuha, 2000, p.439). At the time of data collection, I had been working at the organization as a part-time physical therapist for three years. My primary position

was on the inpatient rehabilitation stroke unit but I also had experience covering in the outpatient neurological setting. To address one of the potential power dynamic issues (Karnielli-Miller, 2009) in insider qualitative research, employment hierarchy, it is important to note that I was not in an administrative position in any capacity and had never been in administrative position, overseeing physical therapists, in the three years at the organization.

A primary benefit to being an insider is acceptance (Dwyer & Buckle, 2009). Insider status can help establish trust and rapport with participants because the researcher shares an "identity, language, and common professional experiential base" (Asselin, 2003, p.100) with them. The insider role "frequently allows researchers more rapid and more complete acceptance by their participants… participants are typically more open with researchers so that there may be a greater depth to the data gathered" (Dwyer & Buckle, 2009, p. 58). In addition, benefits of an insider approach include being known to the organization and thereby obtaining easier entry and access to the setting, as well as having previous knowledge of organizational processes, the work culture, and history of the organization (Asselin, 2003; Coghlan & Casey, 2001).

Recruitment Process and Results

Physical therapists were recruited through posted fliers throughout the hospital and a recruitment letter distributed electronically to all of the part-time and full-time physical therapists. The flyers and emails highlighted the purpose of the study, overview of involvement, and inclusion criteria. Thirteen physical therapists agreed to participate and met the inclusion criteria. A flow diagram of

the recruitment process is provided in Figure 3.1. Informed consent and permission to audiotape was obtained from each participant. To address potential power dynamics (Karnieli-Miller, Strier, & Pessach, 2009), I included the following during the informed consent process: emphasis on my role as researcher and not co-worker, clear and open presentation of the study aims, emphasis on anonymity, and disclosure of potential dissemination of findings (Asselin, 2003). Participants selected pseudonyms to de-identify the presentation of findings. Any names that appear in this dissertation are the self-selected pseudonyms of the participants.

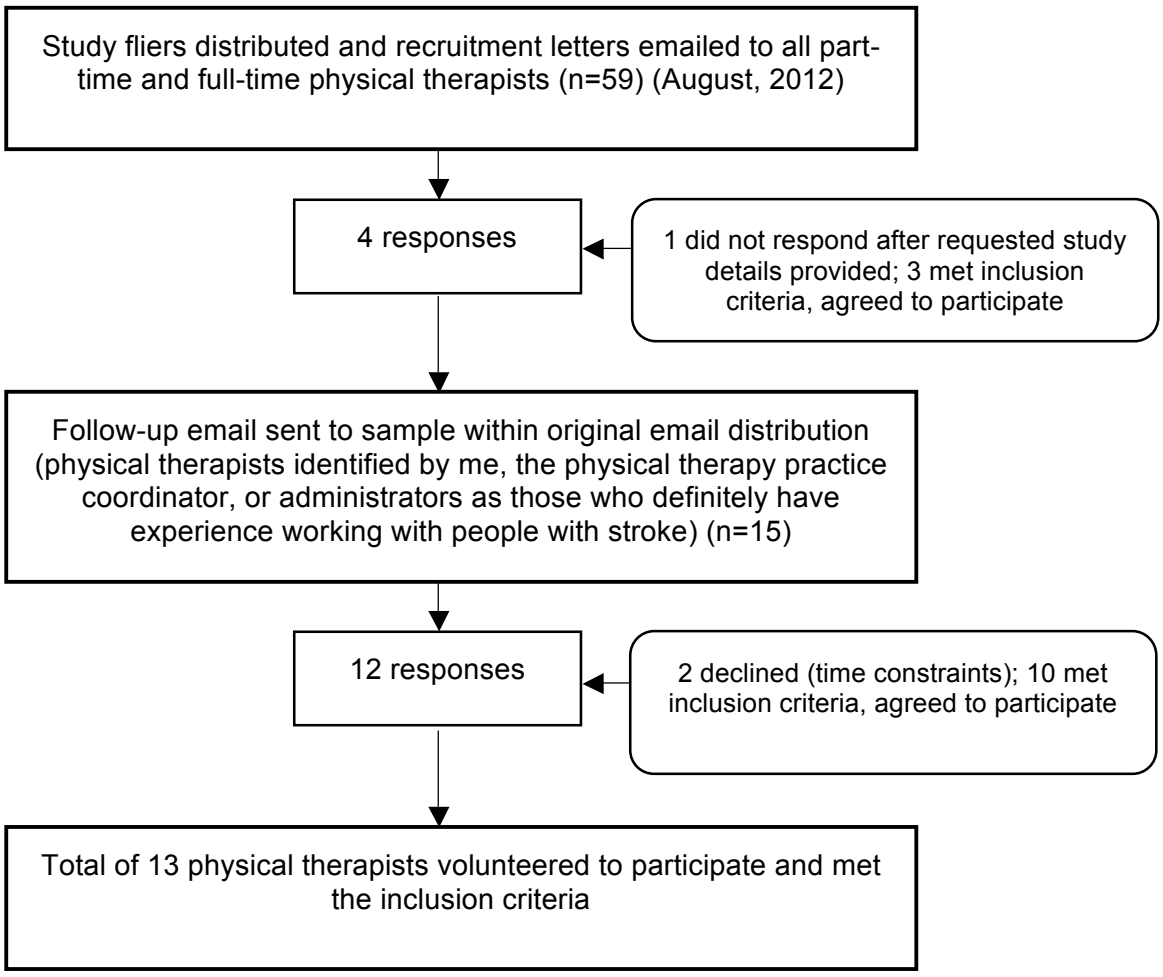
Participant Descriptions

Thirteen physical therapists participated in the study. Each completed a demographic data form that included: age, gender, educational attainment, American Physical Therapy Association and section membership, years of experience both as a physical therapist and working with stroke survivors, current and past practice settings (e.g., acute care, inpatient rehabilitation, sub-acute, outpatient, and home health), certifications, and continuing education (related to stroke, providing education, or communicating with patients/caregivers). For data analysis, descriptive statistics were calculated for the demographic data.

The sample included 10 females (77%) and 3 males (23%), with an average age of 36.6 years (range, 26-53 years) and an average of 9.9 years practicing (range, 1.5-27; standard deviation 8.3). All therapists were white. Therapists represented the following post-acute care settings: inpatient rehabilitation (n=5, 39%), outpatient (n=4, 31%), home health (n=2, 15%), and

Figure 3.1.

Flow Diagram of the Participant Recruitment Process and Results



float (n=2, 15%). Float therapists are therapists who “float” throughout all of the settings based on the staffing needs of the hospital. The terminal physical therapy degrees of participants varied: 3 with a bachelor degree (23%), 2 with a master (15%), 6 with a doctorate (46%), and 2 with a transitional doctorate (15%). The sample included 7 members of the American Physical Therapy Association (APTA), 2 of which were neurology section members within the APTA. No board certified specialists were represented in the sample. Participant characteristics are presented in Table 3.2.

Data Collection and Analysis

In addition to the demographic data collected, additional data collection sources and methods for analysis used in this study are described in the following sections and include: pre-interview reflection activities, one-on-one semi-structured interviews, and a structured assessment of the content of education provided by physical therapists.

Pre-Interview Activities

Pre-interview activities are suggested as a useful means of examining participants past experiences with the research topic (Ellis, Amjad, & Deng, 2011). The purposes of the pre-interview activities were to serve as an “ice-breaker” activity and to enable reflection about patient and caregiver education in their practice as a physical therapist prior to the interview. The pre-interview activities consisted of a guide (Table 3.3), which was developed and finalized following peer debriefing with an experienced qualitative researcher.

Table 3.2.

*Individual Participant Characteristics**

Participant	Current Practice Setting	Past Practice Setting(s)	Age (years)	Gender	Years Practicing	Years Experience with Stroke	Entry-Level Education	Post Entry-Level Education	APTA Member (Section member)
Zelda	Float	AC, IP, SA, OP, HH	45-54	Female	18.5	13	BSPT	MPT, t-DPT	Yes (Neurology)
Demetrius	Float	IP, OP	35-44	Male	13	3	MPT	None	No
Dan	IP	AC, SA, OP	45-54	Male	16	9.5	BSPT	None	No
Bertha	IP	N/A	25-34	Female	1.5	1.5	DPT	None	Yes
Ann	IP	N/A	25-34	Female	3	3	DPT	None	No
Elizabeth	IP	N/A	25-34	Female	2	2	DPT	None	Yes
Molly	IP	N/A	25-34	Female	2	2	DPT	None	Yes
Dee	OP	AC, IP, HH	35-44	Female	13	11	MPT	t-DPT	Yes (Neurology)
Sara	OP	IP	25-34	Female	10	10	MPT	None	No
Maggie	OP	N/A	25-34	Female	3.5	3.5	DPT	None	Yes
Jay	OP	N/A	25-34	Male	2	2	DPT	None	Yes
Abby	HH	AC, IP, SA, OP, Float	45-54	Female	27	15	BSPT	None	No
Mandy	HH	IP, OP	45-54	Female	18	18	BSPT	None	No

*AC=acute care, IP=inpatient rehabilitation, SA=sub-acute rehabilitation, OP=outpatient, HH=home health, BSPT=bachelor of physical therapy, MPT=master of physical therapy, DPT=doctor of physical therapy, t-DPT=transitional doctor of physical therapy

Table 3.3

Pre-Interview Reflection Guide

Please spend some time reflecting on patient and caregiver education in your practice as a physical therapist as it applies to stroke rehabilitation. To assist in this reflection, please answer the following questions and use as much or as little space as you need.

1) List any content areas you have educated stroke survivors and/or caregivers about.
2) What do you feel are the *3 most important areas of education* you provide to your *patients*?
3) What do you feel are the *3 most important areas of education* you provide to *caregivers*?
4) List *3 communication/education techniques* you use with your patients and/or caregivers.
5) Reflect on a time when patient and/or caregiver education went well. What, if anything, facilitated the education?
6) If there is a time when patient and/or caregiver education did not go well, what were the barriers involved?
7) List any *items*, *objects, or resources* you find useful in patient and caregiver education.

The guide included both closed- and open-ended questions related to various aspects of providing patient and caregiver education. The closed-ended questions (questions 1-4) were used to facilitate more concrete thinking about what education participants' provide and how they provide it. The open-ended questions (questions 5-6) were selected to support participants' abilities to recall stories related to providing education and later share them during the interview (Ellis, Amjad, & Deng, 2011). The seventh question enabled participants to list or gather any artifacts they found useful to provide education. Artifacts can include everyday objects, tools, and documents (Creswell, 2007; Norum, 2008). This method was included in this study to determine if participants found any objects (e.g., equipment, brochures/pamphlets) useful in providing education and to identify any objects or resources they wished were available to provide education.

The guide was provided to participants prior to the individual interviews. On average, participants received the pre-interview reflection questions 10.3 days (range, 1-36 days) prior to the interview. The variation in days was due to scheduling and shifting availabilities for the one-on-one interviews. Two of the 13 participants were unable to complete the pre-interview questions ahead of time. In these cases, the pre-interview questions were integrated into the interview guide for their on-on-one interviews. For analysis, the pre-interview reflection responses were collected, coded for meaningful units of data in the same manner as the interview analysis process, and the findings were compared with

the interview findings. The coding and interpretation process is described more in-depth in the next section.

Semi-Structured Individual Interviews

Following the pre-interview reflection activities, semi-structured individual interviews, with open-ended questions, were completed with each participant. Interviews were an essential data collection source as "the purpose of the qualitative research interview is to contribute to a body of knowledge that is conceptual and theoretical and is based on the meanings that… experiences hold for the interviewees" (Dicicio-Bloom & Crabtree, 2006, p.314). Interviews were conducted in an effort to "co-create meaning" (Dicicio-Bloom & Crabtree, 2006, p.316) with the participants of their perceptions and experiences of patient and caregiver education in stroke rehabilitation. Rubinstein (2002) best summarized the rationale for the use of interviews in this study: "Humans are meaning makers; meaning is identified through experience. Qualitative interviewing is one of the very best ways of coming to understand meaning through examining experience." (p.138). The interviews enabled exploration, through conversation, of the participants educational philosophy, their perceptions and experiences of providing education in terms of the preliminary RECAP constructs, and identification of any other constructs.

The interview guide was developed prior to the study. The guide, along with potential probes for additional information, was informed by previous research (section 2), by literature on the educational needs and experiences of stroke survivors and their caregivers, and by the constructs in the preliminary

RECAP model. Sample questions from the interview guide are provided in Table 3.4. The interviews also included questions related to the participants' pre-interview reflection responses and other questions that emerged from the dialogue between the participant and myself during the interview. The interview guide evolved iteratively over time as the data collection and data analysis occurred concurrently (Creswell, 2009). As data analysis was completed, interview questions were refined to better address the purpose of the study. For example, when a participant mentioned something I had not heard before and I determined the concept required further exploration with subsequent therapists, the interview guide was adjusted.

The interviews were conducted face-to-face and at locations based on participant preference, including: private offices or conference rooms at the hospital (n=11), local coffee shop (n=1), and a private conference room at a public library (n=1). The interviews lasted until the interview guide was completed. The interviews averaged 83.5 minutes in length (range, 53 to 141 minutes). As a result of the participants' availability, more than one interview session was sometimes required in order to complete the interview guide. The interview guide was completed in 1 session (n=3), 2 sessions (n=7), or 3 sessions (n=3).

Table 3.4

Sample Semi-Structured Interview Questions

1. Tell me about working with people with stroke and their caregivers.
2. What do you think the purpose of patient and caregiver education is?
3. Describe your experiences with patient and caregiver education (refer to case examples in the pre-interview reflection guide).
4. Please share your responses to the pre-interview guide questions 1 and 2 (most important areas of patient and caregiver education).
5. How do you decide what to educate about?
6. What do you have to do to prepare to educate patients and/or caregivers?
7. What role does the environment play in educating patients and/or caregivers?
8. How do you prefer to educate patients and caregivers? (review techniques and artifacts he/she listed in pre-interview reflection guide)
9. What factors influence how you educate?
10. How do you determine if patient and caregiver education was successful?
11. How did you learn how to educate patients and/or caregivers?
12. When do you educate patients and caregivers?
13. What factors influence when you educate?
14. What limits the ability to provide patient and caregiver education?
15. What supports would you need to optimize patient and caregiver education?

During each interview, I made field notes of commonalities and differences between therapists' perceptions and experiences, follow-up questions to ask, and preliminary thoughts about the potential meaning of the therapists' descriptions. Following each interview, I digitally recorded and then transcribed self-reflective memos (Creswell, 2007), including personal reactions to the interview, potential adjustments to the interview guide questions needed, and any actions required. The reflective memos also served to further clarify my impressions and thoughts about the interview or participant.

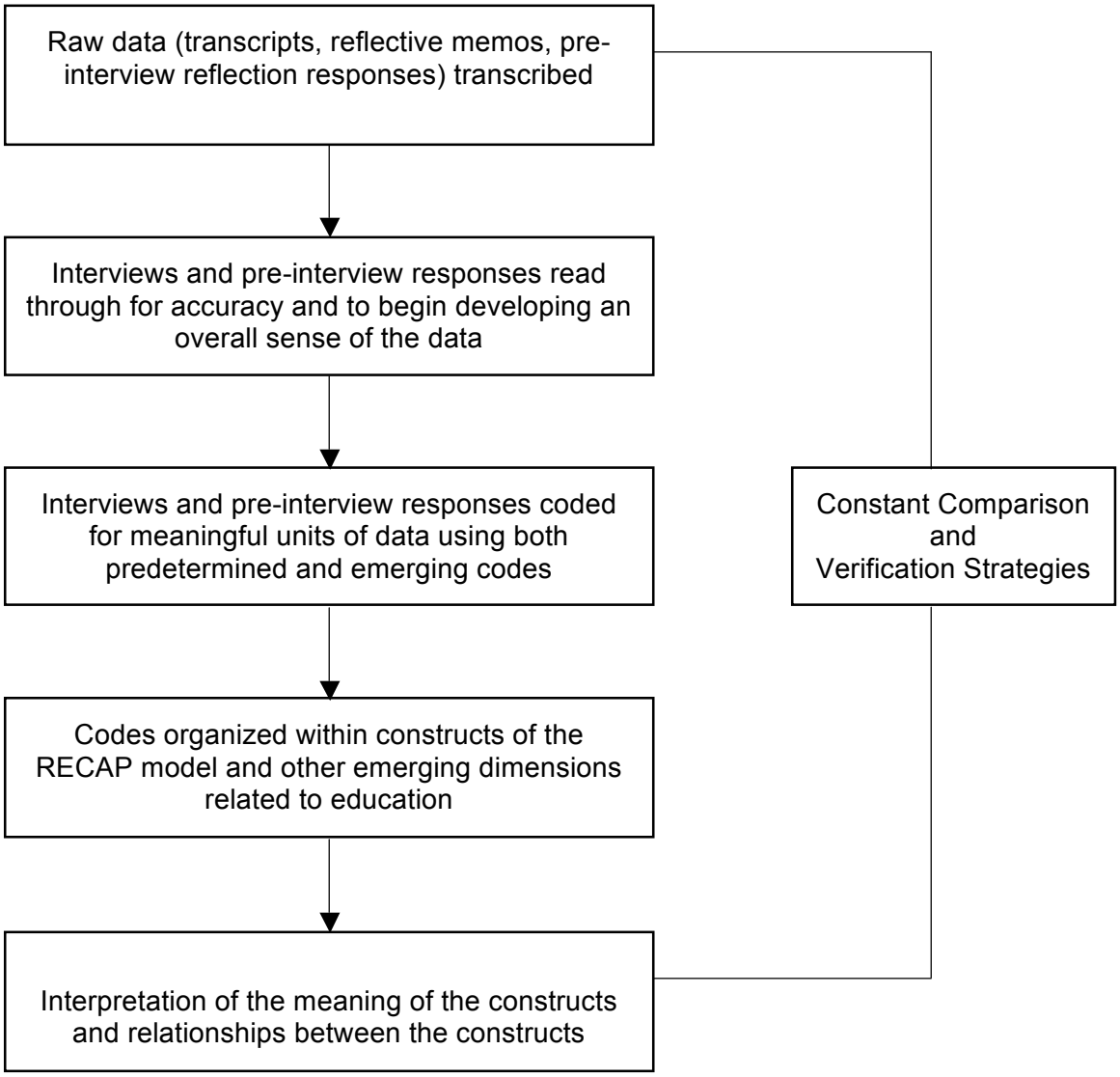
The interviews were recorded with a digital voice recorder and transcribed verbatim by a professional transcriptionist. There were a total of 333 pages of transcription for this study. The transcriptions per participant averaged 25.6 pages (range, 16-43). After each transcription was produced, I listened to each recording while checking the transcription for accuracy and to develop an initial overall sense of the data collected. I then reread through the transcripts and coded meaningful units of data line by line. Coding was completed electronically within the Microsoft Word documents of the transcripts by using multi-colored highlighting. Segments of text were coded through a "template approach" (Dicicio-Bloom & Crabtree, 2006, p. 40), in which the RECAP model served as the template by which "predetermined" or "prefigured" codes (Creswell, 2007 and 2009) were identified. Emerging codes (Creswell, 2009), or segments of text that did not fit the template but emerged and described other dimensions or ideas related to patient and caregiver education, were also coded. Analytic memos (Creswell, 2007), including questions, thoughts, possible interpretations of the

codes, potential theoretical constructs emerging, and relationships between constructs were typed in the margins of the transcripts using Microsoft Word comment functions.

During the data collection and analysis process, I employed a constant comparative method, central to grounded theory approaches (Mellion & Tovin, 2002), in which I constantly compared participants' data sets with each other and with the emerging theoretical constructs. I reflected on possible relationships and connections among the therapist's statements and similarities and differences to statements from the transcripts of previous participants. I electronically cut and pasted the codes from each of the 13 participants' transcripts into Microsoft Word documents, labeled by construct, and analyzed the data until the properties of each construct were defined. Constructs included dimensions within the preliminary RECAP model and other dimensions that emerged that related to education. The constructs were discussed through peer debriefing with an expert qualitative researcher to further clarify the findings and discuss relationships within the data. A flow diagram depicting a summary of the analysis process is in Figure 3.2. The verification strategies noted in the Figure are reviewed at the end of this chapter.

Figure 3.2

Flow Diagram of the Qualitative Analysis Process



Assessment of Content of Education Provided

To examine the content of education provided by physical therapists, I asked participants to provide a list of all content areas they provide education about to stroke survivors and/or caregivers (pre-interview reflection guide question 1; Table 3.3). In the original data collection plan, a card sorting technique was to be used, similar to that descrbied by Jahrami, Marnoch, & Gray (2009) with the exception that a closed sorting technique would be employed (predetermined piles in which to sort cards into). The therapist would sort the cards, individually labeled with content areas, into various piles to stimulate discussion during the interviews.

Prior to the study initiation, I created a "starting" list of content areas that stroke survivors and receivers wanted education about, based on a review of existing literature (e.g., topics in Table 1.1) and topics described by participants in Section 2). I combined this "starting point" list with that of the first study participant's list, to create an emerging "master list". I then labeled each individual content area on a 4" x 6" note card. The first study participant and I used the cards for discussion during the interview. The study participant was asked to sort the cards into piles five different times: ranking of importance, ranking of comfort level in educating about the topics, extent to which the therapist educates about each topic, when the topic should be educated about across the continuum of care, and if the topic should only or never be educated about by a physical therapist. Each card sorting involved discussion regarding the participant's thought processes.

As each new therapist volunteered for the study, his/her list of topics was added to the master list. Additional 4” x 6” note cards were created. The card sorting was completed during the interview with the second research participant. After trialing the card sorting for the second time and receiving content lists from a total of 5 study volunteers, the research design required modification in terms of this data collection source. The card sorting required extensive time during the interviews and was quickly becoming overwhelming to the participant, given the expanding master list of topics with which to sort 5 different times.

I examined the master list for patterns, which included my starting point list and the lists of the first five participants. Based on this examination and peer debriefing with an experienced qualitative researcher, nine domains of content topics were identified. The domains were discussed during an interview with the third research participant. Based on feedback from the third participant, adjustments were made. Table 3.5 depicts the evolution of the domains. The “neuroplasticity” domain was relabeled as “promoting optimal recovery”, to better capture the variety of topics within the domain and because of the intimidating nature of the term “neuroplasticity” to participants. Also based on the feedback of the third participant, the tenth and final domain of “healthcare continuum and team” was added. A chronological audit trail was developed depicting each of the 13 participants contributions to the master list. The final master list included 126 items, all of which fit the final 10 domains and were listed as “examples” within each domain.

Table 3.5

The Evolution of the Domains of Content

Original Domains that Emerged	Final List of Domains that Emerged
Stroke Knowledge	Stroke Knowledge
Functional Mobility	Functional Mobility
Equipment and Devices	Equipment and Devices
Safety and Precautions	Safety and Precautions
Neuroplasticity	Promoting Optimal Recovery
Psychological and Emotional Issues	Psychological and Emotional Issues
Community Reintegration	Community Reintegration
Advocacy	Advocacy
Institutional Support and Resources	Institutional Support and Resources
	Healthcare Continuum and Team

The original card sorting activities plan evolved into 4 structured questions, or fixed choice responses, to be completed by each participant, for each of the 10 domains (Britten, 1995). The 4 structured questions are provided in Table 3.6. A neutral option was not available in order to force a choice and prompt discussion. As such, the questions should not be considered vetted survey questions but rather, questions that prompted discussion to further develop the theory. Counts of the quantitative data from the structured questions are presented to highlight potential trends and general impressions but are not statistically relevant.

The therapists completed the questions during the interview in order to afford them the opportunity to ask clarifying questions and to share reflections about the domains or examples. Member checking was completed in that each participant was asked if the domains made sense, required relabeling, and if anything was missing. Descriptions of the domains and sample quotes from the participants are presented in Chapter 3.5, describing the content of education provided by physical therapists.

Verification Strategies

To establish trustworthiness of the findings, several methods for verification were used. As described by Morse et al. (2002), verification is “the process of checking, confirming, making sure, and being certain… mechanisms used during the process of research… ensuring… the rigor of a study” (p.e1) Lincoln and Guba (1985) described components of trustworthiness, including

Table 3.6

Structured Interview Questions for the Ten Content Domains

Domain Labeled Here
*Think about the domain "X" and circle your response(s) to the following questions. Examples of what is meant by "X" are provided below.**
1) How *important* is it to educate stroke survivors and caregivers about this?
Very Important Somewhat Important Not Very Important Not Important At All
2) How *comfortable* are you with providing education about this?
Very Comfortable Somewhat Comfortable Not Very Comfortable Not Comfortable At All
3) How much is this type of information covered with a stroke survivor and/or his/her caregiver?
Always Covered Usually Covered Sometimes Covered Never Covered
4) When *should* this type of education be provided to patients and/or caregivers? (can select one, more than one, or "all")
Acute Care Inpatient Rehab/Sub-Acute Outpatient Home Health All Settings

*Examples from the master list of 126 content items within domain "X" were provided here.

credibility and transferability. Verification strategies to address these concepts will be described in this section.

Credibility, or the extent to which the findings ring true, was addressed through triangulation and peer debriefing. Triangulation involved corroborating the findings through multiple data sources (e.g., multiple data collection sources, multiple participants) (Creswell, 2007). Peer debriefing involved a peer review process with an expert qualitative researcher. This occurred at multiple points throughout the study. The peer researcher served as a “devil’s advocate”, helped me modify the emerging research design and data collection processes as needed, challenged interpretations, and provided “opportunity for catharsis” (Creswell, 2007, p.208).

Transferability, or the extent to which the findings can be applied to other contexts or therapists, was also addressed by providing detailed descriptions of the primary research site and participants. It was addressed through purposive sampling in which therapists that differed in experience, demographics, and setting were purposefully recruited and encouraged to express their view.

Additional means of verification were used in this study. Transcripts were checked for accuracy to ensure accurate representations of the participants’ statements (Creswell, 2009). Analytic and reflective memos were used to cross-reference the codes and findings. A record of my thoughts and action processes was maintained to demonstrate how the research design and data collection processes evolved. I partook in reflexivity, or a process of self-examination, being self-conscious, and self-aware of the research and the researcher’s role

(Creswell, 2007). Reflexivity also involved the self-reflective memos previously described, to reflect on impressions of the participants, interviews, and emerging findings. Verification was also addressed through a comprehensive review of the literature related to patient and caregiver education in stroke rehabilitation and in physical therapy practice.

Summary of Findings

Ten constructs that described the phenomenon of RECAP by physical therapists in stroke rehabilitation were identified. Six constructs forming the core of the theory were identified and include: continual dynamic assessment and interaction, source (physical therapist), receiver (stroke survivor/caregiver), comprehensive content, delivery through teaching methods and communication, and the timing of education. These constructs form the fundamental core of educational interactions between the physical therapist and stroke survivor and/or caregiver in each encounter and over time along the post-acute care continuum. Four constructs that encompassed the core were identified and include: professional responsibility, multidisciplinary team, complex healthcare system, and the environmental and socio-cultural context. These constructs will be described in-depth in the remaining chapters of this section.

Chapter 3.2: Continual Dynamic Assessment and Interaction

A core construct of RECAP is the continual dynamic assessment and interaction between the physical therapist and receiver (stroke survivor and/or caregiver). RECAP was perceived as a collaboration between the therapist and the stroke survivor/caregiver, involving an interaction through which the therapist delivers content at a point in time. Therapists perceived that historically in healthcare, the practice of educating patients and caregivers consisted of a superior healthcare provider playing a "sage on the stage", imparting information to a receiver playing the role of a passive receptacle to be filled with information (*"I'm the teacher and I know it all, so just listen to me." –Demetrius*). They believe education in healthcare has shifted over time to an active, dynamic interaction between the therapist and receiver, in which the therapist takes into account who the receiver is, in terms of characteristics, values, and input, in order to tailor the education in meaningful ways (*I can't take my values, and my agenda, and my goals and push them on them because that's not what that family wants. –Mandy; It's not necessarily me doing it. It's us doing it together. –Dee).* "Tailored" education was perceived, therefore, as individualized education in which the therapist respects the receivers values, recognizes what is unique to each receiver, and delivers education accordingly (*What do they like to do? What makes their life meaningful? –Demetrius)*. Components of the continual dynamic assessments and interactions included assessments of who the receiver of education should be (stroke survivor and/or caregiver), educational needs, and the outcomes of education.

Selecting the Receiver

Therapists described assessing the need to provide education to the stroke survivor, caregiver, or both. Therapists rarely decided to only educate the stroke survivor and this typically only occurred when there was no caregiver involved at all because therapists perceived caregivers as vital recipients of education (*it's critical… if you don't have the caregiver buying in, you're sunk… if [the caregivers] go, everyone's gone –Abby)*. The caregiver was selected as a primary receiver of education, over the stroke survivor, when the stroke survivor had difficulty understanding due to cognitive or communicative deficits or had poor memory.

Therapists described decision-making to intentionally educate the stroke survivor and caregiver separately or together. For example, some therapists purposely provided some education separately when the stroke survivor had cognitive deficits, unrealistic expectations, or agitation or when there was tension within the inter-receiver relationship. Some therapists described purposely educating the stroke survivor and caregiver together when educating about prognosis, anticipated duration of therapy services, and discharge plans because they wanted to ensure that both receivers were being provided the same information and could process the information together. Overall, therapists preferred that dynamic educational interactions occurred with the stroke survivor and caregiver together whenever possible *"so that nothing gets lost in translation… it's better to have two brains there than one" (Dee)*.

Identification of Educational Needs

The dynamic assessment included identification of educational needs through multiple methods. Therapist-initiated methods included asking questions, identifying impairments and activity limitations, external prompts, or consultation with other members of the multidisciplinary team. Asking questions involved a question-answer interview format and was a main component of initial evaluations, therapy sessions, reassessments, discharge evaluations, and informally outside of scheduled sessions. Questions were based on therapists' perceptions of educational priorities in a given healthcare setting and directed at revealing information unique to the receiver (*What do you need to do when you go home?... Are there any concerns that you have? –Zelda).* Asking questions was perceived to be useful for identifying educational needs about topics receivers might be uncomfortable to initiate discussion about (e.g. depression).

Participants described observing the stroke survivor's physical impairments and activity limitations to identify educational needs and enable a dynamic educational interaction. Through both observation and examination of physical functioning and abilities, such as the framework by Scheets, Sahrmann, and Norton (1999) that Dee mentioned, therapists identified deficits and provided subsequent education (e.g., about the residual deficits of the stroke, potential treatment interventions, how secondary complications could occur if the impairments were not addressed).

Documentation systems, the use of outcome measures, and telehealth monitoring systems were three external prompts by which therapists identified

educational needs. Documentation systems provided prompts to provide education about topics that required mandatory documentation (e.g., safety, pain, medications). The use of standardized outcome measures provided therapists with a means of identifying impairments, activity limitations, and participation restrictions; the presence of which triggered therapists to provide education (*those objective measures, either improvements, or plateaus, or digressions clue me in as to… what information I provide –Jay).* Lastly, the telehealth monitoring system in home health, which can be used by stroke survivors to monitor weight, blood pressure, glucose levels, and oxygen saturation from home, facilitated identification of educational needs and subsequent educational interactions.

Therapists identified educational needs through consultation with other members of the multidisciplinary team caring for the stroke survivor. Therapists described gaining information through conversations with other professionals about educational needs that physical therapy could best address. Consultation also occurred more formally through weekly team conferences in which the health care team would review the stroke survivor's progress, goals, and estimated length of stay. During these conferences, members of the team would inform each other of educational needs to be addressed by a specific discipline.

Receiver-initiated methods, such as the stroke survivor or caregiver asking the therapist a question or directly stating the need for information, facilitated dynamic interactions because therapists had a direct indication as to what education was needed (e.g. when a stroke survivor asked Elizabeth if a walker would be needed at home, she was prompted to educate about

prognosis, current functional abilities, safety, and equipment needs). Unfortunately, receiver-initiated methods were far less common than therapist-intitiated and therapists wished receivers asked more questions to guide the education needed. Therapists speculated that the reasons for the rarity of receiver-initiated questions or statements were the shock of stroke (e.g., in the inpatient phase), new exposure to the healthcare system and settings, personal discomfort with the topic, reluctance to ask for help, not knowing what to ask (*they typically don't have a clue what they want to see –Dan),* or purposely not wanting the therapist to know there is a need for education (*none of them want to tell you what the problem is [once they're home] because then you might say 'You're not safe to be there' –Abby).*

Therapists acknowledged the potential for educational needs to go unidentified and for opportunities for dynamic educational interactions to be missed. The therapists could not directly speak to this because only the receivers of education could attest to educational needs that went unidentified. Therapists, however, did share speculations as to the reasons why educational needs may go unidentified, such as the assumption that the receiver was already educated about something by another source (*things tend to slip through the cracks sometimes… we thought someone else would address it, but we didn't and they didn't –Abby)*.

The Outcomes of Education

Therapists in this study described the continual assessment of the outcomes of educational interactions. Therapists typically repeated the

assessments both immediately following the education and at a point later in time to ensure long-term consolidation of the information. Methods for assessing the outcomes and effectiveness of education included receiver feedback, perceived level of motivation, willingness to participate, and frame of mind, return-demonstrations, improvements in functional mobility over time, and actions taken by the receiver.

Therapists used both verbal and non-verbal receiver feedback as one means of assessing the outcomes of education. Therapists asked clarifying and probing open-ended questions to determine the receivers understanding of the education and if delivery methods were useful and effective. The questions from receivers also indicated if reinforcement of education was required. Therapists also assessed non-verbal cues from the receiver (e.g., facial expressions, posture, body language). The perceived level of motivation and willingness to participate in therapy was viewed as a potential indicator of the receivers “buy-in” and successful education. If the receiver seemed more hands-off, stopped asking questions, or seemed overwhelmed, stressed, or confused, the therapist recognized that more education or adjustments to education needed to occur.

Therapists assessed the outcomes of education about physical tasks (e.g., functional mobility, exercises) through observation of return-demonstrations from the receivers. The therapist looked for understanding and integration of the education as conveyed through action or performance of the receiver. If a receiver was able to demonstrate a skill properly and safely then this indicated understanding of the education the therapist had provided. If the skills were not

performed properly, the therapist provided additional education and opportunities for practice. Therapists observed changes in functional mobility and safety over time as an indicator of the outcomes of education as well. If a stroke survivor began to have less falls or demonstrated improved functional capacity, therapists interpreted this as education that was successfully carrying over into the home. Therapists perceived plateaus, regressions, or safety incidents as potential indicators for reassessment of educational needs (*when they come back a week later… with a broken hip… something wasn't ideal –Zelda)*.

Home health therapists assessed the effectiveness of education about safety and necessary home modifications by observing the home environment. After providing education, the therapist would return and observe if the changes were made (*remove the rugs, come back and they might be moved right back* – Abby). If changes were not made, therapists would be cued to provide follow-up education.

Therapists noted that it could be very difficult and challenging to assess the effectiveness of education.

> *You can educate all you want, but how do you know that it worked?... It's hard to know for sure… there may be times where you think you did a bang-up job and you did great and they walk away and don't remember half of it. –Zelda*

Assessing the outcomes of education was difficult for inpatient therapists because frequently they did not know what happened to the stroke survivors and caregivers once they discharged from the inpatient setting. It was also challenging for outpatient therapists who were confined to the outpatient clinic and unable to observe the stroke survivor in the home or community. While

assessment of education effectiveness about functional mobility was fairly straightforward (e.g., return-demonstrations), assessment of other content areas was more challenging. For example, participants reported not knowing any outcome measures or means to assess stroke knowledge. While receiver feedback was valuable, it was not always a "fail-proof" method of assessment.

> *I don't really recall anybody ever telling me that they didn't understand… I know that there has been several times when I'm sure [the caregiver] didn't understand what I was saying… I think they just are too proud to say that they don't understand… a lot of them are in a hurry and they don't want to be here any longer than they have to and they know if they tell you they don't understand that you're going to have to slow down and start over and they just want to get out of here. –Molly*

Optimal Result of Educational Interactions

Therapists perceived that the optimal outcome of the continual dynamic assessments and educational interactions was an empowered, motivated, and engaged receiver who puts education into action to facilitate an optimal recovery and reconstruction of a self-identity post-stroke. Stroke survivors and caregivers had a *"need to know"* (Zelda) in order to live life post-stroke (e.g., know what happened, why, the residual deficits, the prognosis, how to facilitate recovery, and how to manage post-stroke). Perhaps not surprisingly, several therapists believed the purpose of RECAP was that the receiver would "know". Therapists believed that education equipped receivers with the tools (knowledge/information) that they needed in order to be empowered, motivated, and engaged to optimize recovery and reconstruct a self-identity.

The physical therapists had limited amounts of time with stroke survivors and caregivers. As such, a goal of education was to empower by enabling receivers to self-manage in the absence of the physical therapist. Dan described

attempting to convey to receivers, *"I'm not a 'super-therapist', if I can do this, you can do this"*. Optimal self-management involves the receivers guiding and directing their own recovery and rehabilitation by making the best decisions and choices and focusing their energy and efforts in the best ways possible. Empowered self-management was perceived as critical to receivers reaching goals and optimizing recovery (e.g., improved safety and avoidance of injury with functional mobility for both the stroke survivor and caregiver, improved home safety, optimal relearning of movement, maximal independence for the stroke survivor, prevention of future strokes, prevention of secondary complications, community reintegration).

In addition to empowerment, an outcome of education was to motivate receivers. Therapists perceived improved self-confidence in receivers following education and this boost in confidence seemed to motivate receivers to participate and be more driven in therapy. Education that fostered self-confidence and was encouraging seemed to motivate receivers to be more willing to attempt challenging tasks to optimize recovery *([education] really helps… in their compliance and their willingness to participate with you… how willing they are to try different things with you, things that they might be a little hesitant to try" –Bertha).* Education was also used to motivate in that it provided the receiver with the knowledge of what was possible (*education gives them the future… of what we have seen… a sense of predictability –Jay; realistic timeframes of where you want to get to with each level of care -Demetrius)*.

Another purpose of education was to engage receivers in their recovery and in rehabilitation. Education was perceived to support the receivers' investment in their own recovery and actively engaged them in the rehabilitation process. Stroke recovery is typically a long journey and education was a means of keeping receivers engaged over the long haul by getting them to "buy-in" and carry-over what was focused on in therapy into their daily lives and routines.

In addition to the goal of optimizing recovery through empowerment, motivation, and engagement, another goal of education was to facilitate reconstruction of a receiver's self-identity. Therapists believed that the receivers' ability to transition to living a life post-stroke frequently required reconstruction of a self-identity. As Abby described it, the aim of education was to help receivers be able to live out the rest of their lives with what had happened because in most cases, stroke survivors lived with some residual deficits that never fully resolved and caregivers always had some level of caregiving to provide. Sara shared this description of education to facilitate reconstruction of a self-identity:

> *People always say, "I can't walk." "Well, you are walking. You're just using a walker… You can't compare yourself to who you were because you're a different person now. You've got a whole different set of goals now. It's a whole different life. It's like your second life… like you've been reincarnated… You're still able to do and live your life, it's just not at the level that it was before… to understand that "I'm going to get better, but I'm not going to be the way I was before, but I'm going to come to grips with it… I'm going to be the best that I can be at where I am." –Sara*

Chapter 3.3: Receiver Factors

The second core construct is defined as receiver-related factors that influence patient and caregiver education. Therapists described their perceptions of the influence of receiver demographics, readiness and ability to learn, and caregiver-specific factors. These three domains, and the concepts within each, are depicted in Figure 3.3 and described further in the next sections.

Demographics

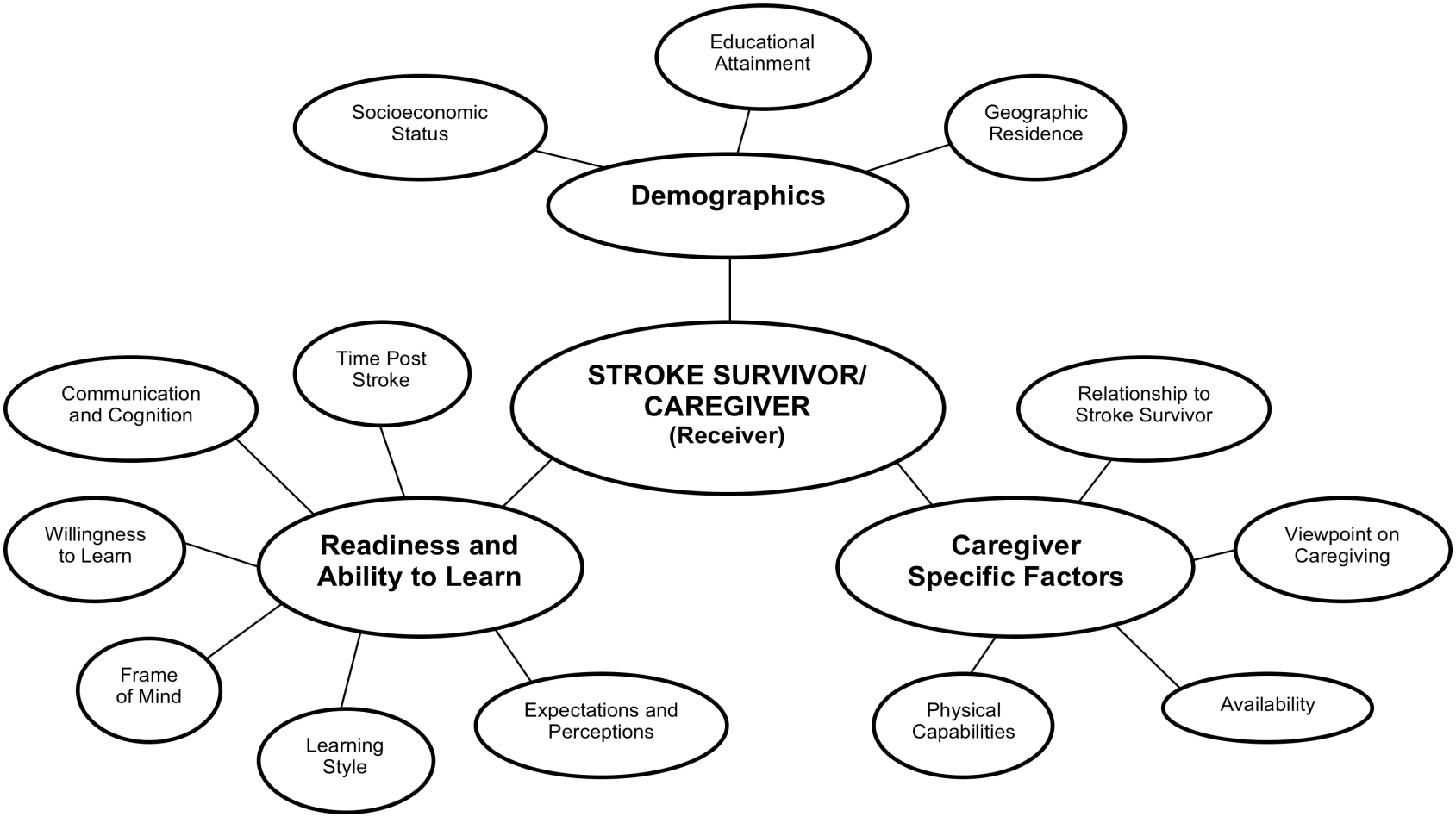
Therapists described how the following demographics of the stroke survivor and/or caregiver influenced education: age, socioeconomic status, educational attainment, and geographic residence.

Age

Therapists described how the age of the receiver influenced the content and delivery education. In regards to content, therapists described how some older stroke survivors did not seem to want education about stroke prevention because strokes were viewed as a natural part of life and aging ("*I'm elderly, so strokes happen" –Dan).* Therapists described continued efforts to educate about healthy lifestyle changes needed for some stroke survivors but noted that these educational efforts and positive outcomes were challenging for older stroke survivors with decades-long poor health habits. Elizabeth described shifting the content of intervention education from recovery to compensatory strategies for some older stroke survivors who had had multiple strokes. Whereas with a younger stroke survivor, education included *"You're young. You want to recover, recovery versus compensation" (Elizabeth).* Some therapists described the

Figure 3.3.

Receiver Factors that Influence Patient and Caregiver Education



perception that younger stroke survivors needed more education about return to recreational activities and vocational rehabilitation referrals than older stroke survivors. Some therapists perceived that older stroke survivors did not need education about sexuality post-stroke.

Therapists described how the age of the receiver influenced delivery of education due to varied learning styles and communication preferences in older versus younger receivers. Sara observed differences in learning styles based on age of the receiver and commented that her older stroke survivors seemed to respond better to written handouts rather than verbal education (*they just want paper, I really feel like they want to hold paper and look at it)*. Regarding communication style preferences, some therapists described perceiving older receivers as being accustomed to *"the medical establishment as authoritarian" (Zelda)* while younger receivers were *"more proactive in their care and need to know" (Zelda)*. When working with older stroke survivors who viewed healthcare providers as authoritative and superior, therapists described not relying on receiver-initiated means to identify educational needs and altering their communication styles to be more direct and authoritative.

Socioeconomic Status

Therapists described how low socioeconomic status influenced the education provided and was a barrier to positive educational outcomes in several ways. When receivers were stressed and overwhelmed about the financial burden associated with stroke (e.g., medical costs, unemployment), it seemed challenging for them to absorb education provided. Outpatient therapists

described transportation issues that would arise for those with a lower socioeconomic status. In these situations, receivers frequently had to miss their outpatient appointments, limiting the amount of time therapists had to provide education.

Home health therapists described the frequent need for education about how to make homes for those with low socioeconomic status safe and habitable. The content of education about equipment and home modifications needed, however, was dictated by what the receivers could afford. Mandy, a home health therapist, described the correlation she observed between low socioeconomic status and poor caregiver or family support in many cases. She described how some families with financial strains seemed resistant to education about appropriate care needed for stroke survivors (e.g., the need for 24 hour supervision or a skilled nursing facility placement). The situation was compounded when the families were unwilling to be caregivers and receive education about how to assist the stroke survivors to function safely in their homes and stroke survivors were unable to afford hired caregivers.

> *Finances … has a huge part… I see families that the children, who are adults, are fighting to keep Mom or Dad out of the nursing home because they don't want the funds to be depleted, but yet not willing to come in and help. –Mandy*

Educational Attainment

The receivers' level of educational attainment and literacy influenced the content and delivery of education. In regards to content, Mandy described the need to provide additional education about safety and prevention of secondary complications to those with lower levels of education.

> *I'm dealing with some pretty… educationally depressed people who just don't get… that "This is so unsafe for your dad to be laying in urine and, he can't get to the bedside commode because you have it across the room." –Mandy*

Type and level of educational attainment also influenced the delivery of education, in terms of communication style and language used. For receivers who were medical professionals (e.g., physician, nurse), therapists described using more medical terminology and providing more detailed education about what the therapist was assessing or about the intervention.

> *If someone's a nurse, I may say a little more medical jargon… 'Cause it's a language that healthcare professionals may understand even better than layman terms. –Jay*

Literacy influenced the delivery of education. For those with lower literacy levels, therapists provided more pictures or demonstrations instead of written materials. Maggie shared the importance of assessing literacy because she mistakenly assumed one of her patients, a high school graduate, could read. She provided him with detailed written instructions and found out later that he could not read. To assess literacy, Jay described asking the receiver if they preferred written instructions, pictures, or other visual aids so that an illiterate receiver would be able to express a preference without feeling embarrassed. None of the therapists discussed health literacy versus literacy and some conveyed the assumption that a high level of educational attainment equated to a high level of health literacy.

Geographic Residence

Approximately half of the inpatient population at the research site comes from a rural area, up to several hours away. Some stroke survivors from rural areas continue to receive home health and/or outpatient services from the

research site upon discharge from inpatient rehabilitation. Given the range of geographic residency of stroke survivors and caregivers, therapists were able to describe how this factor influenced education. Therapists described the following characteristics they associated with geographic residence that influenced education: pre-stroke knowledge, health habits, communication delivery, environmental considerations (e.g., geographic barriers, home designs), access to resources, and the nature of support. Each of these will be described in this section.

Pre-Stroke Knowledge. One therapist described her perception of the differences between rural and urban receivers' pre-stroke knowledge. She perceived that some rural receivers had less understanding about the healthcare system, what the goals are in each setting, services offered in each setting, and the nature of the "long-term" recovery process following stroke. When she works with stroke survivors and caregivers from rural areas, therefore, she makes sure to include education about the overall healthcare system, differences between settings, what can be expected in terms of recovery and prognosis, and what the next steps are upon discharge from the inpatient setting.

Health Habits. Therapists described perceiving a difference in health habits between urban and rural receivers. Therapists described poor health habits of many of their rural stroke survivors and caregivers, particularly in regards to smoking *(everybody in their family smokes. "We all smoke. We all hang out on the porch and smoke." –Sara)* and nutrition ("*My grandmother lived to 95 and she ate biscuits and gravy every day." -Mandy)*. The degree to which

these habits were a part of the culture seemed to influence the receivers' receptivity to the education and their willingness or ability to integrate healthy lifestyle changes educated about.

> *"Is [smoking cessation] something you could keep up at home?" … "No. My wife, and my brother, and my sons, they all smoke and they'd be blowing it my face." –Zelda*

Communication Delivery. Therapists described how geographic residence influenced the delivery of education in terms of communication. A few therapists commented on occasional language differences such as when Demetrius asked me: *"Yeah, like 'leaders'. Have you ever heard anybody [from a rural area] use the term 'leaders' to talk about 'muscles'?"* Some therapists perceived a difference in rural versus urban residents' preferences for communication style from healthcare providers. These therapists, therefore, adjusted their communication style when delivering education. Molly, who was from a rural region, was able to describe the differences in how she communicates with rural versus urban residents.

> *'Cause I'm from there… I slip into how I know to talk to them… like they're family, you've known them for years… more lighthearted… like you're just old friends… I think they take that better. –Molly*

When providers did use a more direct, authoritative communication style, Molly described the negative impact this had on how the receivers perceived the education.

> *I've worked with… people… from rural areas [who] have worked with some other therapists and have taken offense to some of… the methods used to teach them… They just don't take… firm and more direct instructions. They… take that as you're being… rude… that they were being talked down to… that they were stupid and didn't know what they were supposed to do… and they just are taken aback by that, and they don't really take that well. –Molly*

Environmental Considerations. Therapists also considered environmental issues when educating those from rural versus urban areas. Some rural residents had environmental barriers to integrating exercise and activity (e.g., no sidewalks, gravel driveways). For these receivers, therapists described attempts to adjust the education provided about exercise and activity.

> *A couple times a week go to… a Walmart… and make that their walking path… versus the people that live in the subdivisions here in the city. They've got the sidewalks and they may have a local park with a bike trail and a walk trail. –Dee*

The rural environment also impacted education about safety. Molly described obtaining more detailed home assessments (e.g., accessibility, gravel driveways, style of stairs) and then educating about options for safely entering and exiting the home. Abby described different safety recommendations she sometimes had to provide for rural versus urban dwellers (e.g., what needs to be in place in case the rural stroke survivor falls outdoors and does not have any neighbors living nearby). Lastly, the outdoor environment and the social activities that occurred in those environments sometimes warranted additional safety education to be provided.

> *They might want to go out and get back on the four-wheeler right away or get back on their tractor right away… have to be a lot more specific about do's and don'ts, and things that aren't safe. -Bertha*

Access to Resources. Therapists were quick to note the lack of or limited access to healthcare and community resources in rural settings and the impact this had on education. Therapists described providing more education and different recommendations to those being discharged to a rural setting. Therapists described providing education to receivers about the differences

between providers (e.g., orthopedic versus neurologic specialists) and the need to find providers who work with people with stroke when they transition to the next setting (e.g., home health or outpatient).

> *I push them more to advocate for themselves… [If] they're working with healthcare professionals who aren't as familiar with strokes… go somewhere to try to find therapists that… do have some neuro background. –Ann*

Mandy described how this was not possible for some rural residents because they would have to travel several hours to get to providers who specialize in neurological rehabilitation (*there's orthopedic outpatient, but there's no neuro rehab anywhere*). Due to the possibility of limited or no access to continued rehabilitation in their rural communities, Ann described feeling compelled to:

> *wrap up [everything in terms of education needed] as if they're never going to see another therapist again 'cause sometimes they'll call months later and they still haven't gotten a home health therapist to come see them. –Ann*

Inpatient therapists described attempts to provide rural residents with education about possible equipment needs, expanded home exercise program education, and information about how to optimize recovery on their own.

A home health therapist described the lack of local support groups for rural residents and how *"being a town or two away"* could be enough of a geographical barrier to prevent rural receivers from traveling to a city that does have a support group. In these cases, the home health therapist provided education about any local senior citizen groups that could serve as an "unofficial support group". Overall, the lack of available resources in rural settings was a barrier to education in that therapists felt they had to overload receivers with content on the front end (e.g., early in the rehabilitation phase, sub-acute phase

of stroke) and were unable to identify educational needs and provide subsequent content at time points in the chronic phase.

Nature of Support. Therapists described their perceptions of the differences in the nature of support for rural versus urban receivers and how these influenced education. Some therapists described their perception of rural families in which the patriarch of the family had always been taken care of by the family.

> *He was like that before [the stroke]… when he sat down in the chair when he came home from work, his girls took his shoes off for him, his wife brought him a drink. He never moved a muscle once he was home. –Dee*

Therapists described the tendency for these rural caregivers to provide too much support and assistance to the stroke survivor.

> *Overprotective family members who just can't stand to see their family member have to work hard at something… it's hard for them to see someone struggle… and why don't we just baby them, and take care of them, and do it all for Mama? –Zelda*

The nature of this support observed in some rural families prompted education about how to optimize recovery (e.g., education about trying to be as independent and doing as much for oneself as possible).

Therapists also described the influence of the different natures of community support within and across rural and urban areas. Abby described this in saying, *"how [rural residents] get support, how they look for support, how tolerant they are of support is very different".* Some rural receivers had great community supports in place, more so than urban dwellers (*the neighbors looking after [neighbors] –Abby)*. Abby described working with some stroke survivors in urban apartment complexes that did not feel comfortable asking their neighbors

for any support or assistance in contrast to the "neighbors looking after neighbors" culture of rural settings ('*Everybody in my building… all we do is say 'hi' at the mailbox… I could never ask my neighbor to do anything for me' –Abby).* The nature of support for the receiver within the context of their rural or urban environment, influenced what education was provided (e.g., safety recommendations).

Readiness and Ability to Learn

Therapists described their perceptions that the readiness and ability of the stroke survivor and/or caregiver to learn influenced education. Therapists described the following influential factors related to this: communication and cognition of the stroke survivor, learning style, frame of mind, willingness to learn, expectations and perceptions, and time post-stroke. Each of these is described in greater depth in this section.

Communication and Cognition

Therapists described how cognitive and communication deficits in stroke survivors influenced educational interactions in terms of content, timing, and delivery. These deficits were contributing reasons as to why therapists' perceived education in the stroke population required specialized skills. Presentations of deficits were varied in depth and breadth.

> *It's not very black and white for stroke… you get all spectrums… some that are hardly awake during your session… some that don't need speech [therapy] and are totally with it. –Bertha*

For stroke survivors with memory deficits, therapists provided education about progress made to-date because *"people do not remember… where they were and how far they've come" (Zelda)*. Zelda described having these

individuals use a recovery journal as an educational tool to track progress and write goals in. Therapists also provided education more repetitiously because of the memory deficits. For those with impaired attention, or distractibility, therapists considered the environment to best provide education in (e.g., avoiding crowded gym areas) and limited the amount of content provided.

Therapists considered the general cognitive level of the stroke survivor in terms of the person's *"insights and understanding"* (Bertha). What the stroke survivor could comprehend impacted the type and amount of content (e.g., the source may provide less information and involve the caregiver more for those with cognitive deficits). Therapists described starting with the simple and progressing to the complex. For example, Elizabeth selected simpler tasks to educate about and then progressed to more challenging, complex tasks.

The location of the stroke in regards to the right or left hemisphere was an influential factor on education due to cognitive and communication deficit differences between lesions in different hemispheres. Stroke survivors who had right hemisphere lesions were sometimes referred to as *"left hemi's"*, or as having left-sided hemiplegia (weakness). These individuals typically presented with decreased safety awareness, impaired judgment, decreased awareness of deficits, and impulsivity. As such, therapists provided more education about safety and precaution, in general and with functional mobility. Stroke survivors with left hemisphere lesions, or *"right hemi's"* with right hemiplegia, frequently presented with communication deficits, such as expressive, receptive, or global aphasia. Effective education to receivers with aphasia required extra

communication time; therefore, therapists prioritized content more and focused on only what was most important to educate about at a given time. Zelda described altering her methods and style of communication to include better non-verbal communication cues and a more supportive and encouraging style:

> A *lot of times with aphasia, they pick up so much on body language and on facial expression if they don't understand… just being positive, and hopeful, and encouraging goes a long way. –Zelda*

Learning Style

Therapists described perceptions of the influence of the receivers' preferred learning style (e.g., visual, verbal, written, or tactile methods) on their ability to learn information provided through different delivery methods. Therapists described how some preferred learning styles of receivers could be detrimental to education about certain topics. For example, learning how to assist the stroke survivor with functional mobility was difficult for caregivers who preferred to learn through verbal (e.g., hearing the education) or visual (e.g., watching the therapist demonstrate) methods only and were reluctant or resistant to tactile methods (e.g., "hands-on" practice). Therapists described the need for more time and effort to provide education to "hands-off" caregivers

> *Sometimes you have to really pull them in and get them comfortable with taking on that caregiver role… a lot of… family members aren't comfortable doing that… so you have to really take, 15 or 20 minutes trying to get them comfortable even touching their family member to do a transfer, assisting with gait. –Molly*

Demetrius described a situation in which the caregiver insisted she understood all of the education following verbal and demonstration delivery. She declined to provide any return-demonstrations and unfortunately the stroke survivor fell when she attempted to transfer him at home. Hands-on practice may not have

prevented the fall but Demetrius believed it would have helped identify any areas in need of additional education to improve safety. Overall, therapists perceived that education was facilitated when caregivers were hands-on learners and had *"a willingness to jump in there and say, "I'm going to try this, show me how to do it, and I want to get in there and try it myself" (Demetrius)*.

The therapist's preferred teaching method did not always match the receiver's preferred learning style. Molly described how she had to adjust her teaching method in these situations:

> *I prefer doing demonstration… try to start demonstrating and [the caregiver is] a little antsy to just go ahead and try it or they're not really paying attention to your demonstration and they want to just go ahead and get hands-on…then I'll let them go ahead but then I'll try to slow them down and really give them slow verbal instructions and critique them as they're going verbally. –Molly*

Therapists also had to sometimes adjust teaching methods between the stroke survivor and caregiver if each of them had a different learning style.

Due to the influence of learning styles, some therapists described reflecting about *"How does this person learn best?" (Demetrius)* prior to determining how to deliver the education. Ann described taking into consideration learning style regardless of educational attainment:

> *[I] get a sense of how capable somebody is of learning something regardless of their education level… might get somebody that's a Ph.D. and they're just not going to get some things, and you have other people that have done more hands-on caregiver stuff that are more capable. – Ann*

Assessing learning style could be challenging. Therapists could directly ask some receivers what their preferred learning style was because they had *"good insight into… how they learn, what they like to learn, what they're willing to learn"*

(Abby). Other receivers, however, *"don't have that insight… they don't know how to articulate what they need" (Abby).*

Frame of Mind

Therapists described considering the receivers' frame of mind on their ability or readiness to learn and subsequently, what and how much education the receiver could *"handle"* (Dan). Frame of mind was an influential factor because therapists perceived that receivers were not receptive to education or had difficulty processing education if they were overwhelmed, upset, depressed, or anxious. Therapists described the prevalence of depression post-stroke and how it was particularly challenging for stroke survivors and caregivers to receive education when they were *"just depressed and [felt] like giving up" (Dee)*. Depression could negatively impact the outcomes of education because *"if they're depressed, they're not going to progress in therapy, it just doesn't work… they realize they can't do it how they used to and then it's just this big downward spiral" (Sara).*

Therapists described specific time points in which receivers were frequently overwhelmed and education was challenging. These included early in the inpatient phase when stroke survivors were in shock at what had happened or were not recovering as quickly as they had hoped and during inpatient "family teaching days" (a delivery method described in Chapter 3.6), in which caregivers were sometimes overwhelmed at having to miss work in order to attend the educational session or due to the large amount of information provided in a short time span. Mandy described that returning home upon discharge from inpatient

rehabilitation was another time point in which receivers were frequently overwhelmed.

Therapists described attempts to assess the receivers' frame of mind and emotional states (e.g., are receivers' overwhelmed, upset, depressed, anxious) prior to providing education, through conversations with the receivers:

> *The first thing is assess the situation… get to know everybody that's in the room, chat a minute to see… "Are they ready to learn? … [are they] just too emotional and feel like this is too big for them?" –Elizabeth*

and observations of the receivers' non-verbal cues:

> *If they're calm, and they're receptive… you can tell that… things are sinking in and they're asking well thought out questions, then you can really feel like they're ready for information. –Elizabeth*

Molly described how she gauges the receivers' level of engagement as a sign of their frame of mind (*some people are… really overwhelmed … they stop engaging with you after a point).* In any situation in which the receiver did not seem to be in the right frame of mind to learn, therapists would limit the amount of content provided, limit content to only what was absolutely necessary, adjust the delivery style, and/or consider more optimal times to provide education.

Willingness to Learn

Therapists described perceptions of a range of willingness to learn and receptivity to education in stroke survivors and caregivers and how these influenced education provided. Some receivers seemed: *ready to receive the information… really receptive (Elizabeth), very interested, very open-eared… to try absorbing as much as they possibly can (Jay),* and *very excited about knowing what it is that they need to be doing to help themselves (Maggie).* Providing education in these situations was easier for therapists, educational

interactions were viewed positively, and therapists perceived better outcomes from the education.

> *The number one thing is that [the family is] willing to really listen to you and that they respect you as someone that knows what they're talking about and they don't think that they know better or that what you're saying isn't the right thing… willing to listen to you. –Molly*

Other receivers seemed less willing to receive education or did not seem interested in the education. Some therapists perceived this in receivers who did not or could not acknowledge that the stroke had happened, had caused profound deficits, and/or that intervention and education were needed.

> *If there's some denial there as to the fact that something traumatic… has happened, then it's hard to be reasonable about where we are currently and where we need to get to. –Demetrius*

Therapists also perceived decreased receptivity to education in stroke survivors who perceived the stroke as a positive event to have happened.

> *My perception is some of them [think] "I'm now in a nice facility for a little while. I've got a lot of people helping me out." It's a neat little change of pace… "What happened to me isn't so bad after all" because… it changes some of the life settings… the dynamics… family realizes that this person's going to need help… they're not going to be… left alone. –Dan*

These situations in which the receivers seemed disinterested or unreceptive to education could be frustrating for therapists because the therapists felt more invested in the education and stroke survivor's recovery than the receivers seemed. If receivers seemed unwilling to receive the information, unreceptive to the education, or were not "buying-in" to the education provided, therapists had lower expectations for positive outcomes of educational interactions.

Therapists related the concept of motivation with willingness to learn in that those who seemed more highly motivated to recover seemed more receptive to education.

> *One family … very good about, "What should we have him do on his own? What should we practice?" … they were just very receptive to the transfer techniques … very motivated to really be able to help the patient… they had such an investment in it from day one. –Bertha*

Those whom therapists perceived to be less motivated seemed less receptive to education.

> *The patient's motivation…The doctor can refer them to therapy, the family can want them to come to therapy… but if the patient isn't [motivated and receptive] and they're just not wanting to do it, then we're not gonna get anywhere. –Dee*

Therapists acknowledged that for stroke survivors, the perception of decreased motivation might be a residual deficit of the stroke. Given this possibility, therapists were sometimes more diligent in educational efforts rather than perceiving less motivation as less interest in the information.

Expectations and Perceptions

The receiver's expectations and perceptions of the stroke, rehabilitation, and the recovery process impacted educational interactions and outcomes according to the therapists. Realistic, reasonable expectations and accurate perceptions were perceived as facilitating factors for education. When expectations were unrealistic in comparison to what the therapist predicted, education could be challenging.

> *[The caregivers] expected somebody to come home walking and [and the person is going to be going home at a wheelchair level and] you want to talk about how to get them up and down a curb [in a wheelchair] and in and out of the car and in and out of bed… so you spend an hour going through that and at the end of the session, they want to know if they should get a walker. -Ann*

Education to address unrealistic expectations was frequently required by home health therapists when the stroke survivor first returned home, because the receivers had expected a full recovery upon discharge from inpatient rehabilitation only to realize that *"nothing works like it used to" (Abby).* It was also frequently required by outpatient therapists when the receivers approached the discharge time from outpatient, because the receivers expected to only be discharged once a full, 100% recovery had been achieved. In these situations, therapists provided education about the chronic nature of stroke recovery and that some residual deficits may always be present.

Therapists described common misperceptions by receivers regarding what therapy is (*"they think it's going to just fix them." –Dee)*. To address these misperceptions, therapists educated about what therapy is, the role of the therapist, and goals of therapy. Misperceptions about what caused the stroke or could cause future strokes and secondary complications were also common.

> *Her family thought that she had overdone [it] with exercise… so they just stopped doing anything… she just sat, they were so careful with her and wouldn't let her move and did everything for her. –Maggie*

In these situations, therapists described the need to educate about the benefits of exercise and activity to prevent strokes and how to facilitate optimal recovery. Lastly, misperceptions of stroke survivors about their abilities and capabilities prompted therapists to provide education about what survivors were capable of and what was possible.

Time Post-Stroke

Therapists described how the amount of time since the stroke influenced education. Education in the sub-acute phase could be challenging because receivers were typically overwhelmed. In these situations, therapists described prioritizing the content provided, such as focusing education on functional mobility and safety instead of topics that could be addressed later by outpatient or home health therapists (e.g., community reintegration). Education in the chronic phase was also challenging because therapists perceived many receivers to be disinterested and less motivated.

> *Chronic is worse… the education is hard from the fact of a lot of them are so ingrained, their movement patterns are so embedded that a lot of them say, "I can't. I can't do this. I can't change that."… you also get people who are so stuck and embedded in what they've been doing that some of them don't want to listen to some education stuff. -Sara*

Caregiver-Specific Factors

Therapists described factors specific to the caregiver that influence education, including the type and nature of the relationship between the caregiver and stroke survivor, the caregiver's viewpoint on caregiving, availability for education, and physical capabilities.

Relationship to Stroke Survivor

Therapists described their perceptions that the relationship between the caregiver and stroke survivor influenced education. Therapists described assessing both the type and nature of the relationship. Therapists identified the type of relationship (e.g., spouse, parent, child) in order to determine pre-stroke roles of the receivers and identify the other life roles that the caregivers have

(e.g., the caregiver may also be a parent, employee, and spouse). This information helped therapists to better tailor education provided.

Therapists described assessing the nature of the receivers' relationship, or the inter-receiver dynamics.

> *You've got to take each situation and evaluate the whole thing. So I just don't go in and do a physical therapy evaluation… take in the whole family and what's going on. –Mandy*

Therapists described the importance of assessing receiver dynamics as quickly as possible. When this assessment took place prior to providing education (e.g., at the initial evaluation or at the beginning of a session), educational interactions and positive outcomes seemed to be facilitated because the therapist could tailor the education accordingly. Past family dynamics were important and influenced the education provided and the outcomes of education. For example, it was challenging to provide education and achieve positive outcomes when the receivers past relationship was strained and there was long-standing tension. Current family dynamics were perceived to have the capacity to *"make or break"* (Elizabeth) education. Strained, tense, or stressful inter-receiver dynamics was perceived to negatively impact educational interactions and outcomes (*when they've had family conflict… [education is] not going to go well… it's more about them fighting than about the education –Ann).* Relationship strain was also perceived to impact some stroke survivors' functional performance and subsequently the education needed.

> *A patient's doing something really well… then they start fighting with the family member and it completely skews everything and alters their performance…. They were… "standby assist"… they fight with their family member, became "mod assist", and the family member says, "You can't come home now." –Ann*

In this situation, education then had to shift from home discharge planning (e.g., home exercise programs and equipment needs) to skilled nursing facility options. When there was tension or strain, therapists attempted to carefully select what was most important to review. If the source of strain was due to deficits from the stroke (e.g., neuropsychological and behavioral changes), Zelda described providing education that the personality, memory, and/or cognitive changes were attributable to the stroke and not the person.

Viewpoint on Caregiving

Therapists described the perception that the caregivers' viewpoint on caregiving influenced education. "Caregiving" seemed to mean different things to different caregivers. Whether or not the caregiver was willing to be a caregiver and provide the assistance necessary was an influential factor on education provided. Typically, a supportive and involved caregiver was perceived as a facilitating factor in that there was a greater chance of more positive outcomes and the stroke survivor did not have to be the sole receiver of education, which could be overwhelming. Mandy described how "involved" could mean different things though, and it was not always a facilitator for education. She described an example of a very "supportive and involved" caregiver who was providing care in a manner that seemed self-destructive in terms of emotional well-being.

> *She was just so focused on him living and staying alive even though he had no life, he was in a hospital bed, and he was bed bound, and he wanted to die… She hired caregivers, but she was always in the kitchen, going over the schedule, and calling the doctor, and running out and getting his medications, and just micromanaging his illness and his life. …I mean the only way she could cope with knowing he wanted to die was to just manage everything. –Mandy*

Mandy then provided education about more optimal ways to be a caregiver, how to focus on what was really important (spending time with him), and how to balance roles. Bertha also described how "involved" could be a positive or negative factor in that some caregivers were supportive but "*very attuned to letting the patient do as much as they could"* while others "*want to jump in and do it all for them".* The latter would require education about how to facilitate optimal recovery by not doing everything for the stroke survivor and facilitating learned dependency.

A perceived barrier to education was a lack of support or involvement by the caregiver. Therapists perceived that some caregivers were resistant to education because they were resistant to the notion of becoming a caregiver. They may be resistant to adding "caregiver" to their list of roles because they would rather maintain pre-stroke roles. Dee described how she came to recognize this after having a discussion with a friend:

> *It wasn't until my friend… who's a PT; she has a daughter that has some developmental disabilities… I said… "[your daughter is] so lucky she has a mom that's a PT." And she went, "I don't want to be a PT, I just want to be her mom." –Dee*

They may be resistant to shifting out of ingrained pre-stroke roles, or shifting from the person in the relationship who is taken care of to person who provides care (*roles that they had before… men [were] waited on hand and foot and when their wife [has a stroke], they're not able to switch over to the caregiving –Mandy)*. Some caregivers seemed resistant to becoming a caregiver and receiving education about how to assist the stroke survivor out of anger and frustration that the stroke occurred. Dan perceived this was the case when he attempted to

educate a wife (caregiver) whose husband had suffered a stroke because he stopped taking medication to control hypertension, despite her reminders.

Availability

Therapists described how caregiver availability influenced education. Caregiver availability for in-person education was perceived as a facilitating factor because it enabled more practice time for caregivers, repetition of information, and meaningful interactions. In-person education increased the types of teaching delivery methods at the therapists' disposal because they were not limited to phone calls and sending written materials to the caregiver through the stroke survivor. Caregiver availability prevented the stroke survivor from being required to absorb all of the information alone. Therapists believed this helped contribute to improved functional outcomes and recovery because there was improved carry-over of the education. For example, outpatient therapists perceived greater accountability and compliance with the stroke survivor completing exercises when the caregiver was available for in-person education.

The opportunity for the caregiver to receive multiple in-person educational interactions facilitated education because the therapist had a larger amount of time to cover topics. Multiple in-person opportunities avoided overloading the receiver with a large amount of information in a short time span, such as what frequently happened during one-time "family teaching days" (*not one big teaching day that you dump all this information on them… give them a little nugget, here and there, of information –Elizabeth).* More opportunities for in-person education also helped establish rapport, which enhanced the communication between the

therapist and receiver. Therapists perceived that caregivers seemed more comfortable to ask questions and express their educational needs as a result of enhanced rapport.

If being a caregiver was not a new role, then being unavailable for multiple in-person educational interactions was not necessarily detrimental or problematic. Previous caregiver experience was usually perceived as a facilitator to positive educational interactions because the caregivers typically had a larger knowledge base, knew what their educational needs were, and could convey these to the therapist. In these situations, having limited time with the caregiver wasn't usually a barrier.

Physical Capabilities

Therapists described the need to assess caregivers' physical abilities to provide assistance to stroke survivors in order to determine what education was needed. In some instances, caregivers were willing and available but could not safely, physically assist the person (*wife who typically is the more diminutive-statured person is now caring for the larger statured person –Dan)*. The caregivers' physical abilities dictated content, such as safety recommendations (*they look like they're in poor health and they're losing their balance… that changes things completely –Ann)*. Elizabeth sought out caregiver descriptions from the case manager prior to conducting a family teaching session in order to better plan and prepare for educational interactions (e.g., if the caregiver may have difficulty providing physical assistance due to frailty, recent surgery, etc.).

Chapter 3.4: Therapist Factors

The third core construct is the educator (rehabilitation professional), or in the context of this dissertation, the physical therapist. Physical therapist-related factors or characteristics influence RECAP. These factors are described in this chapter and include the amount and type of experience, training received in providing education, knowledge and comfort level with the content provided, teaching and communication skills, ability to plan and prepare to provide education, and personal characteristics (Figure 3.7).

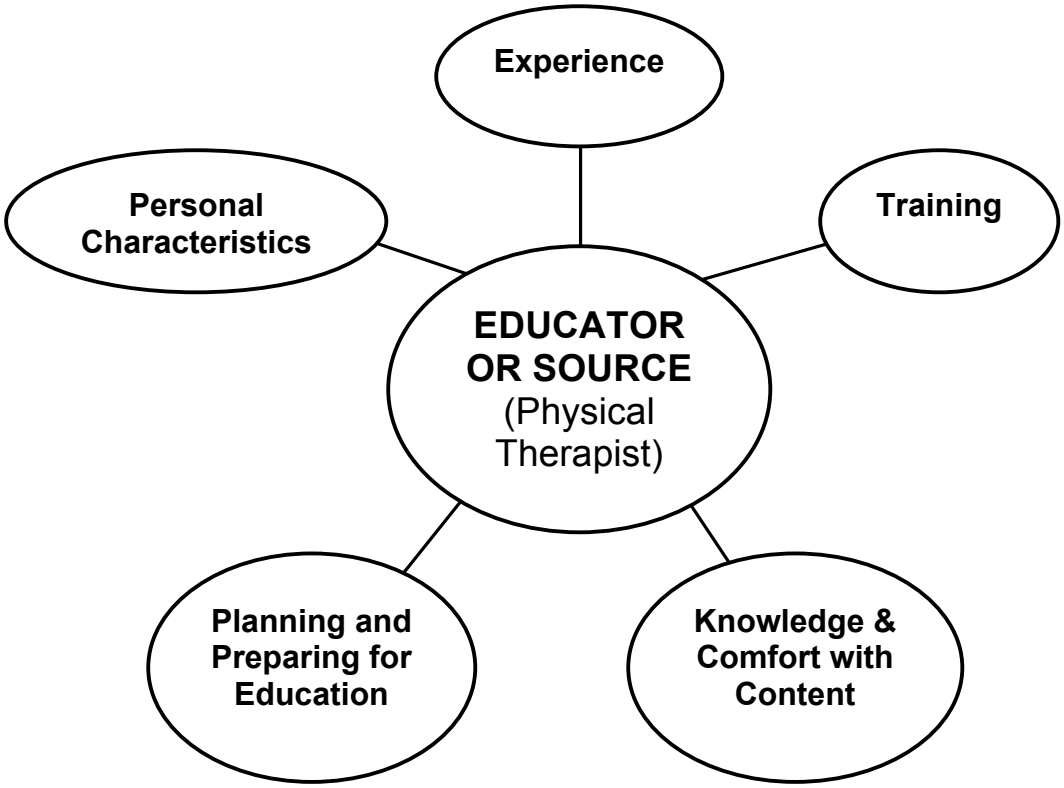
Experience

Experience refers to depth of experience (novice versus expert practitioners) and breadth of experience (experience practicing in different healthcare continuum settings and/or with stroke survivors at different time points post-stroke). In general, therapists recalled that as newer graduates, they felt overwhelmed and intimidated with providing patient and caregiver education (*really overwhelmed… when we started… really intimidating to be placed in front of a family and have to educate – Molly)*. They felt this was due, in large part, to a lack of formal training, both in entry-level programs and on-the-job. Perceptions of training received are reviewed further in the next section. With experience, therapists felt more confident and less overwhelmed.

Additional differences between novice and expert therapists were noted in the following areas: identification of educational needs, identification of appropriate receivers, knowledge and comfort with content provided, teaching

Figure 3.4

Therapist Factors that Influence RECAP



skills, and the overall conceptualization of education within physical therapy practice. Therapists recalled that to identify educational needs when they first started practicing as a physical therapist, they relied heavily on receiver-initiated questions. Molly recalled that as a new graduate, the majority of the education she provided was directed by questions asked by the receivers. As they gained experience, they were better able to sense what receivers' needed.

> *I'm definitely better now than I was three years ago… seeing… what barriers they face just from talking to people over the years and knowing which questions to ask. –Maggie*

Recognition of the importance of identifying caregivers as a receiver of education developed with experience. Early in careers, the primary receiver was the stroke survivor with less emphasis on the caregiver. Over time, therapists recognized the valuable role of the caregiver and the extensive educational needs of caregivers.

> *It is very important to educate the caregivers as well, and I think the longer you work in it, the more important you realize it is… That [caregivers] are as affected… by the disability… I've learned to try to incorporate them sooner. –Zelda*

The amount of experience impacted therapists' knowledge and comfort with content provided. As therapists evolved from novice to expert practitioners, they began to see themselves as experts who were capable and qualified to provide education.

> *It's a progression of your own knowledge and comfortability… As you build your confidence and see yourself more as the expert… [as] a new grad, I wasn't nearly as comfortable providing education. –Bertha*

A better understanding of what content to provide emerged with experience. As a new graduate, Bertha recalled covering "the basics", consisting of functional mobility and how the caregiver could physically assist the person. As a newer

graduate, she also wrote a list of topics to educate about during "family teaching days" so that she would not forget to cover something (a method in Chapter 3.6). Over time, Bertha described including education about general stroke knowledge, prognosis, and typical progression of recovery. She also transitioned away from using a list as a reference for what to educate about. Therapists perceived that with experience, they became more responsive to specific receivers needs and were better able to tailor the education provided. Therapists described becoming more flexible, adaptable, and sensitive to specific receiver needs.

> *Learning how to read someone, and what they need, and what they don't need, and when you're inexperienced, you really flop sometimes. –Zelda*

With experience, therapists evolved their teaching and communication skills to deliver education (e.g., less verbal cues, improved phrasing of cues provided, providing time for stroke survivor to respond, incorporated the use of demonstrations and gestures).

Lastly, the overall conceptualization of education within daily physical therapy practice developed with experience. Therapists described having a limited view of providing education early in their careers (e.g., covering "the basics", providing education one-time on "family teaching days" during the inpatient phase). This view expanded with experience and therapists described realizing the important role of education and how to integrate it on a daily basis. Bertha described this evolution:

> *[As a new graduate] I thought of it very much like… "I do [education] on [family teaching] day and that's all I focus on."… It's been an evolution of understanding… "No. You start teaching Day 1."… education starts from day one and has to progress. And that can really help with …. PT-patient*

dynamics… their understanding of the care and their kind of compliance with the care. –Bertha

In addition to depth of experience (novice versus expert), breadth of experience was also perceived as a facilitating factor for providing education. Therapists who had experience in multiple healthcare settings believed this experience facilitated their ability to provide education because the scope of their "educational lenses" were wider. A therapist who had experience in all post acute care settings described his ability to *"look through those lenses"* and therefore have a greater perspective and knowledge base from which to provide education. He felt better able to predict educational needs because he understood the experience of the stroke survivor and caregiver throughout the continuum of care and throughout the different stages of stroke (e.g., sub-acute, chronic).

Training

Therapists reflected about how they learned or were trained to provide patient and caregiver education. The following five areas emerged from these discussions: what they received in their entry-level educational programs, mentors, on-the-job trial-and-error, observation of co-workers, and continuing education courses.

Therapists recalled learning very little about patient and caregiver education in their entry-level physical therapy programs, especially in the classroom setting.

It seems like [providing education] was mentioned and I knew it was something we would have to do, but… that's something that's really hard to practice and really get a good grasp on in school. –Molly

Some therapists recalled learning “patient and caregiver education” in school only in terms of creating a home exercise program and providing informed consent for procedural interventions. Some therapists recalled professors mentioning areas to potentially educate receivers about in the future but not providing follow-up opportunities to practice. This resulted in frustration and challenges with providing education as a new graduate (*car transfers… really difficult for me [to educate about] because… we never physically went out and practiced that… in school… it was just mentioned –Molly)*.

During clinical rotations as a part of educational programs, therapists perceived a lack of formal structure in learning how to provide education and experiences that varied in terms of quality and quantity. For example, in regards to quantity, one therapist remembered having only one opportunity to educate a caregiver during all of her clinical rotations combined while another therapist described a rotation in which her clinical instructor had her provide education daily. Some therapists had positive learning experiences and opportunities to acquire teaching skills during clinical rotations but with populations other than stroke (e.g., pediatrics, spinal cord injury). Therapists viewed stroke-related education as specialized and despite having these experiences with other populations, they felt ill-prepared to provide education to the stroke population.

> *Other than educating in an outpatient orthopedic setting on home exercise programs, which is completely different than educating the stroke population. –Elizabeth*

Overall, therapists perceived that the emphasis in physical therapy programs was on procedural interventions, to the extent that one therapist

perceived providing education as *“a new thing” (Bertha)* once she began practicing.

Therapists described how the implementation of the following activities in their entry-level programs would have improved their ability to learn how to provide education: 1) inviting actual stroke survivors and caregivers into the classroom and emphasizing education and communication instead of solely focusing on procedural interventions, 2) exposure to stroke survivors and caregivers at various times post-stroke to gain a broader perspective and better understand the educational needs in each setting, 3) use of videos in the classroom of actual therapist-receiver educational interactions, 4) formal and structured training for how to provide education during clinical rotations, 5) development of an educational guide to have as a resource, and 6) encouragement to students to self-reflect on important components of education following a student-patient interaction rather than solely reflecting on the effectiveness of the procedural intervention.

Therapists described learning how to provide education through the guidance of a mentor. For some, the mentor was their clinical instructor during an entry-level clinical rotation. Maggie described how her outpatient clinical instructor instilled in her the value of education, the importance of it, and the concept of providing it pro bono when needed. Demetrius described that the potential downside to learning how to provide education through a clinical instructor was that not all clinical instructors are created equal and not all clinical

instructors are good patient and caregiver educators, which could result in *"a skewed view" (Demetrius)* of what providing education means.

Other therapists described having a co-worker as a mentor. The occupational therapist whom Ann shared a patient caseload with was a primary mentor for her in learning how to provide education. An added bonus was that this mentor was of a different profession and could broaden Ann's perspective.

> *I did a lot of co-treats with an experienced OT, and that was big. I did stuff… that's supposed to be strictly "OT" and stuff that PT's did, and that was really important… watching somebody that's experienced do it… she probably sensed that it wasn't my strongest area and offered to do a lot of co-treats with me… that worked really well because I wasn't comfortable taking the lead, but if she took the lead, it was easier for me to step in. –* Ann

On-the-job experience was the least favored yet most common method by which therapists learned how to provide education. It consisted of trial-and-error educational interactions after they started practicing as a physical therapist.

> *Mostly just on-the-job training… one day, I found out a patient had family teaching day. I said, "I've never done this before," and they said, "Oh, you just go through their functional mobility." –Elizabeth*

During this process over time, therapists describe becoming more adept at identifying educational needs, modifying teaching strategies, and clearly and effectively communicating. While it was a common method to learn how to provide education, it was least favored because therapists described having to learn from mistakes made during actual educational interactions with receivers. This was frequently accompanied by feelings of frustration and embarrassment.

Observation of co-workers' educational interactions with receivers was another method by which therapists learned how to provide education.

> *Two days ago, I was listening to another therapist discuss why she's doing an intervention… and that even helped, just kind of understanding how she explains it to a patient –Jay*

Therapists described observing interactions and noting the content provided, what facilitated or hindered the interaction, and educational strategies and communication styles the co-worker used. This was a common mechanism used early in therapists' careers.

> *When I first started I… listened a lot to what other people were doing and saying, and how they educated, and what areas they've targeted and then developed my own philosophy around that. -Zelda*

In regards to observing co-workers, some therapists described identifying educational role models, or those they believed were excellent educators, and then attempting to emulate them. In addition to observing positive educational interactions, therapists described learning what not to do from observing what they perceived as substandard educational interactions.

Therapists had not attended, nor were they aware of, any continuing education courses, seminars, or lectures focused on providing patient and caregiver education. Two therapists mentioned attending general stroke or intervention specific courses (e.g., neurodevelopmental techniques training courses) and how these helped them provide better education because it improved their knowledge base as a therapist.

Knowledge and Comfort with Content

Therapists described how their knowledge and personal comfort level with the content to be provided influenced education. Therapists described having a lack of knowledge or expertise about certain topics, and therefore, felt incapable of providing education about those topics. If the survivor or caregiver raised

questions about those topics, therapists did their best to refer to a more appropriate source. In some instances, however, therapists described not having the knowledge of who to refer the receiver to (e.g. who conducts driving evaluations, who can facilitate the receiver's ability to return to work, dieticians). A summary of the structured interview question regarding the comfort level with educating about the 10 domains of content is provided in Table 3.7 and more specific topics therapists were less knowledgeable or personally comfortable with will be described next.

Therapists described providing education about what they "knew". In other words, the knowledge base of the therapist dictated the content provided. For example, therapists who were abreast of best practice guidelines and research about stroke interventions described integrating this into the education provided while those who were not informed did not include it. One therapist was unaware of the increased risk of a second stroke following a first stroke and, therefore, did not provide education about stroke prevention to stroke survivors. Whether or not what therapists knew was accurate and comprehensive was perceived to facilitate or hinder education provided. When therapists did not have the knowledge required to provide education, it was perceived to negatively impact the receiver.

> *We're not as well in touch with that [information] anymore… patients end up paying the price because we don't know what the [insurance] regulations are –Zelda*

Home health therapists described the negative impact of inpatient providers educating receivers that home health is provided three times a week, when in actuality, it was determined on a case-by-case basis and was typically only one

Table 3.7

Physical Therapists' Comfort Level with Content Domains (n=13)

Content Domain	Comfort Level in Educating About This Category			
	Very Comfortable	Somewhat Comfortable	Not Very Comfortable	Not Comfortable At All
Stroke Knowledge	8	5	0	0
Functional Mobility	13	0	0	0
Equipment and Devices	13	0	0	0
Psychological and Emotional	2	10	1	0
Promoting Optimal Recovery	12	1	0	0
Healthcare Continuum and Team	12	1	0	0
Advocacy	2	6	5	0
Safety and Precautions	12	1	0	0
Community Reintegration	4	7	2	0
Institutional Support and Resources	2	3	7	1

to two times per week. This misinformed education by inpatient providers caused frustration and anxiety for the receivers as perceived by the home health therapists. Generally, if therapists did not know something, they preferred to refer to another provider or say nothing at all because they did not want to misinform the receivers.

Specific topics that therapists mentioned not knowing much or anything about included: depression, research clinical trials available for the stroke survivor and inclusion criteria for the studies, awareness of local and community services, programs that facilitate return to driving or work, pharmacology and the impact of medications on mobility, groups that advocate for people with stroke, sexuality-related issues, insurance and financial resources (e.g., government services, disability), and stroke support groups that are available.

> *People aren't educated enough about support groups, but then again I don't even know what support groups are out there for stroke. That's a problem…we don't know any of that. –Sara*

Therapists described efforts to improve their knowledge bases. Some described attempts to attend continuing education courses but it was frequently challenging to be granted the time off from work in order to attend the courses. Time available to research information to inform education while at work (e.g., online searching, reading journal articles/reference texts) was negligible. Consultation with other members of the healthcare team during work hours to facilitate knowledge was more common. As examples, Demetrius described receiving information from the physician about what education to provide receivers about returning to driving and from the equipment vendors about what equipment would be covered by insurance.

Therapists expressed the need to be better informed and for mechanisms in place to improve the knowledge base of therapists. This was viewed as important because what therapists did not know, they could not teach. Therapists advocated for improved organizational support and efforts to keep therapists knowledgeable. Therapists described how this was a priority in the past with activities such as weekly inservices to update therapists about changes in insurance regulations and what equipment would be covered. While the mandatory inservices kept therapists' abreast of equipment information, they also provided a networking opportunity in which therapists could capitalize on each other's knowledge bases about other topics. Over time, productivity standards increased, greater demands were placed on therapists' time, and processes to keep therapists informed were suspended.

Therapists described feeling uncomfortable on a personal level about educating about certain topics. Discomfort with the psychological/emotional domain topics (reviewed in Chapter 3.5) was most prevalent. Sexuality-related education was a topic therapists typically hoped *"to dodge"*. Bowel and bladder related education was another area therapists attempted to *"steer away from*" and this was usually in regards to providing education to receivers of the opposite sex. Lastly, education about prognosis (e.g., that residual deficits may linger long into the chronic phase of stroke) and making positive health behavior changes (e.g., the need to lose weight) were sometimes perceived as difficult and uncomfortable conversations. Some therapists described the importance of setting aside personal discomfort and providing the education needed.

Like sexuality…. not everyone feels comfortable addressing that… if people bring it up or if you think that's something they want to know about… helping them feel comfortable to talk about it or problem-solve positional issues… to address all of who they are, and what they're going to need, and not just what you're comfortable to talk about… that's more client-centered . –Zelda

Planning and Preparing for Education

The concept of planning and preparing demonstrated an important distinction between how therapists perceived education versus procedural interventions. Education was not a process therapists concretely and consciously thought about in comparison to procedural interventions. Therapists spent time reflecting about and planning procedural interventions while education provision was less structured or planned. Therapists could readily describe how they selected procedural interventions and developed a plan to progress those interventions. When asked how they plan, prepare for, and progress education, many grappled with the concept. Several described a lack of structure or framework for providing education.

I never just go in and say, "Today, I'm going to educate on this." … The education's free flowing according to what comes up. –Sara

After further in-depth discussion, therapists were able to share their perspectives on some general thought-processes and tangible activities to enable them to provide education. First and foremost, they attempted to develop an understanding of the receiver and the receivers' educational needs. This enabled therapists to determine educational priorities and plan the optimal delivery methods of education.

More tangible preparation activities that were sometimes used included making a list of topics to review, reviewing resources to acquire knowledge of

content to provide, consulting with other therapists, gathering equipment needed (e.g., assistive devices, theraband), coordinating a car for car transfer training, coordinating with the caregiver to be available for education, and gathering handouts or brochures about stroke, ramp building, and functional mobility tasks. Preparation of home exercise program handouts was common but therapists noted the extra preparation time and efforts required to tailor them to individuals with stroke. The computerized exercise software typically produced material that was difficult for stroke survivors to understand clearly. Researching community resources was another type of preparation activity. Outpatient and home health therapists described researching safe instructors to get horseback riding lessons from and where community gyms are located and which ones offer classes suitable for the stroke population.

Inpatient therapists described two preparatory activities prior to educating caregivers about how to assist the stroke survivor with functional mobility. One method was "self-practice" by the therapist, in which the therapist would pretend to be the stroke survivor and practice a functional mobility task. This was especially common for preparing to educate about more complex tasks such as stair training with crutches. Self-practice enabled the therapist to place him/herself in the stroke survivor's position and think about what the caregiver needs to know in order to assist the survivor and how the task should be explained at each step.

> *If it's something that I don't teach or practice that much… before I teach it to the patient or family, I have to practice myself… going up and down steps with crutches, I was like "Oh, let me think this through to make sure I'm not telling them the wrong thing," so I had to get out the crutches and practice it myself. –Bertha*

The other inpatient method was “pre-training” the day before the caregiver was scheduled to receive education. Molly described having the stroke survivor attempt all of the functional mobility tasks that she planned on providing education about to the caregiver the next day. This facilitated problem-solving and improved planning prior to the caregiver being present and it optimized the limited amount of time the caregiver was available.

Personal Characteristics

Personal characteristics of the therapist that were perceived to influence education included gender, geographic residence, frame of mind, attention, other roles, and perception of the receiver. The therapist’s gender was mentioned as an influential factor only in regards to providing education about toileting and sexuality. Therapists were sometimes less comfortable providing education about these topics to receivers of the opposite sex.

Therapists from rural areas described how their geographic backgrounds influenced education. A mix of rural and urban stroke survivors sought treatment at the study site. Therapists from rural areas described how it was easier to establish rapport with receivers from rural areas simply by having that in common. Therapists from rural areas also had an intimate understanding of rural settings and environmental barriers, which they perceived facilitated education to rural receivers. Molly described asking more detailed questions about the home environment, especially the outdoor environment, and incorporating functional mobility in the outdoors into training and education that she provides during the inpatient phase.

> *I'm from an eastern Kentucky area, so… I try to delve into the home environment, especially outdoor home environment… I know there's a lot of gravel driveways, there's a lot of really hilly wraparound stairs that go up the mountainside… try to take them outside… a lot of the people that live in rural areas like to go outside… they have more land and they like to get out and walk in their yard or down the road to see the neighbors... I try to talk about that more… if somebody tells me they're from… the city… I don't probably go into that as much. –Molly*

Therapists who were not from rural areas typically did not consider geographic residence as an influential factor.

Therapists described how their frame of mind prior to and during interactions could influence education. Having a presence of mind, or as Elizabeth described it, *"I feel prepared and the day has gone well for me",* positively influenced educational interactions. If the therapist had a hectic and stressful day or if there were personal issues causing stress, providing education was perceived to be more challenging. In these instances, therapists described doing their best to *"try to go into that situation calm and collected" (Elizabeth).*

The therapist's ability to attend to the moment and to the receiver was perceived to influence education. Some therapists described having an *"increased distractibility level"* or being *"personally… pretty easily distracted"*. They described the need to consider the environment in which education would be provided, in order to minimize distractions. Therapists described how the socialization that occurred in gym settings was sometimes detrimental to their ability to pay attention and focus on the receiver. In light of this, therapists would attempt to manipulate the distracting environment to support focused education (e.g., *"get us back in a corner where I can focus on the patient but they're*

focused toward me and the wall" –Demetrius) or finding a different environment (e.g., a private treatment room).

One therapist described how the other roles that therapists have in life could influence education. She described how her role as a mother influenced education in several ways. Through becoming a mother, Zelda came to value the important role caregivers' play and the importance of educating them about how to manage as a caregiver and the need for respite (*being a mom… learning the importance of taking care of yourself so you can take care of your person – Zelda)*. Being a parent also influenced how she educated stroke survivors about recovery and learning how to function again.

> *When [my kids] were real little, I was very fascinated with brain development and how you acquire skills, and how an infant does it and how someone relearning does it… My work with neuro patients and being a mother of young kids… they've dovetailed well for me. –Zelda*

Participants described how a therapist's perceptions of the receiver (e.g., the receiver's level of motivation, the receiver's interest in the education being provided) could influence the education provided in regards to amount and type of information. Therapists described how misperceptions about receivers' characteristics could hinder education. Maggie assumed her high school educated receiver was literate, provided him with detailed handouts, and then found out later that he was illiterate. Demetrius described the need to take care to avoid misperceptions clouding the therapist's lens when providing education *(like in wound care, "see the whole person and not the hole in the person")*.

Chapter 3.5: Comprehensive Content

The fourth construct forming the fundamental core of the theory is defined as comprehensive content provided to stroke survivors and caregivers during educational interactions. As described in the methods, 10 domains of content that physical therapists educate about emerged. The 10 domains are described in this chapter, followed by descriptions of content priorities for the therapists. The examples of content within each of the 10 domains that participants provided during the pre-interview reflection activities, as well as supporting sample quotes from the qualitative interviews, are provided in an appendix at the end of this chapter.

Domains of Content

Stroke Knowledge

Therapists described educating about general stroke knowledge. This included topics such as what a stroke is (e.g., type of stroke, general area of the brain involved, what caused it), the residual deficits that occurred due to the stroke, prognosis (e.g., average timelines to achieve goals, factors that influence prognosis, the typical progression of recovery), stroke prevention, how to minimize risk factors, and how to recognize the signs and symptoms of stroke should a second stroke occur. Therapists strongly believed that stroke survivors and caregivers needed to be educated about what happened to the brain and subsequently the body, why it happened, what it caused (residual deficits), what the future may hold, and how to prevent it from happening again.

Functional Mobility

Educating about functional mobility was a primary component of education. Therapists described educating receivers about the proper technique and mechanics for transfers, bed mobility, stair mobility, ramp mobility, gait, and wheelchair mobility. Education to caregivers about how to physically assist the stroke survivor as well as communication strategies for them to use during the assistance was also emphasized.

Equipment and Devices

Education about equipment and devices included: the need for devices/equipment, types of devices for gait, wheelchair features and options, orthotics and other braces, footwear, and recreational equipment. Therapists also educated about electrical stimulation units, how to use a gait belt, and how to use ace wraps (e.g., for edema management, for dorsiflexion assistance during gait). Lastly, therapists described providing education about how to create equipment out of materials at home (e.g., bolsters out of towels for positioning or exercises).

Psychological and Emotional Issues

Therapists described providing education about a range of topics related to the psychological and emotional well-being of the receiver. Therapists provided education to caregivers about the need for support and self-care, including respite services, establishing daily routines, and balancing the caregiver role with other life roles. Due to the chronic nature of stroke recovery, therapists provided education to help keep receivers' motivated and understand the long journey required. Examples of this included education about coping

strategies, redefining goals and expectations, and how to keep a stroke recovery journal, such as a weekly journal with each entry including progress made to-date, challenges still present, and goals. Some therapists also educated about depression in that it can be common post-stroke for the survivor, common for the caregiver, the benefits of counseling and anti-depressants, and to consult their physician about options. Other areas that were educated about but with less frequency were sexuality and sexual function, support groups available, and return to hobbies and leisure activities.

Promoting Optimal Recovery

Therapists described providing education about how to promote optimal recovery. Topics within this domain included education about physical therapy interventions (e.g., the purpose, benefits, options), the home exercise program, the concept of recovery versus compensation (e.g., neuroplasticity principles such as the need for greater intensity and repetition, involving the hemiplegic body parts), how to prevent secondary complications in order to enable optimal recovery, and how the caregivers can support optimal recovery.

Healthcare Continuum and Team

Therapists described providing general education about the healthcare continuum in regards to the different types of settings (e.g., inpatient rehabilitation, sub-acute rehabilitation or skilled nursing facilities, outpatient, home health, and community-based exercise places), expectations in those settings, and expected goals associated with those settings. Therapists also provided education specific to physical therapy within the healthcare continuum

(e.g., physical therapy goals and plan of care for the setting the receiver was currently in, estimated length of stay, rationale for discharging from physical therapy). Therapists also educated about the healthcare team, such as the role of each discipline (e.g., physician, nurse, physical therapist, occupational therapist, speech-language pathologist, case manager, etc). Along these lines, therapists educated about who the receiver should consult for education outside the therapists' realm of expertise and knowledge base.

Advocacy

Education related to advocacy was mentioned but was typically rare. A few therapists described educating about how and why receivers could become involved in activities associated with raising public awareness of stroke. A few educated receivers about what to tell their family members and support networks about regarding stroke. Knowledge of resources or organizations that advocate for people with stroke was lacking. One therapist did describe providing education to stroke survivors about becoming an advocate for oneself, such as advocating for services and supports.

Safety and Precautions

Therapists described providing extensive education about safety and precautions. They provided education about the impact of residual deficits on safety and precautions to take, such as how to be safe with functional mobility due to balance or strength deficits. Therapists educated caregivers about using proper body mechanics to avoid injury and how to safely use a gait belt. Therapists educated stroke survivors about floor transfers and precautions to

take in case a fall should occur. Therapists also educated about secondary complications (e.g., how to reduce the risk of developing them, how to manage them when they occur), precautions associated with medications, supervision needs at home, and home modifications required for safety.

Community Reintegration

Outpatient and home health therapists primarily provided education about topics within this domain. Therapists educated about going out in the community and community mobility (e.g., driving, transportation, equipment needs in the community). Some therapists also provided education pertinent to returning to hobbies and work within the community.

Institutional Support and Resources

This category was rarely educated about, due in large part to a lack of knowledge by the therapist described in Chapter 3.4. Some therapists, however, described providing some education about insurance regulations (e.g., the amount of physical therapy covered, what equipment would be covered). Home health therapists described educating about possible resources to access to get equipment and home modifications paid for.

Prioritizing Content

Therapists described attempts to prioritize content provided because receivers had different educational needs. Prioritization was especially important when numerous barriers to education were present and therapists had to consider carefully how best to focus educational efforts (*what battles are we going to choose – Mandy).* Prioritization was also essential because therapists

did not have unlimited amounts of time with receivers. Therapists described prioritizing education by what educational needs were identified (Chapter 3.2) and in consideration of specific receiver factors (Chapter 3.3) that have been previously described. There were also priorities based on what healthcare continuum setting the stroke survivor was in and these will be reviewed more in-depth in Chapter 3.7 regarding the timing of education. Therapists described prioritizing education by their perceptions of what was most important to educate about to any receiver and by individual personal preferences. These are described further in this section.

As part of the pre-interview reflection activities, therapists were asked to list the three most important areas of education that they provided to patients and the three most important areas for caregivers. These were considered overall priorities for any stroke survivor and/or caregiver and results are provided in Tables 3.8 and 3.9. “Safety” was the topic area most frequently listed by therapists for education to both survivors and caregivers. For education to stroke survivors, every other topic listed was noted by less than 50% of the participants indicating a wide spread of what therapists perceive as “most important”. For education to caregivers, after “safety”, education about how to assist the stroke survivor with functional mobility and exercises were the next most common. Only 38% of the participants listed topics related to caregiver self-management as a priority. Therapists also completed structured interview questions regarding how important it was to educate about each domain and how often each domain of content was covered. Participants’ responses are provided in Table 3.10.

Table 3.8

Most Important Areas of Education Provided to Patients as Perceived by Physical Therapists

Topic	Therapists (n=13)
Safety	10 (77%)
Prognosis (expected future gains, recovery process, discharge planning)	5 (38%)
Exercises (proper technique, involving the caregiver, written/pictures, incorporating exercise into functional tasks, how exercise relates to improved function)	5 (38%)
Functional mobility (optimal techniques, new ways of moving)	4 (31%)
General stroke education (medical condition, residual deficits)	4 (31%)
Optimal recovery (how to facilitate affected extremities, normal movement versus compensation, active participation)	3 (23%)
Equipment needs (assistive devices and bracing)	3 (23%)
Instill confidence (reassurance)	2 (15%)
Purpose/goal of treatment (informed consent concept)	2 (15%)
Positioning	1 (8%)
Medications	1 (8%)
Be an advocate for oneself	1 (8%)
Adaptation to return to work and recreational activities	1 (8%)
Home modifications	1 (8%)

Table 3.9

Most Important Areas of Education Provided to Caregivers as Perceived by Physical Therapists

Topic	Therapists (n=13)
Safety	9 (69%)
How to facilitate/assist with functional mobility (transfer training)	8 (62%)
How to assist with exercises	5 (38%)
Becoming and managing as a caregiver (need for respite and self-care, encouragement, support, balancing roles, establishing routines, day-to-day management)	5 (38%)
Body mechanics	4 (31%)
Home safety/modifications (planning/preparing for home situations)	2 (15%)
How to promote progress with the stroke survivor	2 (15%)
General stroke information	2 (15%)
Prognosis (progressing toward discharge, need for change in direction of intervention)	2 (15%)
Positioning	1 (8%)
Resources (clinics that provide screenings/services, home care, outpatient, support groups)	1 (8%)
Explanation of skilled physical therapy interventions	1 (8%)
Rehabilitation process and the healthcare continuum	1 (8%)
Medication management	1 (8%)
Monitoring stroke survivor depression	1 (8%)

Table 3.10

Structured Interview Question Results Regarding Importance of and How Often Content Domains Covered (n=13)

How Important it is to Educate About this Topic	**Stroke Knowledge**	**Functional Mobility**	**Equipment and Devices**	**Psychological and Emotional**	**Promoting Optimal Recovery**
Very Important	12	13	13	12	13
Somewhat Important	1	0	0	1	0
Not Very Important	0	0	0	0	0
Not Important At All	0	0	0	0	0
How Often The Category Is Covered					
Always Covered	4	12	11	3	12
Usually Covered	7	1	2	6	1
Sometimes Covered	2	0	0	4	0
Never Covered	0	0	0	0	0

Table 3.10 (continued)

Structured Interview Question Results Regarding Importance of and How Often Content Domains Covered (n=13)

How Important it is to Educate About this Topic	**Healthcare Continuum and Team**	**Advocacy**	**Safety & Precautions**	**Community Reintegration**	**Institutional Support & Resources**
Very Important	11	8	13	12	9
Somewhat Important	2	3	0	1	4
Not Very Important	0	2	0	0	0
Not Important At All	0	0	0	0	0
How Often The Category Is Covered					
Always Covered	8	0	12	6	2
Usually Covered	4	2	1	5	1
Sometimes Covered	1	8	0	1	9
Never Covered	0	3	0	1	1

Therapists described prioritizing content based on topics they personally believed were very important or felt personally passionate about, personal "soapboxes" so to speak. As Zelda describes it: *"each therapist has their own little thing"* or *"little pearls of wisdom"* that they want to pass on to receivers. Some therapists' personal passions were conveyed when they described education about certain topics. A personal passion of Sara's was to educate about depression because she believed depression could have a negative impact on outcomes and receivers typically were not discussing it with their physicians. Educating about stroke knowledge was a priority for Zelda because *"people need to know what has happened to them"* and because this would be priority information should she have a stroke. Personal priorities varied by therapist and therapists had difficulty recalling the origins of their "soapboxes".

Chapter 3.6: Delivery of Education Through Teaching Methods and Communication Skills

The fifth core construct is defined as delivery of education through teaching methods and communication skills. Therapists' descriptions and perceptions of concepts within these domains are reviewed in this chapter.

Teaching Methods

A variety of teaching methods were described by participants and included verbal (in-person or on the telephone; individual or group formats), written (source and receiver created), visual (demonstrations, pictures, videos, anatomical models), and tactile (return-demonstrations and role-playing).

Verbal Methods

Verbal delivery refers to verbal communication about educational topics in which the survivor/caregiver received information through hearing. Some therapists acknowledged potential limitations to the effectiveness of verbal delivery methods, such as limitations in what receivers may be able to absorb through auditory means (*attention spans are relatively short in [people], so therefore, most of the stuff that we transmit is probably lost quickly –Jay*) and the level of distractions. Therapists described, however, that verbal delivery was still one of the most common methods and sometimes the only method used to provide education.

Some therapists preferred verbal delivery for certain topics, such as general stroke information. Some therapists used outcome measures as a tool to provide verbal delivery of education about deficits present, prognosis, and

progress or plateaus (*look at your numbers, look how much you've improved since you've been in therapy –Sara).* An outpatient therapist mentioned the use of websites as another tool to guide the verbal delivery of education. As issues arose, she would try to find an informative website and then share the information with the receiver verbally.

Verbal delivery involved interactive discussion/conversation between the therapist and receiver (e.g., back-and-forth question and answer format) or more of a "lecture" or "presentation" of information from the therapist. Specific verbal delivery formats that will be discussed in the next sections include *individual in-person* delivery (one therapist providing education to the stroke survivor and/or caregiver), *individual telephone* conversations, *in-person group conferences* (therapist, stroke survivor and/or caregiver, and other healthcare team members), and an *in-person class* (one or more therapists and multiple stroke survivors and/or caregivers).

Individual In-Person. "In-person, individual" formats consisted of one therapist providing education to the stroke survivor and/or caregiver. One strategy specific to individual verbal delivery was visualization or visual analogies. When educating a patient about the importance of involving the hemiplegic lower extremity, Zelda described verbally sharing a 'kickstand' analogy.

> *"You have to ask this leg to do the work. You don't want it to just be a 'kickstand'. You want to bear your weight on it, you want it to hold you, you want to learn to trust it." –Zelda*

Therapists felt comfortable educating about a wide array of topics with this format, but some noted a preference to avoid this method for certain content,

such as sexuality and making healthy lifestyle changes (e.g., smoking cessation, weight management).

> *Printed him off different recommendation ideas from our VHI software package that has… energy conservation techniques [for sexual activity]… for ideas without really getting into it too much. –Jay*
>
> *I think [the need for losing weight is] still one of those areas that, by and large, you can hear it talked about on the news, but you can't talk about it with your [patient]. –Dan*

As previously described in Chapter 3.3 regarding caregiver availability, therapists preferred individual, in-person education to educate caregivers instead of using the telephone because multiple delivery methods could be used in conjunction with the in-person verbal education (e.g., demonstration, return-demonstrations) (*I'll call the caregiver and ask if they can schedule to come in… they can see what's going on, and what we're working on –Dee).* Therapists noted that a barrier to education was that some caregivers were unavailable to meet in-person with the therapist.

"Family Teaching Day" occurred in the inpatient rehabilitation setting and was a formal individual, in-person method that consisted largely of verbal delivery of education. Case managers invited the caregiver(s) to come for the day and receive information and training from healthcare providers. It included attending the stroke survivors' therapy sessions and having conversations with other providers (e.g., nurse, case manager, psychologist). One therapist described the potential benefit of this method was that the caregivers perceived they were receiving a special, formal educational session. Overall, however, therapists perceived more barriers than benefits with this form of verbal delivery for several reasons: 1) multiple healthcare providers provided a large amount of information

to receivers in a short time span which could cause “information overload” (*they get bombarded with so much information… they get home and what do they really remember of that –Zelda)*, 2) it may be the first time the caregiver was seeing the extent of the deficits from the stroke (*that one family teaching day is really stressful for the family… a lot of them haven’t even seen their family member [perform physical tasks] yet… a lot of them are overwhelmed. –Sara)*, 3) while it was an optimal time for the therapists (e.g., during their work hours), it was sometimes an inopportune time for the caregivers (e.g., during their work hours) and the caregivers were distracted, stressed, and not ready to receive the education (*someone’s off work and they’re thinking about… missing their day of work -Dan)*, 4) there was a limited amount of time that the therapist had for “hands-on” caregiver practice *(you have an hour to prep them to go home without any healthcare professionals with them 24 hours a day like we have here –Ann)*, and 5) the primary (and sometimes sole) delivery method was verbal which could be overwhelming to learners. Dan summarized the barriers in saying: *Most of the best teaching that I’ve had is not done on the family teaching day. It’s been on some other day when they were there and it wasn’t that they had this “super day”.*

Individual Telephone Conversations. The use of telephone conversations varied based on setting. Home health therapists used it frequently. Telephone conversations were rare for inpatient therapists but some believed this form of delivery for educating rural caregivers might be a good supplement to the one-time “Family Teaching Day”. Rural caregivers frequently were unable to travel the

long distances to reach the inpatient rehabilitation settings and be present in-person on a regular basis; therefore, most of the education for them occurred on the “Family Teaching Day”. Therapists suggested that telephone delivery might be one mechanism to add repetition of information and establish rapport with these caregivers. The barrier to telephone use at the inpatient phase, however, was time constraints (e.g., having the time for a telephone conversation, organizing/scheduling the phone call). Overall though, therapists preferred in-person education rather than the telephone because they could incorporate other methods when the receiver was physically present (e.g., demonstrations, return-demonstrations).

In-Person Group Conference. In-person group conferences were a means of providing education with the stroke survivor, caregiver, and healthcare team present. The home health therapists reported this happened only on occasion. Inpatient therapists reported that this was something that occurred with other neurological populations (e.g. spinal cord injury, traumatic brain injury) but not with stroke. They viewed this delivery method favorably and wished it were implemented for their patients with stroke. Having a conference once per week during the inpatient phase would be ideal but they suggested a minimum of two times, once near admission and once prior to discharge, in order to provide education about what happened to them, residual deficits caused by the stroke, expected progress, what to expect in therapy, current status, and how to start planning for the next phase.

In-Person Class. In-person classes were used exclusively in the inpatient setting and included educational classes and stroke support groups, in which one or more healthcare providers would share information with a group of multiple stroke survivors and/or caregivers. Educational classes for stroke survivors occurred occasionally (e.g., a diabetic education session). Therapists suggested the need for caregiver-only education classes, as a valuable delivery method and environment for caregivers to learn, especially early in the inpatient rehabilitation phase. They noted, however, that this would require hospital administrative support, in the form of time and educational materials, in order for them to plan and implement these classes successfully.

A stroke support group typically met once per week in the inpatient phase. A primary benefit was the facilitation of peer-to-peer interactions and education, or the ability to learn from other stroke survivors and caregivers, rather than solely from healthcare providers. Stroke survivors in the chronic phase of recovery were invited as speakers and this provided inpatients with encouragement, hope, and valuable information. Another benefit was the ability to discuss certain topics with greater ease. Demetrius described leading an all-male support group in the past and how this facilitated education about sexuality and other difficult topics that male stroke survivors were reluctant to ask about or discuss in other environments and situations.

> *It was like a guys' discussion…almost like a support group… it [included] sex education… [but] it didn't always just focus on… sex… lots of the guys were married or had significant others… there really was a fear of… "When can I return to intimacy… and is that going to be safe? Am I going to have a stroke?" … it was just a very open format for people to discuss whatever. –Demetrius*

In addition to sexuality topics, therapists suggested a support group would be the ideal method for providing education about what a stroke is, risk factors for stroke, the risk for having a second stroke, stroke prevention, healthy lifestyle changes, coping strategies, home and community safety, and options for returning to hobbies and leisure-activities.

Therapists knew of no community-based stroke support groups or educational classes, for stroke survivors nor caregivers. They noted this as a barrier to meeting long-term educational needs of those affected by chronic stroke. Due to the absence of community-based support groups for stroke survivors, outpatient therapists described attempting to provide their patients with the benefits of peer-to-peer education by scheduling stroke survivors at the same time and introducing them to one another.

Written Methods

Therapists described delivering education through written materials, in which the stroke survivor and/or caregiver received information by reading or writing. Written methods included handouts (reading) or receiver created materials (writing). When therapists referred to “written materials”, they were referring to hard-copy paper materials, not electronic resources such as websites in which receivers read information online. Aside from the outpatient therapist mentioned previously, who would on occasion find a website to share information with the receiver, no other therapist mentioned providing website suggestions to receivers. Overall, written materials were viewed as an important method of delivery to accompany verbal education.

Definitely having written stuff because… you forget half of what somebody told you, so having it all written down, lots of details. –Dee

Handouts. Handouts were the most commonly identified artifacts that assisted therapists in providing education. Therapists preferred to never solely provide education through handouts out of concern that the receiver would never read the material. In some situations however, such as caregivers who were unavailable for in-person education, this was the only means of providing education. They were the primary method used to educate about home exercise programs in each setting. Other topics provided in handouts included ramp building instructions, energy conservation techniques, stroke knowledge (e.g., stroke prevention), building a standing frame, and general home safety. Therapists also described the use of a "to-do list" to provide education in a written form. Mandy described how the home health therapists occasionally provided "to-do lists" to caregivers as a guide for making the home safer. Inpatient therapists described using a "to-do" list or checklist for how to complete functional mobility (e.g., steps to completing a safe transfer) and posting it in a patient's room, on the walker, or on the wheelchair.

Therapists described how the receivers' level of educational attainment and the presentation of written materials influenced the written delivery method. Therapists preferred electronically produced, rather than hand-written, material whenever possible and they considered font size with the electronically produced products. No one made reference to health literacy in regards to written materials but one therapist mentioned consideration of reading level.

> *I'm pretty sure I remember hearing… when the hospital puts together educational material, they try to do it at a certain grade level…if we have a client that's lower than that…I think we always try to find some advocate that does understand the material. –Dan*

A barrier for therapists to provide education through the written delivery method was not having access to the written resources they needed. Therapists wished they had materials to provide about basic stroke information, managing blood pressure, fall prevention, and other safety-related topics. Another barrier was having materials of poor quality for the stroke population, such as the software system to create written home exercise programs. While the system worked well for the orthopedic population, the materials created were typically difficult to read, hard for the stroke survivor to understand, and the exercises were difficult to adapt for the stroke population. Despite the limitations of the software system, some therapists preferred to use this because the only other alternative were handouts *"that looked like copies of copies or things from the 80's and 90's"* (Dan).

Therapists wanted easy access to professional-looking materials such as a *"multicolored, nice… brochure, in layman's terms, of what stroke is, and what its effects are, and some of the things to think about" (Dan).* Therapists wanted materials that were *"user-friendly… not too wordy [with] nice pictures" (Bertha).* Therapists believed the presentation of materials was important to capture the attention of the receiver and increase the likelihood that the receiver would actually read the information. Some therapists described the need for professional looking material that was available both to send electronically and to print in a hard-copy format, depending on the receiver's preferred learning style.

Something you could just email… and [they could] bring it up on [their] phone, but then also for the older people, you could just print it. –Molly

Handouts provided in the inpatient setting were sometimes placed in "educational binders". These were binders available for any healthcare provider to place written materials in. The binders were conceptualized as tools that could help the receivers manage the large amount of written material, have something to take with them into the chronic phase of stroke, and as a resource to take with them to future appointments to help coordinate care. Some therapists assumed materials about stroke knowledge were placed in the binders but were not certain. Therapists described only using the binders as a place for the home exercise program handouts and only if the receiver indicated that this would be useful. Therapists described how many receivers purposely asked them not to place anything important in there because it wasn't viewed as a useful resource (*patients say, 'oh, don't put it in there, I'll never find it' –Molly).* Molly described how receivers would potentially view it as a useful, valuable resource if healthcare providers reinforced this. In other words, if healthcare providers did not view it as valuable or demonstrate how to use it, the receiver would likely follow that lead. Molly described how the binder was not integrated into the patient's rehabilitation as an educational tool; therefore, receivers viewed it only as something to throw papers into and never look at again.

I've gotten away from [placing the exercise program in the binder] and started to just hand it to them because every time I open it… there's nothing else in [there]…I'll usually say "This book over here." … "What book? I've never seen that." … they have no idea what it is, it's never been opened, there's nothing else in it… if we used…it throughout their stay [it would be better]; I don't think it can be used just on discharge… I think if we just constantly referred to it and went to it more. –Molly

Home health and float therapists described dichotomous cases regarding the binders in which receivers either loved them or found them useless.

> *I've had people that have used their binder, and loved it, and did great, and I've had people… "That's just heavy. I can't open that… It doesn't work for me." So it doesn't do any good if you have your exercises in that binder if you only have one hand [and] can't get them open. –Abby*

One therapist suggested that even if the binder was not useful to the receiver initially upon returning home, it could be a useful resource in the chronic phase of stroke when new questions arose later.

Receiver-Created Materials. Some therapists reported asking the receiver to write as a means of providing education. Two examples provided by therapists were a stroke recovery journal and home exercise program log. Zelda described using the stroke recovery journal to educate receivers about progress being made, areas still in need of therapy, feasible goals to work toward, and that stroke recovery is a long process. The home health therapists described asking receivers to keep a daily log for exercises and activities. They used the exercise log to actively involve the caregiver and to educate about progress being made, exercise goals, and the importance of exercise in stroke recovery.

Visual Methods

Therapists shared insight about visual methods of delivering education in which the stroke survivor and/or caregiver received information by watching or seeing. These included demonstration, pictures, videos, and anatomical visuals. Therapists considered visual delivery a valuable method (*I think visual aids are huge. –Dee).* They were especially useful in stroke rehabilitation because stroke survivors sometimes had difficulty following verbal commands and/or hearing

impairments and because much of the education to be provided was complex and sometimes difficult to convey verbally.

Demonstration. Demonstration was one of the most common teaching methods cited by therapists. It was the preferred method for educating about functional mobility tasks (e.g., bed mobility, transfers, walking, stairs) because therapists perceived that receivers learned this information best when they were able to watch the tasks be performed prior to practicing them. Demonstration was frequently used for caregiver training in which the therapist demonstrated how to assist the stroke survivor. This was helpful in teaching caregivers how much or how little assistance to provide (*Letting family see how much you make them work or struggle at something before you step in and help – Zelda)*. Demonstration was a definite favorite of home health therapists because the environment was most meaningful to the receivers and the therapist could demonstrate exactly how to perform a task in the environment the receiver would be performing it in. Therapists described concern about whether or not the receiver was passively observing the demonstration or was actively engaged and learning.

> *The family is there in body… they're passively there, but they're not actively there… 'Cause then, when it is time to do the hands-on [practice]…you would've thought if you've watched me do something… that now you would know how to do that. –Dan*

Pictures. Pictures were used as part of the home exercise program written handouts. Home health therapists also described using pictures in the form of visual graphs created by analysis of the telehealth monitoring system. The therapists would use these graphs to educate the receivers about blood

pressure, glucose, and weight management. Therapists described using pictures of functional tasks at previous places of employment but not having these types of resources at their current facility. Pictures they wished they had included transfer training, stairs, wheelchair use and parts, and curb management. These would be especially useful for caregivers who aren't able to be physically present for education during the inpatient phase.

> *An illustration of how to guard people on stairs or how the patient should ascend and descend… taking a wheelchair up and down a curb… parts to a wheelchair… Family members struggle with… how to lock and unlock the brakes if they haven't been there and helped their family member with that… that's intimidating if you're taking the patient home for the first time and you can't even unlock their brakes much less do the seatbelt and know where the anti-tippers are… [or how to] fold it up to put it in the car… so basic components of the wheelchair would help…a diagram of the wheelchair… a picture of a person going up a curb or up a stair… a simple illustration that an art student could draw. –Molly*

Similar to the written handouts, therapists wanted pictures or illustrations that could be available to receivers electronically or in printed hard-copy format.

A few inpatient therapists described taking actual photographs of important moments of a transfer sequence and posting these by the stroke survivor's bed for both the nursing staff and caregivers to better understand how to safely assist with transfers. Inpatient therapists also described asking caregivers to take photographs of the home (e.g., entryways, bathrooms, bedrooms, stairs) and then these photographs were used as tools to provide education about home safety and home modification and equipment recommendations.

Videos. Videos were not being used by any of the therapists for people with stroke, nor did they think any other healthcare providers on the team were

using them as educational tools. Videos were mentioned as useful delivery methods being used for other diagnoses (e.g., a video for outpatients with Parkinsons). Some therapists recalled the past use of educational videos for stroke survivors in the inpatient setting (e.g., about what is stroke, risk factors, prevention), but when the member of the healthcare team who spearheaded that effort left, so did the use of the videos. Therapists described the potential value of using these and wished they had them available. Therapists suggested the need for videos for caregivers, available during the early inpatient phase, about introductory educational topics such as a review of basic stroke information, the healthcare continuum, expectations for the inpatient setting (e.g., typical goals), what to start thinking about regarding discharge plans, and how the caregiver can make the most of each visit (e.g., how to be an active observant of therapy sessions).

> *We should have a video that everyone that checks into our hospital [watches]… You know how people that watch the total hip and total knee [videos], … "Here's what rehab looks like… some of the things to consider in the rehab environment… things that you need to consider as a stroke survivor or stroke family member… things you should think about to get the most out of your rehab stay here." –Dan*

Videos in the inpatient setting would enable stroke survivors to make the most of the time they had available (e.g., evenings, weekends). Zelda suggested creating an educational center, or "stroke information area", in which receivers could access the videos in the evenings, on the weekends, and on breaks between therapy sessions. Receivers would also be able to learn about topics that were less comfortable to discuss verbally.

> *When you're bored on the weekend… watch a video about whatever it is that you pick… even like sexuality… everyone has [questions about it]… But not everyone feels comfortable addressing that or asking questions about it. –Zelda*

Demetrius recalled watching short educational videos on a "patient education channel" in the Labor and Delivery department at a local hospital, when he and his wife were awaiting the birth of their child. He perceived the videos (e.g., about "Shaken Baby Syndrome") to be a useful method and how powerful visual images could be when providing education. He wondered if an inpatient "stroke education" channel could be developed. He also suggested a series of short (10-15 minute) videos, which receivers could access through smart phone technology, would be of value. Ann believed that for some receivers, videos about functional mobility tasks could be superior to written handouts as a resource to take home upon discharge from inpatient. Bertha suggested that videotaping the "Family Teaching Day" sessions could provide caregivers with a useful educational resource.

Anatomical Visuals. Therapists reported they did not have any neurological anatomical models or posters available with which to provide education to receivers. Therapists described occasionally using the orthopedic models available, such as a spine, to educate about posture-related issues or back pain. Some therapists believed that neurological models, posters, or diagnostic imaging would be useful to educate about stroke (e.g., what's happened to their brain, generally the area involved and subsequent deficits).

> *I think that's a good idea… even just a generic brain poster with… what different areas are responsible for would be helpful…because sometimes I… say… "This is a really common symptom with a stroke that's happened in the part of the brain that yours has happened in." –Bertha*

> *It would be really cool to have… 'cause I think it would be helpful for them to understand… I don't think that they get what happened in their brain… if they could see it… even if they could see their MRI… "This is why you have to work so hard. This is why you have to have things rewired." –Dee*

Others did not think anatomical visuals would be useful. One therapist believed educational time and efforts would be better devoted to more practical topics, such as functional mobility and safety. Others were concerned about the level of detail of neuroanatomy to which they would have to educate about if using a model, and they could not envision the depth of content they would provide.

Tactile Methods

Therapists described the use of return-demonstrations and role-playing as tactile delivery methods in which the stroke survivor and/or caregiver received information by doing or feeling. Tactile methods were frequently included in education delivery to reinforce and confirm learning, even if receivers expressed their understanding of information following verbal or visual methods.

> *It's like a light bulb. …involving the caregiver, and actually having them [practice], like if I were to teach a class… or give a lecture I'd try to involve the people and have them to do something physical. –Zelda*

Return-Demonstrations. Return-demonstrations, also referred to as the "show-back" method, involved "hands-on" practice in which the receivers would practice the task themselves by "returning" the therapists' demonstration. Therapists perceived return-demonstrations as valuable methods because of the perception that the method facilitated active learning. These were used frequently, therefore, to follow up therapist demonstrations out of concern for the potential for passive observation with demonstrations described previously. Return-demonstrations were used commonly for education about functional

mobility tasks (e.g., bed mobility, transfers, walking, stairs) and home exercise programs. This method was perceived to be valuable in facilitating stroke survivors' understanding of functional mobility deficits and safety issues.

> *I might have somebody attempt something that I know they won't be able to do, with me being there close by to help when things go wrong, so that I can document they're really not able to do it safely. People that… have poor safety awareness or poor awareness of their deficits… I think you have to sometimes set them up to fail so that they realize [they're not ready to return home]. –Ann*

The method was also valuable in educating caregivers about what they were or were not physically capable of in regards to assisting the stroke survivor. This was important at the inpatient phase when trying to determine discharge placements (e.g., home versus a skilled nursing facility).

> *I think it's important for families to experience what nursing… and what therapies are doing with their loved ones 24 hours a day… part of the education is helping people decide where the best fit for that person is for recovery, safety, and maybe for the family as well.* –Dan

Role-Playing. Role-playing involved two possible scenarios. A therapist would pretend to be the stroke survivor and asked the caregiver to practice assisting him or her with functional tasks or exercises.

> *I sometimes bring the caregiver in and have them try it on me so that I can give them feedback about what worked and what didn't. –Zelda*
> *Out on homecare with stroke patients… if there's a Hoyer [mechanical lift to dependently transfer the patient]… I'll get in there myself and… have the caregiver do that with me before we attempt to do it with the patient. –Demetrius*

In other cases, the caregiver was asked to pretend to be the stroke survivor while the therapist played the caregiver's role. This enabled the caregiver to feel what the stroke survivor experienced (e.g., with correct versus incorrect transfer technique from the caregiver).

I have the caregiver sit down and pretend they're the patient… then maybe I do something wrong that they had done with the patient and then do it right and let them feel the difference… it's like a kinesthetic thing that helps them place that memory. –Zelda

Teaching Method Preferences

Therapists described preferences for certain delivery methods. This was reflected both in the qualitative interviews and in the pre-interview reflection activities. As described in the methods, prior to the interview, therapists were asked to list three communication or education techniques used for education and any artifacts, or objects, they found useful in providing education. Therapists' responses are provided in Tables 3.11 and 3.12.

Some therapists described personal preferences for a primary type of delivery method. For example, some preferred verbal delivery of information while others preferred demonstrations. Despite some having a personal preference for one delivery method, therapists believed that to optimize the effectiveness of education it was important to be adaptable and flexible in delivering education. The delivery needed to be tailored to a receiver's learning style, regardless of the therapist's preferred style. Other receiver characteristics, in addition to learning style, that influence delivery of education were reviewed in Chapter 3.3. For example, therapists described assessing the frame of mind of the receiver (*you can tell they're overwhelmed and need more things written down –Dee).* Regarding the stroke survivor's cognitive and communicative abilities, if a stroke survivor had difficulty following verbal directions, the therapist would deliver education through other means.

Table 3.11

Communication or Education Techniques Used for Education

Topic	**Therapists** (n=13)
Demonstrations	11
Return-demonstration or show-back	6
Verbal (e.g., discussion, question-answer, feedback post return-demonstration)	11
Written (e.g., exercise handouts)	10
Visual (e.g., pictures, spine model)	3
Teach back	1
Humor	1
Story-telling or clinical narratives	1
Websites	1

Table 3.12

Artifacts Useful in Providing Education

Artifact	Therapists (n=13)
Handouts	
Home exercise program	12
Standing frame building instructions	1
Home safety	1
Transfers	1
Daily exercise log	1
Energy conservation	1
Ramp building	2
Educational binder	1
Websites	1
Equipment	2
(Assistive devices, braces, gait belts, mirror)	
CEU course materials/manuals	1

All therapists agreed that providing education through multiple delivery methods was optimal for the receivers to learn. Zelda summarized why multiple modes of delivery was so important for optimal educational outcomes:

> *That goes back to the early childhood development and learning… the multisensory experience. The more of your senses that you can involve in a learning process [it] helps get that more firmly placed in your mind. So if [receivers] talk about it, and see pictures of it, and… remember what it [felt like during the return-demonstration]… -Zelda*

Using multiple delivery methods was also ideal to address differences in the learning styles between the stroke survivor and caregiver.

> *I usually use multiple ways because the caregiver may be one learning style and the patient may be another, and so I try to use a combination. That way it hits home to everybody that's in the room as best it can. –Elizabeth*

Communication Skills

Therapists believe communication is a critical component of the delivery of education and a prominent reason for why they believe education provision is a skilled activity.

> *[It's] how you relate and the words you use… Learning how to talk to people 'cause I think that's one of the things that's wonderful about being a PT… it's both a science and an art… how to talk to someone and read them, and how to motivate them can be very different than how you motivate someone else… basic communication things and interpersonal skills… learn who likes what and how to make them be motivated. –Zelda*

As Zelda alludes, communication was perceived as central to the therapist achieving the purpose of education (e.g., to motivate) and the role of the educator (e.g., making education meaningful). Therapists' believed communication was vital to delivering content because of their perception that clear and effective communication reduced anxiety and fear in receivers whereas unclear or confusing communication produced anxiety and stress. Dimensions of

communication that will be reviewed include: use of language, communication tools, communication style, and communicative environment.

Use of Language

Therapists considered the language they used during communication when delivering education. Language was important because complex or confusing terminology was perceived to overwhelm the receivers and be detrimental to learning. Typically therapists attempted to use layman terms and avoid medical jargon (*I'm not telling them "proximal" –Bertha).* Some described starting out with a certain type of language and then making adjustments based on perceptions of the receivers' understanding.

> *I don't want to say that I "dumb it down", but I always start off with a certain type of language… If [I say] "watch that leg for… signs of fatigue" and they don't [seem to] know what that means… [then I'll say instead] "Watch for that foot dragging." –Molly*

Even if receivers had a high level of educational attainment, therapists described attempts to *"keep it at that basic level pretty much across the board [and] not be above their head" (Dee)* because of their belief that even college graduates may not understand healthcare terminology. The only situation in which this was not the case was when the receiver was also a healthcare professional.

> *If someone's a nurse, I may [use] more medical jargon… 'Cause it's a language that healthcare professionals may understand even better than layman terms, honestly. –Jay*

Therapists described consideration of word choice to match what would motivate the receiver best. For example, Abby avoided the word "exercise" in education for some receivers because they were resistant to anything classified as "exercise".

> *I want you to have other options 'cause I know you don't like exercise… So we talked about walking when she goes to the bathroom and I gave her bridges but I didn't call them "bridge exercises". I said "when your bottom hurts you, this is what you could do to make your bottom less tender." Not "exercise". –Abby*

Therapists described the need to adjust the language and terminology used to educate the stroke survivor and caregiver in some cases, due to cognitive and communicative deficits of the stroke, so that each receiver could understand.

Communication Tools

Therapists described using the following communication tools as a means of delivering education: humor, educational pearls, storytelling, and analogies. Participants described using humor or amusement when providing education as a means of making the receiver feel more at ease and to reinforce educational content. Demetrius described the use of an appropriate joke at the beginning of the all-male support group that *"lightened the mood"* and helped establish a more relaxed environment and comfortable space to discuss topics such as sexuality.

Therapists described using educational pearls, or helpful tips. These were used to reinforce concepts and facilitate the receiver's memory of the concept. For example, Zelda described teaching stroke survivors *"the chicken wing"* technique to safely get through a door with a walker. Educational pearls typically involved a short phrase and/or creative phrasing to help the receiver remember the information.

Mandy described the use of storytelling as a communication tool to make information more meaningful to receivers. Stories of what other stroke survivors and/or caregivers had experienced was perceived to add meaning to the education provided.

> *"Storytelling", using examples of other people, not their names, but examples of what happened to so-and-so when they didn't have their phone with them, and fell, and they laid on the bathroom floor for 12 hours until somebody came. –Mandy*

Lastly, therapists described the use of analogies as a communication tool to make information more meaningful and understandable. Therapists provided the following examples of the use of analogies to:

1) learn skills and reinforce the need for mass practice:

> *I've used the analogy of how… when… toddlers are trying to learn how to walk… how much they had to practice to learn that… It's that mass practice… that's what the patient has to get to be able to relearn… "How many times did you fall down and you had to get back up? … And you just had to keep picking yourself up and going again, and that's how you learned how to walk. Every time you learned a new skill, it required a lot of practice. A lot of trial and error." –Dee*

2) understand how mental practice helps in learning skills:

> *A patient on the [robotic gait orthosis], I try to get them to close their eyes and think about what it feels like [to walk], and I talk to them about mental imagery and mental practice… the research study with the free throw shooters who actually did it or who just thought about it… how the Olympic divers… you see them going through it in their head. –Zelda*

3) reconstruct a self-identity post-stroke:

> *It's like if you have always wanted to be a basketball player in the NBA but then you realize that you're too short and you're never going to make it, you have to refocus your dreams. –Sara*

Communication Style

Therapists described a variety of possible communication styles and how the styles influenced education. Most therapists described having a "supportive and encouraging" style. Therapists recognized that much of the education provided was leading the receiver toward major life changes (e.g., physically assisting a more dependent person, smoking cessation, becoming more physically active). Conveying optimism and having an encouraging tone was

used when educating about how important making the life changes were and that the receiver could actually make those changes. Part of the "supportive and encouraging" style was celebrating receivers' achievements, both big and small, in order to educate about progress made and motivate them to continue. Non-verbal communication was also described as an important part of the "supportive and encouraging" style.

> *People that can't speak… a lot of times with aphasia, they pick up so much on body language and on facial expression if they don't understand… I went in there… knelt down, I held her hand, I looked in her eyes. –Zelda*

A few participants described having a "tough love" communication style in some situations. This typically was used when receivers were resistant to making positive changes or continuing on an optimal road of recovery (e.g., continuing with an exercise program upon discharge from outpatient). A "direct, matter-of-fact" type of communication style was also described. One therapist described using this to educate about prognosis, expectations, and forming realistic goals.

> *"Your leg will never be like it was before. I'm not saying it's not going to get better or your arm's not going to get better, but it will never be as strong as it was before." … I feel like it's better to be up front with people and to tell them the truth than to give false hope… I just have to make it realistic because I am not a miracle worker*. –Sara

When asked how receivers responded to this approach, Sara said:

> *They usually get very upset. Some people won't accept what I say and then I tell them… "Who's to say that you won't prove me wrong? … Your goal is to prove me wrong." [and then] they work harder… [others] respect the fact that I tell them the truth… because… I just look at them eye-to-eye and say, "Listen, this is what I've seen and this is what I know." –Sara*

With any style, therapists described attempts to convey care and concern for the receiver because *"people need to realize that you're obviously concerned*

about their well-being" (Demetrius) in order to establish rapport and get buy-in to the education provided.

> *Treating people with value… goes a long way toward establishing rapport with them… to say, "You're a person who has worth" … you don't want to come across as "I'm just doing this to check this off." –Demetrius*

While therapists described preferences for certain communication styles in certain situations, they also described the importance of adapting styles to meet the needs of the receiver.

> *I think I have a routine style, but I adjust it on the situation. If I need to be more authoritative… I can change it. –Elizabeth*

> *If they're younger and spunky and I feel like they can handle it… I might be a little more aggressive. If they're frail and they're little old ladies, then I'm a little sweeter… It changes with the client's personality and what they can handle. If they're depressed, you're not going to come at them aggressive… whatever's going to motivate them. –Sara*

Bertha described adjusting her communication style based on the hemisphere of the lesion because typically stroke survivors with right hemisphere lesions were more impulsive and those with left hemisphere lesions were more cautious and apprehensive.

> *I absolutely adjust my style. Especially with people that… don't have the safety awareness or are more impulsive, I'm not as encouraging… "This is what we're going to do and this is how we're going to do it." People that I think have more… apprehension about moving… you have to be more encouraging. –Bertha*

Therapists also described adjusting styles depending on who the receiver is (e.g., more encouraging to the stroke survivor while being more authoritative with the caregiver, or vice versa). Maggie described adapting her style to the stroke survivor in response to the caregiver's approach in some situations. She described a husband (caregiver) who was very critical of and had little patience

for his spouse (stroke survivor). In turn, Maggie would adapt her communication when providing education to a more supportive and encouraging tone.

Adapting communication styles was not always easy and it usually required practice and experience. Molly described the challenge in adapting her style for receivers from urban areas, who sometimes preferred more direct, authoritative styles, compared to those from rural areas, who preferred providers speak to them as family would.

> *It's been harder for me to talk to people that are… more from in the city… to be more direct and authoritative… they want you to be serious… and sometimes I'm trying to be a little bit more lighthearted and they're like… "Are you serious?" –Molly*

Communicative Environment

Therapists described the impact of the environment on the ability to communicate effectively during education. Typically, therapists preferred quieter and calmer environments in which to provide education. Therapists described attempts to manipulate the environment in order to achieve this.

> *Turn off the TV so that everybody is engaged in… the education that's going on… close the doorway and block out any hallway noise so that they're focused and can listen… start in the patient's room because it's quieter, I can control that environment more… it's more private. They can ask questions and there's not as much chaos. –Elizabeth*

Quiet and calm environments were especially sought out to conduct initial evaluations, when caregivers were present for sessions, and when educating about any topics in which the receiver may become emotional about (e.g., amount or lack of progress to-date, prognosis). A quiet, private environment could enable receivers to *"feel safe… if they need to express emotion" (Elizabeth)* during an educational interaction. Quieter, calmer, and more private

environments also facilitated optimal education by decreasing distractions not only for the receiver, but for the therapist as well.

> *Personally, I'm pretty easily distracted… if there's multiple people talking and if I'm halfway interested in the conversation… it's easy for me to start talking to somebody else. –Demetrius*

Sometimes therapists had optimal environments at their disposal (e.g., the patient's private hospital room, a private treatment room in outpatient). This was more common for the inpatient and home health therapists given the availability of the patient's room in the hospital or a private home in the community. It was more difficult for outpatient therapists to access or create optimal environments because of the constraints of the physical space. The few private treatment rooms available were typically in use for procedural interventions so most of the education had to take place in the crowded gym or in the busy hallways leading to the gym. The only choice therapists had to optimize the gym environment was to educate receivers in a corner of the room, facing the wall. While the gym was a primary environment for procedural interventions for both the inpatient and outpatient settings, it was perceived as being detrimental to education in many cases.

> *The gym is just so busy and insane… it's hard if you have a big group of people… it's hard for… your patients and even your family members… to focus. –Bertha*

The inability to access or create environments best suited for education was a barrier to providing education in all settings. In these situations, therapists described attempts to supplement verbal delivery with other teaching methods (e.g., demonstrations, pictures, written handouts).

In some cases, participants described purposely starting out therapy or education in quieter environments and then shifting to more distracting, noisy settings. This would enable the therapist to identify additional educational needs if the stroke survivor had more deficits emerge in distracting environments. It also enabled the therapist to educate the caregiver about differences in the stroke survivor's abilities in a quiet versus distracting environment.

Chapter 3.7: The Timing of Education

The sixth and final core construct is defined as the timing of education. Therapists described the timing of education in terms of time within the physical therapy episode of care and within a specific post-acute care continuum setting.

Within a Physical Therapy Episode of Care

Therapists described that education was provided at points of time within the physical therapy episodes of care including the following time points: initial evaluation, therapy sessions, reassessments, and discharge evaluations. Priorities for education at initial evaluations included topics related to safety, expected length of stay and duration of therapy, anticipated discharge plans, expectations for the setting the receiver is in, feasible and realistic goals, residual deficits noted, why residual deficits need to be addressed, how the residual deficits will be addressed in a treatment plan, prognosis, and positive factors going for the stroke survivor. Education provided during therapy sessions was determined based on the receivers' needs. Education at reassessments, or reevaluation time points, typically included progress or plateaus, the estimated length of continued therapy needed, any changes in the intervention plan required, and plans for continued therapy or activity post-discharge. Education reiterated at discharge evaluations included progress made to-date and plan for continued therapy or activity. Additional descriptions of education provided within an episode of care but specific to healthcare continuum setting are provided in the next sections.

Within a Healthcare Continuum Setting

Therapists also described that education was provided and prioritized based on when they received physical therapy services in regards to setting within the continuum of care (e.g., inpatient rehabilitation, outpatient, and home health settings). In the following sections, descriptions of how each setting and time points within each setting influenced education. This will include the therapists perceptions of what was a priority to educate about within the setting. Table 3.13 provides the results of the structured interview question regarding when, in terms of setting, the content domains should be covered. This data will be referred to in the following sections as well.

Inpatient Rehabilitation

During inpatient evaluations, therapists described assessing the following in order to identify educational needs and tailor education provided: the receivers' goals and concerns, social factors (e.g., presence/involvement of a caregiver, employment, what a normal day consists of, hobbies), health habits, the built home environment (e.g., entranceways, stairs, flooring type), and resources available. Based on the information gathered, therapists described providing subsequent education during the evaluation. Bertha described also initiating stroke knowledge education during the evaluation.

> *You're doing all these weird things like testing proprioception and no one knows why you're moving their big toe… "After a stroke, this might be affected so I'm testing to see, and here's what I found." –Bertha*

Table 3.13

*Structured Interview Question Results Regarding Timing of Content Domains**

Content Domains	Setting Category Should Be Covered In					
	All Settings (Acute and Post-Acute)	Post-Acute Care (IP, SA, HH, OP)	IP/SA Only	OP Only	IP and OP	OP and HH
Stroke Knowledge	13	0	0	0	0	0
Functional Mobility	12	0	1	0	0	0
Equipment and Devices	12	1	0	0	0	0
Psychological and Emotional	9	3	0	0	1	0
Promoting Optimal Recovery	12	1	0	0	0	0
Healthcare Continuum and Team	13	0	0	0	0	0
Advocacy	8	1	0	1	2	1
Safety and Precautions	12	1	0	0	0	0
Community Reintegration	7	3	0	1	0	2
Institutional Support and Resources	12	1	0	0	0	0

*Abbreviations: IP = inpatient rehabilitation, SA = sub-acute rehabilitation, HH = home health, OP = outpatient

Educational priorities for the daily therapy sessions included safety, functional mobility, and preparation for discharging home. These priorities related to what the therapists believed was the purpose of the inpatient rehabilitation setting, *"to get them to the next place… where they're going to live" (Dan).* In order to facilitate the stroke survivor discharging home, an educational emphasis on safety, functional mobility, and discharge planning (e.g., home accessibility, caregiver support needed) was perceived to be paramount. An emphasis on educating about equipment and devices also emerged from the interviews. The therapists focused this education on options for assistive devices to optimally facilitate functional mobility, rental wheelchair needs, and prognosis for how long the equipment would be needed. If costly custom braces were needed, therapists provided education that the therapist in the next setting would address that in order to allow more time to pass and see if deficits resolved.

Some of the therapists described providing stroke prevention education in the inpatient phase in the hopes that the shock of the stroke would serve as a catalyst for positive health behavior changes. Others believed this type of education would be more suitable to provide in the outpatient and home health settings.

> *We're not really there yet… we're so focused on the [stroke] they had, we're not talking about prevention yet… I don't feel they're ready to have that thrown at them… even bringing up the fact that they can have another one. –Molly*

Other topics that therapists perceived were less of a priority and would be better addressed in the outpatient and home health settings included: return to work, return to hobbies, advocacy, and sexuality/sexual function. Therapists described

that these were less of a priority because of the perception that receivers were not ready to receive that type of education at the inpatient phase and may be more receptive to it at a later time point. One exception to advocacy education not being a priority was that education about advocating for oneself was a top priority for Ann.

The plan for continued therapy influenced the education during the inpatient phase. If the therapist knew that the stroke survivor would receive outpatient or home health services, the therapist tended to focus education on what the receivers needed to know in order to get home and function safely until the next provider took over. If the stroke survivor was not going to receive on-going therapy, the therapists felt compelled to educate more and about topics that they may not typically cover. Ann described attempts to educate stroke survivors as if they are not going to see another therapist again because of reports from past patients that home health was not initiated for months upon discharge.

> *If they're never going to see another therapist again, what are the top things? What's gonna keep them from coming back into the system. –Ann*

Determining when to educate caregivers was part of the educational planning process for inpatient therapists. Therapists perceived that the culture of the inpatient environment promoted healthcare providers as the primary sources of assistance to the stroke survivor while inadvertently nurturing a passive caregiver.

> *Sometimes we hold them back in a sense… Families still see enough caregivers here, provided by the facility, to think that they don't really see their need to then jump in and be taught what they're watching other people do. –Dan*

This perceived aspect of the inpatient culture made caregiver education challenging because instead of providing education throughout the inpatient phase, functional mobility education and training was typically conducted during the one-time "Family Teaching Day" described in the previous chapter. Therapists described struggles in determining when to schedule the "Family Teaching Day". Some believed that it needed to be as close to the time of discharge as possible when the stroke survivor had regained more function and best mimicked what the caregiver would experience at home. Therapists described that the downside to scheduling "Family Teaching Day" close to discharge was that it left limited, if any, time for the therapist to assess the effectiveness of the education. Multiple caregiver training and education sessions would enable therapists to assess the receivers' learning. Ultimately, therapists described determining when to schedule it on a case-by-case basis and based on when it would be most valuable.

> *With some people, I wait towards the last week. Some people, somewhere in between… it's based on that sense of…"Is this valuable to do it now?" I guess I make a decision in my mind of value. –Dan*

Therapists suggested the need for a shift in the inpatient culture to an emphasis on early, active, and frequent caregiver involvement and education. Providing caregivers more education and opportunities to practice functional mobility tasks with the stroke survivor was suggested to support caregivers' feelings of preparedness and confidence because it provided more opportunities for learning as well as feedback from the therapist. Therapists cautioned that the potential for caregiver injury, from assisting a more dependent stroke survivor

early in the inpatient phase, had to be taken into consideration. When this might be the case, therapists suggested that early caregiver education still needed to be emphasized but take different forms. Early caregiver education could involve caregiver educational classes, encouragement of the caregiver to be an active observer when they visit, and completion of a home assessment form to enable the therapist to provide education about equipment and home modifications required.

> *"We'll do family teaching… down the road," … [Instead], maybe we should say, "While you're here, you should soak up as much as you can. You should be… seeing if you can participate in some of the things we're doing." … I don't think we do a great job at informing families up front that "Part of the time here… should be you also preparing for when you're going to be doing what you're watching those therapists and nurses doing." –Dan*

Therapists suggested the need to avoid implying that caregiver education would take place later on the formal "Family Teaching Day" because many caregivers understood this to mean that was the only time education would take place.

Home Health

Therapists described that receivers had a profound need for education upon discharge to home from the inpatient rehabilitation setting. The therapists believed this was due in large part to the shift of no longer having a multidisciplinary healthcare team available and assisting the stroke survivor 24 hours a day and the caregivers did not fully realize the extent of care that the team had been providing. It was also perceived as an overwhelming time point for stroke survivors because it was challenging to return home to former life roles with residual deficits from the stroke. The initial evaluation and initial therapy sessions, therefore, were perceived as an important time for providing education.

At the initial home health evaluation, therapists described asking questions such as: *"You've been home a day, two days, three days... What have you found you can't do that you were able to do before?" (Mandy).* Assessment of functional mobility educational needs was a priority because now that the receiver was in the home environment, they had new environmental issues to manage that were not present during the inpatient rehabilitation phase (e.g., clutter, lower surface chairs, high beds, narrow hallways). Therapists also assessed the need for safety-related education and described this as the top priority *(our first priority is are they safe, they know what to do, they know how to call us -Abby).* Demetrius described providing education about carrying a cell phone, keeping a cordless phone on a low table, or getting a Life Alert system in case of a fall.

The priorities for education throughout the remainder of the home health phase were safety (e.g., medication management, positioning, home safety, functional mobility safety) and caregiver management (e.g., balancing roles, need for respite). The availability or involvement of other disciplines involved with the stroke survivor's care required physical therapists to serve many roles (*I think I need a social work degree –Mandy).* The therapists described feeling a responsibility to provide education about a wide array of topics, that other disciplines would typically take the lead on in other settings (e.g. education about medication management that may typically be educated about by a nurse or physician).

> *We become everything… I probably do less physical therapy than anything else because… the people that live alone, you're their whole support system… we do [education about] everything, even medications, 'cause the nurse doesn't come in all the time. –Mandy*

In regards to what education was not a priority for the home health setting, therapists noted that education about advocacy was not something they focused on. The therapists thought it was important but other topics took priority.

The nature of the environment influenced education during the home health phase. Abby described this in saying, *"it's almost a mirror image because in the hospital, you control the environment; in the home, they control the environment*." As such, therapists had to carefully consider what education to provide because the receivers may not allow the therapist to return for future therapy visits.

> *Assess everything that's going on before you even say anything 'cause you've got to get a feel for how that's going to be accepted. –Mandy*
> *We are guests in their home. They call the shots. I mean, we had somebody lock the OT out yesterday. –Abby*

The plan for continued therapy also influenced education. If the stroke survivor was interested in transitioning from home health to outpatient, the home health therapist prioritized education toward this goal (e.g., emphasis on education about community mobility in order to get to the outpatient clinic).

Outpatient

Sara described how the educational priorities shift from inpatient to outpatient because of the shifting purposes of the settings. She perceived that the goal for inpatient therapists was to provide education about safety and functional mobility in order to prepare the receivers to go home. The goal for outpatient therapists was to identify any barriers the receivers faced in attempting

to return to life roles and provide education accordingly. Based on the pre-interview reflection questions about what was most important to address, patterns that emerged for outpatient therapists were education to stroke survivors about the home exercise program and its incorporation and relation to function and education to caregivers about how to assist the stroke survivor with a home exercise program.

> *In order to really maximize the gains that they're potentially going to make, a home exercise program is pretty necessary. –Jay*

Education about long-term equipment needs was also a priority in the outpatient setting (e.g., bracing, wheelchairs) because this was the point in time when plateaus in recovery typically occur. Jay viewed outpatient as the most important setting to provide education about community reintegration because the receivers were at a point in time when they were attempting to go out in the community. Education about long-term residual deficits and prognosis also became a priority in the outpatient setting (e.g., muscle hypertonicity) because it was a period of time when receivers seemed to realize that some residual deficits were not resolving and plateaus in progress were occurring.

> *A lot of times, I end up being the first person that tells them they're not going to be like they were before.* –Sara

Therapists described providing education early in the outpatient setting in order to achieve educational goals. Maggie described how she researched gyms and exercise classes for stroke survivors early on while they were in outpatient rehabilitation. She provided them with this information, asked them to try exercising at the gym or in the exercise class, and then asked follow-up questions about how the class went and what they thought of it. This enabled

them the time to process the education, follow the recommendations, and for Maggie to provide follow-up education as needed.

> *If I don't see it through, it's not going to happen. So they can go ahead and try it and be held accountable. If I ask them how it was, then they're more likely to do it rather than discharging them and going "OK, go find that exercise class. –Maggie*

All Settings

The float physical therapist participants, who worked with stroke survivors in all of the post-acute care settings, provided their perspectives on what should be covered in all settings. Based on their pre-interview reflection about what was most important to address, patterns that emerge were an emphasis on education to stroke survivors about safety and functional mobility and education to caregivers about safety and managing as a caregiver. Demetrius also shared his perception of the importance of educating about stroke knowledge throughout the continuum to ensure that the receivers integrated the knowledge.

All of the therapists that participated shared their perceptions of what education should be covered in all settings. Results of the structured question about when a domain of content should be educated about yielded the following percentages of therapists that believed the domains should be educated about in all settings (acute care and post-acute care settings): stroke knowledge (100%), functional mobility (92%), equipment and devices (92%), psychological and emotional (69%), promoting optimal recovery (92%), healthcare continuum and team (100%), advocacy (62%), safety and precautions (92%), community reintegration (54%), and institutional support and resources (92%).

Overarching Principles of the Timing of Education

Therapists described their perceptions of overarching principles related to the timing of education. With few exceptions, therapists believed that education should be initiated early and repeated frequently in order to facilitate the receivers' ability to learning (*benefit from the repetition of hearing it, it might finally sink in –Zelda)*. Therapists perceived repetitious education over time as critical for achieving positive outcomes (e.g., receiver knowledge acquisition, functional mobility improvements). Providing education early in the physical therapy episode of care also enabled therapists to assess the receivers' mastery of the information and determine if further education was needed.

Repetitious education was believed to be important for increasing the likelihood of motivating positive health behavior changes (e.g., smoking cessation). Multiple repetitions of information were also perceived to be important for educating about complex topics (e.g., medication management, functional mobility) and information that may be difficult to digest (e.g., the need for a physician referral for a potential issue).

> *I've had a patient that had a stroke that appeared to also have Parkinson's, so trying to educate the family as far as why I believe that they should seek a neurological consultation from a physician… it can require two or three sessions before they will even consider referrals. – Jay*

Therapists also described how multiple repetitions of education could help emphasize the importance of the topic. For example, Abby described the need to educate about psychological and emotional topics in every setting, such as caregiver management and support, in order to reiterate how important the information was.

To achieve the principles of early and repetitious education, therapists described the need to include education in each and every physical therapy session (*it should be something that occurs daily –Ann; you teach all along the way –Zelda; it's just ongoing… it's every single time we see them -Dee).* Therapists described the need for repetitious education not only within settings but also across continuum settings. Therapists described situations in which the receivers had either misunderstood information provided, been misinformed, or not informed at all in the previous setting.

> *You get ones that clearly there's some misunderstanding about the brain, and about stroke. –Bertha*

> *In outpatient…they'll ask me "What kind of stroke did I have?" They still don't even know. They have no clue. –Sara*

This highlighted the importance of assessing educational needs and providing education repetitiously across settings.

> *They may have covered it in inpatient, but there's so much… They're getting ready to go home, they're still in the shock… from this big life event… [need to make] sure that all the bases were covered, and that they have a good understanding, and that we can build, that they've got that good foundation that we think they have, that we know that they've gotten in inpatient. –Dee*

Therapists described the need for long-term education into the chronic phase of stroke because new issues arose over time and receivers' educational needs changed over time. Given the limited amount of time that therapists had with receivers, it was challenging to predict and provide them with all of the education that they would require into the future. Therapists suggested the need for improved access to educational sources in the chronic phase of stroke.

Chapter 3.8: Encompassing Constructs

Four constructs encompassed the fundamental core and included: professional responsibility, multidisciplinary team, complex healthcare system, and environmental and socio-cultural context. These are described further in this chapter and suggest the influence of perceived role, practicing as part of a multidisciplinary healthcare team, the complex healthcare system, and larger environmental and socio-cultural context on the practice of RECAP by physical therapists.

Professional Responsibility

Therapists described a sense of professional responsibility and obligation to provide RECAP. As one therapist noted, if you are a stroke survivor or caregiver for someone who has had a stroke, *"you should not be prevented from accessing [information]… you should be supported in your seeking of that knowledge" (Zelda).* Education was perceived as the duty of the physical therapist to support receivers' acquisition of knowledge post-stroke. If education was not being provided then therapists believed they were failing to meet their professional responsibility to stroke survivors and their caregivers.

Therapists perceived RECAP as a *"huge"* part of what physical therapists do and of stroke rehabilitation. Others described education as: *a "10" being the most important (Dee), vital to everything (Molly),* and *it should be one of the primary focuses of [physical therapy] (Ann).* It is important to note, however, that therapists conceptualized RECAP as a *part* of physical therapy practice and distinctly different than the other *part* of practice, procedural interventions.

Therapists conceptualized “physical therapy intervention” as the procedural interventions physical therapists’ provide. As described in the Guide to Physical Therapy Practice (APTA, 2003), procedural interventions include: therapeutic exercise, functional training (in self-care, home management, work (job/school/play), community, and leisure integration or reintegration), manual therapy, devices and equipment, airway clearance techniques, integumentary techniques, electrotherapeutic modalities, physical agents, and mechanical modalities. Therapists conceptualize “education” as a part of physical therapy practice, separate from but typically in conjunction with the procedural interventions. The overall conceptualization of education versus procedural interventions influenced the provision of education. For example, therapists planned and prepared for education differently then for procedural interventions (as described in Chapter 3.4).

As part of their professional responsibility, therapists described the roles of the physical therapist as educator (Table 3.14). The first role of the therapist was to educate with respect and empathy for the receiver. Participants believed that a therapist who respects and empathizes with the receiver will educate in a manner that optimizes educational interactions and outcomes because the therapist will value the receivers’ role in the process and educate in a manner that therapists would want to be educated should roles be reversed.

> *Having a mutual respect for patients. I treat people as I want to be treated. Personally, I want to know why we’re doing what we’re doing. –Jay*

> *I value the golden-rule… “How do you want to be treated in this situation? Would you want to be treated like … you don’t have a brain, or would you like to be treated like a person?” –Demetrius*

Table 3.14

The Roles of the Physical Therapist as Educator

1. Respect the receiver 2. Empathize with the receiver 3. Create educational moments 4. Capitalize on educational moments presented 5. Be flexible in teaching methods 6. Use multiple teaching methods 7. Provide information repetitiously 8. Engage the receiver as an active learner 9. Make education meaningful to the receiver

Empathy fostered the recognition that this may be the receivers' first experience with stroke. Participants believed that therapists who recognize this can *"start from scratch"* (Zelda) with each new receiver and begin with the basics of education and progress from there. Even though the therapist possibly worked with dozens of stroke survivors, they could view each receiver with a fresh perspective and recognize that it was all new to the receiver.

To facilitate learning, the therapist as educator had several roles: create educational moments, capitalize on educational moments presented, be flexible in teaching methods, use multiple delivery methods, provide information repetitiously, engage the receiver as an active learner, and make education meaningful to the receiver. The concepts of the flexible use of multiple delivery methods and the provision of information repetitiously fit within the RECAP model and are described more in-depth in Chapters 3.6 and 3.7 regarding the delivery and timing of education. The remaining roles listed will be reviewed in this section.

Opportunities for education and learning could be created by the therapist or were sometimes presented fortuitously. The roles of the therapist were to create educational moments and capitalize on moments presented. Examples of creating moments were purposefully conducting education in various environments (e.g., within the hospital hallways as well as outdoors over real environmental barriers the receiver may face in the community), fostering a supportive and open communicative environment in which receivers felt comfortable to discuss their educational needs, and the use of certain teaching

methods in the delivery of education such as return-demonstrations. The use of these strategies by therapists created educational moments (e.g., when the receiver struggled with real environmental barriers, felt comfortable to discuss educational needs, or demonstrated difficulty during a return-demonstration, the therapist provided appropriate education). Communicative environments and teaching methods are reviewed more in-depth in Chapter 3.6 about the delivery of education. Examples of capitalizing on fortuitous educational moments included: educating a stroke survivor about smoking cessation after he complained about feeling short of breath with an exercise, educating the caregiver about where to hide a house key after a stroke survivor locked the caregiver and therapist out of the house, educating about car transfer safety and technique when a therapist was walking into work and saw a stroke survivor attempting to get out of the car in the parking lot, re-educating about Lifeline technology after a stroke survivor fell at home and could not call for help, and educating about how to decrease fall risk when traversing rugs after a stroke survivor's walker caught on a floor runner.

Another role of the therapist was to engage the receiver as an active learner. This could be achieved by holding the receivers' responsible and accountable for learning (e.g., "quizzing" them on what information has been retained, asking them to provide a return demonstration of mobility skills). Therapists described how engagement as an active learner could also be achieved by getting the receivers' direct involvement with tasks (e.g., giving them "homework" such as creation and/or maintenance of a daily exercise log or the

completion of a home assessment form). Lastly, it was achieved by facilitating problem solving by the receiver (*Where are you going to put things [throughout the house] so that… you can reach within your balance range and not fall over? – Abby).*

Therapists described the importance of making education meaningful by finding the receivers' "buy-in", or in other words, what's motivating, what drives them, what's going to get them invested, and what are they willing to do. To achieve this, therapists attempted to identify what roles the receiver had in life pre-stroke, the receivers' goals, and what activities or tasks would be meaningful avenues for providing education. For example, therapists described making education meaningful by tailoring it to the receivers' goals and interests (e.g., walking the dog, gardening, fishing, daily routines/chores). Therapists directly asked the receivers' their goals and interests or they sometimes had to rely on *"being able to read people" (Zelda).* An example of "reading people" was when a therapist perceived a receiver to be competitive and motivated by progress so the therapist educated about outcome measure scores to make the education more meaningful. Therapists also "read people" by recognizing the receiver's strengths and how they were inclined to learn best.

> *Their capacities or the things that they're good at... I can always tell the farmers… they're always tinkering with their wheelchair, makin' suggestions…. They are mechanically inclined…, being able to utilize that understanding to show them about basic mechanics of a transfer, and where your feet need to be… just little pieces like that that you can pull in and make it more meaningful to them is helpful. –Zelda*

Therapists believed that meaningful environments were required in order to make education meaningful. Therapists perceived enhanced education at the

inpatient and outpatient phases when the environment could be simulated to mimic the receivers' home environment.

> *If they're going to be doing the standing exercises, like at their sink at home, then I'll try to have them do it at our sink… make it as realistic as possible... I'll ask them to either bring pictures in from home, or measure their step height, or sit down on their couch and have someone measure… how low the couch goes so that we can try to simulate. -Dee*

Inpatient and outpatient therapists attempted to use the outdoor environment surrounding the hospital in order to simulate receivers' communities (e.g., real curb steps, grass). Home health therapists enjoyed providing education in the receivers homes because no simulation was required and the environmental context was inherently meaningful to the receivers.

Therapists described how challenging it could be to make education meaningful. It was difficult to find the right motivators and "buy-in" for some receivers and this was a difficult barrier to education for therapists to overcome (*I ask, "What do you do for fun?" and they just say, "Watch TV" and I don't really know where to go from that. –Jay).* Another challenge was finding the receiver's buy-in quickly in order to maximize the limited number of physical therapy sessions. Despite the challenges, therapists describe doing their best to reflect on who the receivers were, what their values were, and what their buy-in could be. In addition to identifying the receivers' general interests and goals, therapists' considered other receiver-specific factors that supported their ability to engage the receiver as an active learner and make education meaningful (Chapter 3.3).

Multidisciplinary Team

Stroke rehabilitation occurs in the context of provision of services by a multidisciplinary team. Therapists described their beliefs about the provision of

education within this context. Overall, therapists believed in a team approach to providing education to stroke survivors and their caregivers (*it should be cross-discipline… everyone should be touching on [the education provided] –Bertha)*. They believed that each profession/discipline was responsible for taking the "lead" on educating about certain topics but that optimally, each member of the team was reinforcing the other's education provided (*we have our strengths and our expertise… [but] we're all just working on the whole person together –Dee)*. Therapists described feeling territorial on very few, if any, topic areas (*we're all a team and if a client needs that, whoever can deal with it when they need it… should address it –Zelda)*. Therapists believed that reinforcement and duplication of education from multiple providers optimized the outcomes of education because it facilitated more repetitions of the information and enabled receivers to hear the information from multiple sources.

Therapists believed that given physical therapists training and expertise, they should take the lead on educating about: gait training, assistive devices for gait (selection, use, and progression), stair training, wheelchair mobility and design choices, high level balance, the physical therapy home exercise program, lower extremity bracing and orthotics, lower extremity electrical stimulation devices, and transfer training. Therapists believed members of other professions on the team were "experts" on certain content areas and should take the lead educator role for those (*there's things that I probably leave to other members of the team just because I feel like it's not my area of expertise. –Demetrius; we have to collaborate with the people that know the stuff even better than us. -*

Dee). Examples of topics therapists perceived other disciplines were better suited to take the lead on included: insurance, government services, financial resources, transportation options (case management); toileting, bowel and bladder, dressing, grooming, sexuality (occupational therapists); depression and anti-depressants (psychologist, physician); causes of stroke, weight management, cholesterol management, nutrition (physician, nurse, dietitian).

To better provide education as part of a multidisciplinary team, therapists believed that knowledge of and access to other professionals facilitated education. When therapists believed the receivers' educational needs were outside the scope of what they could provide, the ability to consult other professionals and capitalize on their expertise was important. In these situations, therapists viewed themselves as the *"point of entry person" (Dee)* for the receiver to access the right source (healthcare provider) needed.

Inter-source communication was perceived as a critical factor to facilitate the provision of education as a multidisciplinary team. Through communication with other professionals on the team, therapists were able to gain an understanding of what was already educated about and what needed to be reinforced without having to solely rely on assumptions. This was especially important when time with receivers was limited. For example, if the physical therapist knew that the occupational therapist was educating about certain topics and that no further reinforcement was needed, the physical therapist could focus educational efforts elsewhere. If the physical therapist was informed that education provided by another team member required reinforcement, the

therapist could provide it. Through communication with other providers, therapists could also find out how the receiver learns best and coordinate the delivery of education among providers working with the receiver.

Barriers to Providing Education as a Multidisciplinary Team

Therapists described barriers to providing education within the context of education provision, by a multidisciplinary team, in the healthcare system. A healthcare team framework in place, at the inpatient rehabilitation phase, that was perceived to be a potential barrier to education was a case manager serving as a relay point between the receivers and the healthcare providers. While some positives to this were noted, therapists described how this process might hinder optimal education in that the case manager was responsible for conveying a large amount of education from the entire team and effectively communicating the information.

> *It's a lot of information for a case manager to relay and even though they're familiar with that stuff, they maybe don't know how to put it into terms that the family member can understand as opposed to [the] therapist. –Ann*

Inpatient therapists suggested the need for conferences between the team and the receivers, rather than meetings solely between the case manager and receivers, in order to optimize education provided by the team.

> *Family conferences, where all the therapists will meet with the family halfway through the patient's stay… I see benefit in that… it's one thing to hear it from the case manager who's reading the notes, it's another thing to hear it from the therapist who has had their hands on the patient day in and day out. –Elizabeth*

Therapists described a lack of educational accountability and educational coordination within the healthcare team. Therapists described that there were no

processes in place for determining who on the team was providing education, what education was provided, and if the education was successful or needed to be reinforced. This lack of communication between providers was problematic both within and across settings.

> *I think that's a huge issue, is just there's a lack of communication… [the therapist in the next setting has] no idea what we've done in inpatient… what we've told the family… that's really frustrating is they almost have to start over. –Bertha*

Members of the team primarily communicated with each other through the following means: verbal (in-person or telephone) and through documentation. Communication through documentation for home health therapists involved the use of a book to record vital signs and coordinate care with each other that would be completed each visit. Inpatient therapists communicated with each other via "functional status boards", marker boards at each patient's bedside in which providers could share information with each other (e.g., how the patient transfers). A barrier associated with these was that the information was not always updated regularly.

Prior to the implementation of an electronic medical record system in which education was documented, inpatient therapists trialed a paper checklist to record education provided by the team. The checklist included a comprehensive list of educational topics, a numerical scoring system related to how the receiver understood the information provided, and how the education was provided. The theory behind the checklist was to enable providers to educate as a team and identify what was educated about, how, when, and if the education was successful. Unfortunately, the checklist was perceived as not clinically friendly,

time-consuming, disorganized, overwhelming, and ineffective. Instead of being a useful tool to organize the education provided by a large team and a tool to enhance educational interactions, it was viewed as another mandatory thing to complete.

The inpatient and outpatient therapists described the impact of the implementation of an electronic medical record (EMR) system on education. Overall, therapists believed that the EMR did not change or influence how education was provided; rather, it influenced their ability to communicate with each other through documentation about education provided. Therapists perceived the electronic version of the paper educational checklist difficult to use. Therapists described a preference for documenting the details of education in long-format (paragraphs) rather than click boxes.

> *It didn't influence how I did the teaching. It did influence how I documented the teaching. I used to document it much more thoroughly and much better. And now it's just a chart where I just click "x". –Bertha*

While documentation of education provided was challenging, it was equally difficult to find education-related information in the EMR prior to working with a patient (e.g., what content had already been covered, what still needed to be covered, how the receiver learns best).

Effective and comprehensive communication and documentation of education provided was suggested to be useful because providers would know what content had been covered, what content needed reinforcement, what still needed to be covered, and how the receiver learns best. Given the time constraints with a receiver, if a therapist knew ahead of time that something had been covered and was understood, they could then focus educational efforts on

other topics. Therapists suggested the need for easier and effective communication pathways between providers within and between settings. Therapists believed that the ability to coordinate education was important to meeting stroke survivors' and caregivers' educational needs. Coordinated education by the team would facilitate prioritization of education that did not have to rely on therapists' assumptions of education already received, as well as the avoidance of mixed messages and conflicting education between providers. Therapists described the need for an educational framework or educational standards with which to guide best practice for physical therapists and the multidisciplinary team to provide education to stroke survivors and their caregivers.

Complex Healthcare System

Therapists described perceptions of providing education within the context of the current healthcare system. Therapists described the negative impact to planning and providing education by *"the pressures of healthcare" (Zelda)* on physical therapy in general. Therapists described pressures to do more with less in that optimal patient outcomes were expected despite higher productivity standards, lengthening documentation standards, and limited amounts of time approved by third party payer sources for stroke survivors to receive physical therapy services. Therapists described that an emerging trend by third party payer sources was limited number of visits allowed and increased number of reassessments required, both of which negatively impacted the therapists' abilities to provide education.

> *The barrier to outpatient therapy right now is just the insurance limitations… six visits and then you have to do a reassessment, and then you might get four more visits... and have to do another reassessment and that just cuts into your education time because you're constantly, every fourth or fifth visit, you're having to do another stupid reassessment. –Dee*

Therapists also described barriers to providing education within the context of the healthcare system that were associated with educational reimbursement.

Education and Reimbursement

Billing practices within the healthcare system influenced education provided and highlighted important distinctions between therapists' views on education versus procedural interventions. The home health therapists did not feel conflict or ethical pressures regarding education and billing due to a different guideline for reimbursement. This was not the case, however, for inpatient and outpatient therapists. In describing their thoughts about billing for education versus procedural interventions, discrepancies in practice, a lack of clear guidelines, and influences on practice and the provision of education were evident. Procedural interventions were perceived as physical therapy "interventions" and were what third-party payers reimbursed for physical therapy services. There was no consensus about whether or not there was a billing code for education. Some therapists assumed there was one in existence because they had a code to bill for it at other healthcare organizations they had worked at previously, but they noted that a code for education was not being used at their current facility. Others believed that education was not billable. All therapists

agreed that they could not charge for anything when providing education solely to the caregiver, without the stroke survivor present.

Given the absence of an education-specific code, therapists described including time spent verbally educating into codes for procedural interventions, providing all education simultaneously with procedural interventions, and/or providing education pro bono outside of the regular therapy sessions. Time spent verbally educating was sometimes included in codes used for a procedural intervention (e.g., time spent educating about gait was included in the gait training code, education about exercises was included in the therapeutic exercise code). For education that did not directly relate to a code, therapists selected procedural codes most closely associated with the type of education provided (e.g., education about stroke knowledge or equipment needs was billed under the therapeutic activities code).

Some had no issues or concerns with billing a procedural intervention code for time spent solely on verbal education and not actual physical activity because they viewed education as a primary and critical part of what therapists do. They believed time spent educating was valuable and therapists should be allowed to include it as part of a physical therapy session as was appropriate. Some therapists had qualms or felt some level of ethical conflict about spending too much time on verbal-only education because of the billing issues (*there's always that thought in my mind, "Is what I'm doing meeting the billable requirements?" –Dan; I am a little bit wary of spending too much time. -Maggie*). In these situations, despite believing that education was valuable and important,

there could be a sense of pressure to spend more time on the physical performance of tasks and less time on verbal educational interactions. Some therapists described attempts to provide education during a stroke survivor's rest break from an activity or multi-tasking with combining education and activity (e.g., providing education while a stroke survivor was completing an activity).

> *I try to multi-task… it's hard to… do physical stuff and take in stuff, but if we're just… working on standing tolerance, I'll sit there and try to throw in some education. Or during rest breaks a lot… we'll walk and when they have to sit down, get tired, while they're drinking water… I'll start talking about education… I'll cut it off when… I feel like they've rested long enough. –Molly*

This was feasible in some cases, but challenging in others, especially in light of cognitive or communicative deficits associated with stroke.

> *Some people, you can walk and talk with people, but you've screwed up their walking and you've screwed up their talking, so you've gotten nothing accomplished. –Abby*

Therapists described providing education pro-bono outside the regularly scheduled session due to billing conflicts, but this was not always feasible and challenging due to time demands. Therapists did not receive organizational support for it in that thearpists had to provide it on their own time. Some inpatient therapists described educating the receiver after their shift ended. Outpatient therapists tried to find time before or after the session to provide education but this was frequently difficult given the back-to-back scheduling of patients to be seen. Some outpatient therapists visited the stroke survivor's home to provide an educational consultation as a pro bono service.

Therapists perceived education as an important and vital part of what physical therapists do and believed it should be considered a skilled intervention.

Therapists described that education was a skilled task that required the skills and expertise of the therapist to provide patient-centered education, to communicate in an effective manner, and to be flexible and adaptable in teaching methods. As such, some believed that education needed a billable code. Therapists suggested that a code for education would eliminate pressures to multi-task in situations where that was not possible, eliminate the strain on therapists to provide pro-bono education that was not supported by the healthcare organization, and it would provide a more accurate representation of how time was spent with receivers. Therapists described how the education billing code would have to have limitations though (e.g., a maximal time allotment, documentation to indicate that it was provided, what was provided, teaching methods used, and how the learning of the receiver was assessed). The restrictions would be required in order to prevent fraudulent billing or mismanagement of time spent with stroke survivors and caregivers.

Environmental and Socio-Cultural Context

The environment and socio-cultural context influenced RECAP by physical therapists. The larger socio-cultural and environmental context of eastern Kentucky and the Midwestern region of the United States influenced the RECAP experience of the participants as revealed in their descriptions of the stroke survivors and caregivers they provided education to and the differences they noted between rural and urban receivers. Therapists also described the influence of the environments in which education was conducted.

Therapists believed that meaningful environments were needed to make education meaningful and optimize outcomes. Therapists perceived hospital environments that were not designed as meaningful home and community-like environments or were not adaptable to create simulated environments were barriers to education. Simulating meaningful environments was challenging, if not impossible, for inpatient and outpatient therapists given the hospital design and equipment available.

> *That's the limitation with outpatient, is because it's a very sterile environment, the mats aren't squishy like their bed and they're not as high… our chairs aren't as low as their recliners. –Dee*

The environmental design of the traditional "gym" for inpatient and outpatient therapy was viewed as being designed and useful for orthopedic populations, not neurological populations. Gyms were designed for therapeutic exercises, not for retraining functional tasks. Dee described the downsides of this in regards to stroke rehabilitation:

> *[The outpatient clinic is] a very sterile environment… it's good for strengthening, but I don't know that with stroke; it's not so much about strengthening as it is relearning that functional movement… rewiring that pathway… being in that functional… more motivating environment, I think it would just come more naturally. –Dee*

Therapists also described not having all of the equipment needed in the hospital environment to provide education. For example, inpatient and outpatient therapists suggested the need for a car to be available indoors, which many had seen at other hospitals, in order to provide education about car transfers when caregivers were not available to bring in cars or when the weather prohibited outdoor practice.

These barriers to education from environmental limitations within the healthcare settings were compounded by the restrictions within the healthcare system to accessing meaningful environments such as the home or community. Inpatient therapists were typically confined to the hospital, outpatient therapists were confined to the outpatient clinic, and home health therapists were confined to the person's home. Therapists described how it was difficult, therefore, to educate about community reintegration when none of the therapists in any setting had the ability to conduct physical therapy sessions and provide education to the receiver in the community. Inpatient therapists described the use of community educational outings in the past and how beneficial these were in educating about equipment needs for community mobility, functional mobility (e.g., car transfers), overcoming environmental barriers. At the time of this study community outings for stroke patients were not being used and had not been used for many years. Outpatient therapists described how they used to be allowed to conduct sessions at stroke survivors' homes in order to educate about home modifications and address other needs. Over time, the therapists were informed they could no longer do this due to liability concerns.

Some outpatient therapists described providing pro-bono educational consultations to receivers in their homes and communities.

> *I've gone out to people's houses… made some suggestions… I've gone to gyms with them too… pointed out what they should do and how to get in, troubleshooting… one lady had difficulty getting into her hairdresser. I went with her and… we talked to the lady that owns the building about putting in a ramp for her. So I think they ended up pouring part of the sidewalk, like pouring a ramp for her to get up. –Maggie*

Therapists conducted pro-bono education in the community because the ability to directly see and problem solve issues enabled the therapists to provide meaningful education. Therapists described how it was sometimes impossible to problem-solve home and community educational issues from the confines of the clinic. Therapists suggested that the ability for therapists in any setting to conduct education in the person's home or community would facilitate education in many areas (e.g., home modifications, return to work, community mobility). Therapists also suggested that their ability to create and tailor home exercise programs to the person's home and community environments would theoretically support improved compliance with exercise and in turn, improved functional outcomes and recovery post-stroke. Therapists advocated for home and community-based rehabilitation services because while pro-bono sessions were completed, they were time-consuming and had to be conducted outside of the therapists scheduled work hours. In other words, the pro-bono sessions were a service from the therapist but not from the healthcare organization.

SECTION FOUR: THE RIBBON CUTTING

Chapter 4.1: Evolution and Implications of RECAP

The purpose of this dissertation was to develop a theory of "Rehabilitation Education for Caregivers and Patients" (RECAP) by physical therapists in stroke rehabilitation that is grounded in the experiences of stroke survivors, their caregivers, and physical therapists. Qualitative research methods with a grounded theory approach were used. Potential constructs of RECAP were identified, rooted in previous research of the experiences and perceptions of receiving education of stroke survivors and caregivers, and formed the preliminary theoretical model. The theory was further grounded and evolved through a qualitative study investigating the experiences of receiving education for stroke survivors and their caregivers in rural Appalachian Kentucky, a region with a high incidence of stroke and underserved in terms of healthcare services (Section 2). The theory was also grounded in a second study investigating the experiences and perceptions of education for physical therapists across the post-acute care stroke rehabilitation spectrum (Section 3). This fourth and final section will present the theory that emerged and the theoretical model; including integration of the findings from the 2 studies with that of previous research. The section concludes with the limitations and recommendations for future directions.

The RECAP Theory and Model

The theory of RECAP generated from the data of this dissertation is: Physical therapists' continually assess the educational needs of stroke survivors and caregivers, in order to participate in dynamic educational interactions that

involve the provision of comprehensive content, at a point in time, delivered through diverse teaching methods and skilled communication. This phenomenon is influenced by factors associated with the educator (physical therapist) and receiver (stroke survivor/caregiver). RECAP occurs in the context of the physical therapist's professional responsibility, the multidisciplinary team, a complex healthcare system, and the environment/socio-cultural context. The theoretical model (Figure 4.1) depicts the six core constructs and four encompassing constructs as well as their relationships and interactions.

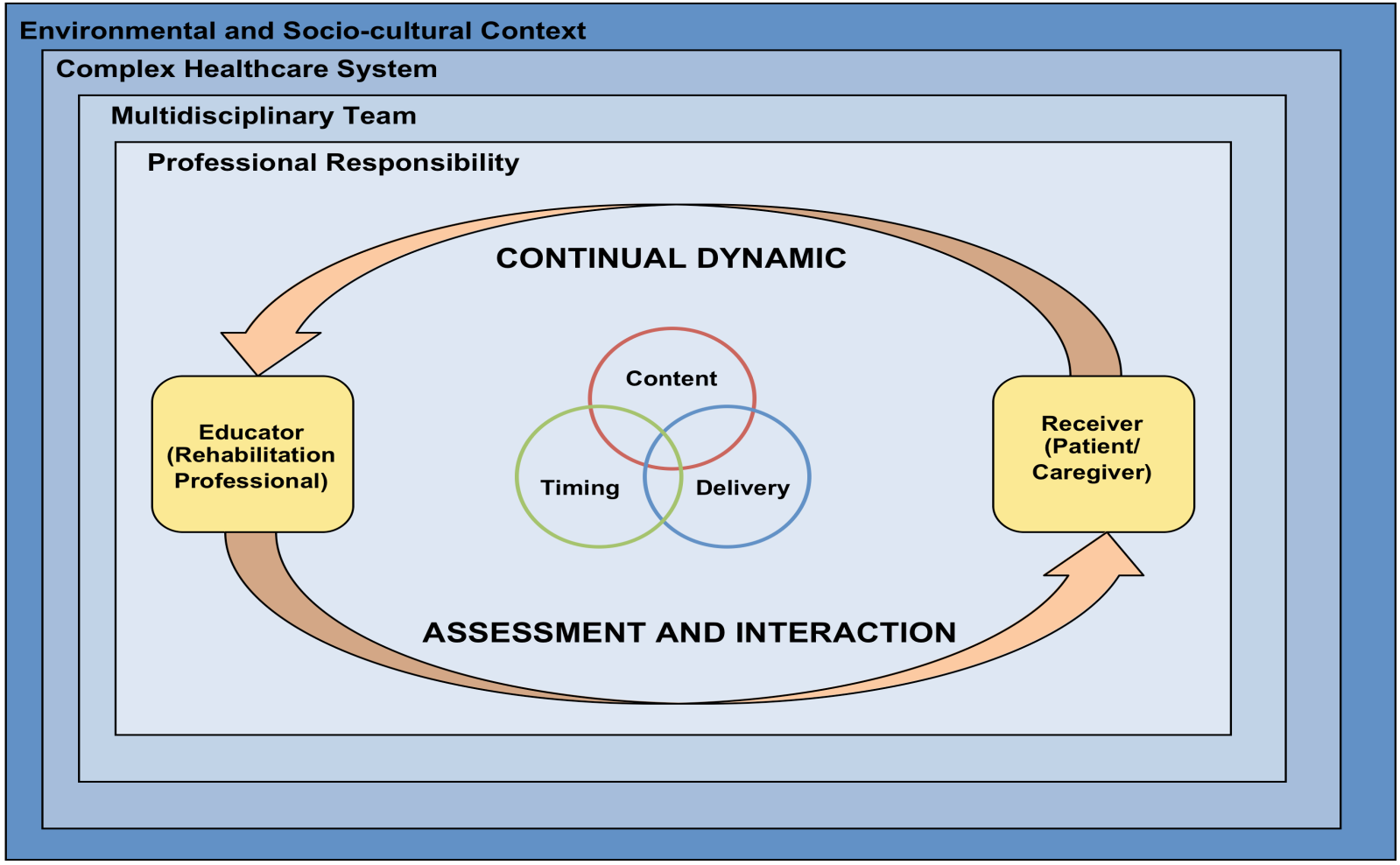
Core Constructs

Six core constructs of RECAP in physical therapy stroke rehabilitation practice were identified: continual dynamic assessment and interaction, educator (physical therapist) factors, receiver (stroke survivor/caregiver) factors, comprehensive content, delivery through teaching methods and communication skills, and the timing of education. These were fundamental elements of each interaction between a physical therapist and stroke survivor and/or caregiver.

Continual Dynamic Assessment and Interaction. Educational interactions occurred between the physical therapist (educator/source) and stroke survivor and/or caregiver (receiver) in which the physical therapist delivered content at a point in time. RECAP also involved a continual dynamic process of an assessment of educational needs and the outcomes of education. The model reflects the non-linear nature of RECAP in that therapists continuously assessed educational needs, provided education, and assessed the outcomes of education both within a physical therapy session and throughout the physical therapy

Figure 4.1.

Rehabilitation Education for Caregivers And Patients (RECAP) Theoretical Model



episode of care. These dynamic assessments and interactions involved the therapist taking into consideration the characteristics of the receiver to tailor, or individualize, the education provided by selecting the appropriate content, considering the timing, and having a willingness to adapt delivery teaching and communication methods to meet the needs of the receiver.

Assessment of who the receiver of education should be (stroke survivor and/or caregiver) was also described. Physical therapists and caregivers in this dissertation believed in the importance of caregiver inclusion in educational interactions. Caregivers were perceived to serve a profound role in the rehabilitation and recovery of the individuals with stroke as stroke survivors relied heavily on them to absorb and integrate all of the information provided. As noted in a systematic review of qualitative studies about the challenges caregivers of stroke survivors face (Greenwood, Mackenzie, Cloud, & Wilson, 2009), receiving needed information is a commonly identified challenge. Continual improvements in outreach efforts to address the informational needs of caregivers is called for (Brereton & Nolan, 2000; King & Semik, 2006). By providing information and support, healthcare providers play an important role in facilitating and supporting how quickly and in what manner the caregiving role is adopted (Brereton & Nolan, 2000).

The dynamic assessment of educational needs involved multiple methods, including therapist-initiated and receiver-initiated methods. Identification of each receiver's unique educational needs contributed to the ability to provide "tailored education". The need to avoid solely relying on receiver-initiated methods was

made clear. The findings from the Section 2 study are consistent with previous research that suggests a lack of identification of educational needs may be attributed to reluctance by patients and caregivers to ask questions in addition to missed cues by providers (Eames, Hoffman, Worrall, & Read, 2010; Wiles, Pain, Buckland, & McLellan, 1998). Similar to the theme of "not knowing" in a study investigating the barriers to accessing stroke information (Eames, Hoffman, Worrall, & Read, 2010), participants in this study typically did not actively seek out information because they did not know what to ask. When providers did not proactively provide education, opportunities for educational interactions were missed. This is consistent with another study in which caregivers reported only receiving information when they directly asked providers questions (Brereton & Nolan, 2000). Findings from the Section 3 study indicated that potential barriers to identification of educational needs related to the therapist included: reluctance to ask questions about uncomfortable topics, assumption that the receiver already received education about a topic, and the assumption that a lack of questions from the receiver is a lack of interest.

Therapists described continual assessment of the outcomes of education provided, both within sessions and over time. This involved assessments of verbal and non-verbal feedback from the receiver, return-demonstrations, improvements in functional mobility over time, reduction of residual deficits, and the perceived level of the receivers motivation, willingness to participate, and frame of mind. The optimal result of dynamic educational interactions, that therapists strived for, was an empowered, motivated, and engaged receiver who

puts education into action to facilitate an optimal recovery and reconstruction of a self-identity post-stroke. This goal was echoed by stroke survivors and caregiver participants in this study who described challenges in adapting to life post-stroke and a loss of personal identity and sense of self (Danzl et al, 2013). Further, improved communication from providers is suggested to help individuals redefine identity post-stroke, exit the sick role, and regain health (Anderson & Marlett, 2004). Assessment of outcomes was challenging, however, and indicated the need for development of improved strategies to assess the effectiveness of education.

Educator Factors. Educator/therapist-related factors that were perceived by physical therapists to influence education included experience, training, knowledge and comfort with content, planning and preparation of education, and personal characteristics. Therapists believed that providing education was more challenging when they were novice therapists due to a lack of formal and structured training in providing education in their entry-level academic courses, clinical rotations, and new employee orientation/mentoring. There was a prevalence of “annual competency checks” to ensure therapists had the skill sets to perform procedural interventions but no manner in which to support or establish competence in providing education. There was a need for knowledge translation mechanisms to translate knowledge of the evidence and of community resources to therapists so that they in turn could provide this education to receivers. A sense of personal discomfort with certain topics indicated a need for alternate delivery methods to verbal provision in order to

ensure educational needs were met. Barriers to planning and preparing for education may stem from how education is perceived within the profession of physical therapy (discussed further in “professional responsibility”), and due to limited time and resources. Overall, the issues regarding training may be attributed to a lack of a guiding educational framework and establishment of educational standards. Future research is needed to assess how RECAP is taught in entry-level programs, the application and effectiveness of the RECAP model to development of entry-level and continuing education curriculum, and the use of the RECAP model to establish educational standards.

Receiver Factors. Receiver-related factors that were perceived by physical therapists to influence education included demographics (age, socioeconomic status, educational attainment, geographic residence), readiness and ability to learn (learning style, frame of mind, willingness to learn, expectations and perceptions, time-post stroke, communication and cognition), and caregiver-specific factors (relationship to stroke survivor, viewpoint on caregiving, availability, physical capabilities). It is possible that these perceptions of the receiver might not be shared by stroke survivors and caregivers, however, they are important to note because the therapists perceived them as influential to their practice of providing education. The demographic data indicate a consideration of geographic residence (rural versus urban) may be warranted when tailoring the delivery, content, and timing of education, a concept that had not previously been explored in physical therapy educational practice. The category “readiness and ability to learn” is in accordance with suggestions that greater benefits and

outcomes will be achieved when education is provided at a time when stroke survivors and caregivers are ready to receive it (Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011). The category “caregiver-specific factors” provides insight into the nuances of providing education to caregivers, another concept that had not been previously explored in physical therapy stroke practice. Overall, the data from these categories of receiver-factors might provide useful insight to practicing therapists, by bringing to the surface of conscious thought a recognition and better understanding of factors to consider when providing education.

Comprehensive Content. Ten domains of content, spanning a comprehensive range of topics, provided by physical therapists, emerged from the data. The domains aligned well educational needs expressed by stroke survivors and caregivers in this study as well as those in previous research. Consistent with other research (Sullivan et al., 2008), stroke survivors and caregivers in this study described a lack of foundational stroke knowledge, including stroke prevention, awareness of risk factors, and recognition of warning symptoms. This is consistent with a study assessing stroke knowledge of rural, Appalachian West Virginia residents (Alkadry, Wilson, & Nicholas, 2006). Conducting community screenings of stroke risk, such as described by Pearson (2010) in a study assessing cardiovascular risk of women in Appalachian Tennessee, would help determine how widespread stroke risk and knowledge deficits are in Appalachian Kentucky. If awareness of stroke warning signs, risk factors, and prevention is found to be a regional problem, healthcare systems

and community leaders may want to consider implementing a stroke education program; a service demonstrated to be effective for rural dwellers in improving stroke knowledge (Pierce et al., 2011). Additionally, a qualitative study by Sullivan et al. (2008) that provides insight and suggestions for the development of stroke prevention campaigns may be a useful resource for providers interested in addressing pre-stroke education.

Consistent with previous studies (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011; King & Semik, 2006), caregivers in this study described the need for information to caregivers about becoming and being a caregiver, services available (e.g., respite), and management of psychological and emotional issues. Physical therapists in this study described varied extents to which they provided this type of education. While some indicated that this type of education may fall more upon other providers (e.g., case management), their belief that education needs to be reinforced across providers supports the notion of physical therapists providing comprehensive education to caregivers. King, Ainsworth, Ronen, & Harke (2010) call for expansion of caregiver education beyond concrete task topics (e.g., assisting with functional mobility, exercises, medication management) to a holistic, comprehensive approach that also includes behavioral issues, stress management techniques, how to effectively communicate with the stroke survivor, and identification of support systems and resources. Work by King & Semik (2006) provides potentially useful caregiver education tips (p.41) that physical therapists could provide in which advice *to* caregivers *from* caregivers is

described; topics include preparation for caregiving, enhancing the stroke survivor's emotional and functional abilities, and sustaining the self and family.

Findings from this study reinforce those of previous research (Brereton & Nolan, 2000; Greenwood, Mackenzie, Cloud, & Wilson, 2009; Hafsteinsdottir, 2011) in highlighting the importance of including the following topics in stroke education: general stroke information (what is stroke, residual deficits, what caused the stroke, prognosis), the role of therapy to facilitate recovery, how to facilitate functional mobility, neuroplasticity and reassurance of the possibility of recovery, preventing secondary complications and future strokes, and financial resources. Findings from our participants about the need for information about the healthcare system in terms of settings and services in the continuum of care, how to navigate the system, and the role of patients and caregivers does not seem to be a well researched area.

The manner in which therapists prioritized content was complex. Therapists described the top 3 areas they believed were important to educate about, priorities based on what healthcare setting they practiced in, and priorities based on each unique receiver's needs. Future research may include a prospective study assessing the educational priorities according to stroke survivors and caregivers as they traverse the rehabilitation continuum to provide better insight to physical therapists.

Delivery Through Teaching Methods and Communication. Participants in this study described a variety of teaching methods to deliver education (verbal, written, visual, and tactile). Assessment of education delivery is important

because inappropriate presentation of information (e.g., format, language) can be a barrier to optimal education (Eames, Hoffman, Worrall, & Read, 2010). Verbal provision of education was a common method reported by participants. A study by Garrett & Cowdell (2005) indicates a preference by stroke survivors and caregivers for verbal provision as the primary means of education but with additional support through other formats. For example, participants in the study by Garrett & Cowdell (2005), suggested accompanying verbal education about complex anatomical information with pictorial or 3-D formats (e.g., posters, models, videos, and diagnostic scans). Physical therapists in this study described a lack of access to these types of pictorial and 3-D formats. Data from this study echoed previous research (Eames, Hoffman, Worrall, & Read, 2010 and 2011; Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011) in indicating the need for multiple teaching methods of education delivery.

Some participants described written materials as helpful adjuncts to the education provided verbally and as useful resources into the chronic phase of stroke. Individualized stroke information booklets have been found to improve stroke knowledge and recognition of risk factors (Lowe, Sharma, & Leathley, 2007). Some research, however, has found poor recall in stroke survivors and caregivers of having ever received written information (Hanger et al., 1998; O'Connell et al., 2009). This supports the concept of using individualized, meaningful written information that is revisited at multiple time points. Hoffman, McKenna, Worrall, & Read (2007) found that computer-generated individually tailored written education packages for stroke survivors improved satisfaction

with both content and presentation. Providers interested in creating written materials for stroke survivors and caregivers are referred to work by Hoffman & McKenna (2006) that provides a guide for improving the design and content of written materials provided to stroke survivors as well as work by Rose, Worrall, & McKenna (2003) and Rose, Worrall, Hickson, & Hoffmann (2011) for designing aphasia friendly written materials. An example of a written guidebook for caregivers has also been created by research out of the Veterans Administration and may be a useful resource (Rittman, 2007).

While literature is emerging regarding the design of stroke education websites for survivors and caregivers (Kerr, Hilari, & Litosseliti, 2010; Korner-Bitensky et al., 2008; Rochette, Korner-Bitensky, Tremblay, & Kloda, 2008), the large majority of participants in this study did not report websites as a teaching method used. This may have been attributed to a lack of access to computers and the Internet in remote rural settings or it may be due to providers lack of awareness of the websites available. Given the emergence of the technological age, efforts to inform therapists of online resources to share with stroke survivors and caregivers would be well invested. Future research into the development and effectiveness of electronic educational resources (e.g., iPad applications, videos, websites) may be warranted to modernize physical therapy education.

Stroke support groups and educational classes were suggested as needed methods of delivering education. With the exception of stroke survivors at the inpatient phase, survivors and caregivers did not have access to these types of delivery methods. Stroke support groups could be a valuable avenue of

providing information that is currently lacking in the region. Work by Marsden et al. (2010) provides a description of the successful implementation and benefits of a stroke support group in rural Australia that combined exercise, education, and socialization. Johnson & Pearson (2000) studied the effects of a structured education course for stroke survivors living in the community, consisting of 8 classes over one month, and found improvements in depression and sense of hope compared with the control group. Denby and Harvey (2003) also provide a comprehensive guide and structure for their development of an inpatient program of educational classes.

Physical therapists, stroke survivors, and caregivers in this study considered effective and clear communication from providers as a critical component of education. This is in accord with an article penned by the wife of a stroke survivor promulgating communication as the key to stroke recovery and positive outcomes (Anderson & Marlett, 2004). Anderson & Marlett (2004) suggest that communication is the overlooked rehabilitation tool; *"we have assumed that it is the science of medical treatments that produces outcomes and have overlooked the role of the art of communication"* (p.442). Findings from the stroke survivors and caregivers in this study, such as the impact of the phrase "small stroke" and the belief held by some participants that the brain damage was permanent, support existing literature that suggests inadequate communication can lead to misconceptions, anxiety, and fear (O'Connell, Baker, & Prosser, 2003; O'Mahoney et al., 1997; Rodgers, Bond, & Curless, 2001). In other words, poor communication may equate to education lost in translation. Stroke survivors

and caregivers described the importance of providers' ability to actively listen and support the voice of the stroke survivor and caregiver. This conveyed a sense that providers cared and it facilitated greater personal connections, which in turn supported greater buy-in to the education provided. Physical therapists described recognition of the influence of communication skills and styles. Future research investigating communication and listening styles of therapists would be useful for therapists to self-assess their styles and understand how their styles could be adapted to meet the needs of the receivers.

Timing of Education. The timing of education referred to when education was provided at different points within a physical therapy episode of care and at different time points along the rehabilitation continuum of care. Timing is a less well-understood concept to physical therapists compared to content and delivery of educational interactions. For example, the raw data from the initial coding in the study with physical therapists yielded 38 pages for "content", 27 pages for "delivery", and only 4.5 pages for "timing".

The retrospective nature of the studies in this dissertation may have contributed to the challenges in pinpointing when certain education as provided or needed at different time points. Existing research, however, can provide guidance on this concept. For example, a systematic review on informational needs of stroke survivors and caregivers reports the need for information at the inpatient rehabilitation phase about why the stroke happened and psychological and emotional issues and at the chronic phase about local agencies and support services (Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011).

In a study about survivors and caregivers perceptions of accessing information, poor timing of information was a noted barrier (Eames, Hoffmann, Worrall, & Read, 2010). The study highlights the challenge of correctly timing information, as some participants wanted more information early on while others wanted less because they were overwhelmed and could not process the information provided (Eames, Hoffmann, Worrall, & Read, 2010). Considering individual factors or phases the survivor or caregiver is going through may be a helpful means of correctly timing education across points of the continuum. For example, the "Timing it Right" framework, described by Cameron & Gignac (2008), provides a guide for timing the provision of education based on 5 phases caregivers experience: event/diagnosis, stabilization, preparation, implementation, and adaptation.

Stroke survivors and caregivers in this study attested to the need for education to be provided repetitiously throughout the rehabilitation continuum settings and into the chronic phase of stroke. All of the participants experienced a sharp decline in healthcare support upon discharge from the inpatient phase, similar to the experience of limited follow-ups in the chronic phase for survivors and caregivers in Scotland (Salisbury, Wilkie, Bulley, & Shiels, 2010). Consistent with work by Brereton & Nolan (2000), this isolation from the healthcare system resulted in limited or no awareness of services in their rural communities, decreased support, lack of referrals, and lack of access to information. Caregiver informational needs were most apparent upon discharge from inpatient services, consistent with work by Brereton & Nolan (2000), who noted even the caregivers

who were present frequently throughout the inpatient phase, did not fully realize the impact of stroke until they returned home.

Physical therapists shared the belief in repetitious education provided into the chronic phase but noted the challenge in achieving this. Other studies have assessed educational needs at certain time points post-stroke and indicate the need for long-term educational provision (Garrett & Cowdell, 2005; Hanger et al., 1998; Wiles, Pain, Buckland, & McLellan, 1998). Stroke is a chronic condition that requires chronic education. Survivors and caregivers have unmet and evolving informational needs years post-stroke (Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011; Hanger et al., 1998; King & Semik, 2006). Findings from our study confirm the need for multiple repetitions of information in order to build on the education provided and make sense of the information as survivors and caregivers progress through the stroke journey (Garrett & Cowdell, 2005). Improved educational supports upon discharge from inpatient services and at a post-discharge follow-up time may help to meet informational needs over time and at key transitional points.

Encompassing Constructs

Four constructs that encompassed and influenced educational assessments and interactions were identified: professional responsibility, multidisciplinary team, complex healthcare system, and the environmental and socio-cultural context.

Professional Responsibility. Therapists perceived RECAP as part of their professional responsibility and obligation to stroke survivors and caregivers. The

therapists perceived roles as educators influenced educational interactions through attempts to make education meaningful and tailored. Therapists conceptualized RECAP has a part of physical therapy practice but with distinct differences to procedural interventions.

While educating patients and caregivers is included under the umbrella of "physical therapy intervention" in the *Guide to Physical Therapy Practice* (Rothstein, 2001), therapists did not perceive RECAP as an "intervention" or as the "rehabilitation". Rather, they perceived the procedural interventions as "interventions" and "rehabilitation". In the *Guide*, education to patients and caregivers is conveyed as playing a supportive role to the 9 procedural interventions. This may have been intended to emphasize the importance of integrating education with each procedural intervention, however, not recognizing education as a potentially valuable intervention in and of itself may contribute to it not being reimbursed, the minute amount of research devoted to it in contrast to procedural interventions, and the perception of stroke survivors and caregivers that their educational needs are not being met.

Multidisciplinary Team. The practice in stroke rehabilitation of service provision through a coordinated, multidisciplinary team influenced educational interactions. Physical therapists in this study believed that a team approach to providing education was paramount. They described the belief that each discipline takes the "lead" on certain content but that each discipline reinforces education from others. This repetition and duplication of education was perceived to be important for achieving optimal outcomes. Inpatient therapists also

described the belief that having a single person provide education (e.g., the case manager) to the stroke survivor and caregiver was potentially problematic. These perceptions stand in contrast to educational practice paradigms set forth in clinical practice guidelines.

The following recommendations are currently advocated for in the clinical practice guideline set forth by Duncan et al. (2005): 1) identify a specific team member to provide information and 2) document education in the medical record to avoid duplicate information provision across disciplines. Identifying a specific team member to provide information may be detrimental to physical therapy practice if a team member in another discipline is designated as the point person for providing education. Avoiding duplication of information provision fails to consider the inability of a person to retain the information if presented in a single session due to poor concentration, fatigue, anxiety, and stress (Denby & Harvey, 2003). In a qualitative study assessing information needs of individuals with stroke and caregivers (Garrett & Cowdell, 2005), they expressed a desire to revisit information frequently in order to build on it or make sense of it along their stroke journey, supporting the need for the repetition of information. These clinical practice guideline recommendations stand in contrast to the theory that information is most effectively retained when the entire healthcare team is continuously reinforcing the information (Denby & Harvey, 2003). Also, health behavior changes are more likely to occur if multiple providers use multiple mediums to present the same concepts (Denby & Harvey, 2003).

Barriers to providing education within the context of a multidisciplinary team included poor inter-source communication, difficulty with documentation of RECAP, and a lack of educational accountability processes. These contributed to challenges in assessing who on the multidisciplinary team was providing what education, when, and how as well as what education from other team members needed reinforcement. These barriers also contributed to assumptions by therapists that education had already been provided by someone else and did not require reinforcement. The concept of educational accountability is similar to the concept “who is responsible” in work by Eames, Hoffman, Worrall, & Read (2010).

These barriers suggest the need for healthcare organizations and future research to assess means of establishing educational accountability, effective documentation methods for education, and effective communication pathways between providers in different settings. This is consistent with work by Garrett & Cowdell (2005) who suggested a lack of clear structure for providing education leads to missed educational opportunities. O’Farrell & Evans (1998) describe a nursing model for providing stroke education that may be a useful concept to physical therapists. They describe the need to improve the provision of education in a timely manner and to better prepare stroke survivors and caregivers as they transition through the healthcare continuum. As a result, they developed a “Stroke Education Record” to identify potential learning needs, a record that traveled with the stroke survivor to each new setting so that the next nurse could

build on the teaching previously provided and quickly identify remaining educational needs.

Complex Healthcare System. The healthcare system influenced educational interactions. Physical therapists described limited time to devote to RECAP given restrictions on visits and increasing numbers of reassessments required by insurance payers. The concept of reimbursement for education versus procedural interventions also resulted in ethical conflicts and requires further examination into the reimbursement regulations for education versus procedural interventions.

Environmental and Socio-Cultural Context. Lastly, the environment and socio-cultural context influenced educational interactions. Therapists practicing in other geographical regions and providing education to various cultural groups may experience variations in the nuances of the RECAP constructs. The perceived need for therapists to provide RECAP in meaningful environments was evident. The data indicate the need to explore the impact of adaptable healthcare environments to enable physical therapists to create more meaningful educational interactions, alternative designs for the traditional gym, and a healthcare system that enables physical therapists to provide education to the receiver in the community.

Limitations

Transferability of the findings has to be determined by physical therapists on a case-by-case basis, given the descriptions of the participant and recruitment sites. The experiences and perceptions of the participants in this study may not

be representative of physical therapists who work in stroke rehabilitation in other organizations or geographical locations. The data is also limited to rehabilitation settings and those in acute care or long-term care settings may have differences in experiences. Participant observations were not a component of the study design, therefore, the data emerged from the perceptions of the stroke survivors, caregivers, and physical therapists. Stroke survivors in the study described in Section 2 were an average of 3.6 years post-stroke and while long-lasting impressions of receiving education provide valuable insight about the education provided, a retrospective description may not have fully captured the participants' experiences of receiving education. A study aimed at examining stroke survivors and caregivers experiences of receiving education, as they traverse the healthcare continuum post-stroke, using both interviews and participant observations, may reveal additional nuances.

Future Directions

The findings of this dissertation leave many questions to pursue in further research studies. Further exploration of the overlapping areas of content, timing, and delivery in the model would be useful to better meet the educational needs of stroke survivors and caregivers (e.g., what content is presented best in which format, when should certain delivery methods be used). Development of an educational self-assessment measure in which therapists could assess factors such as their teaching styles or the content of education they tend to focus on is needed to provide therapists with a tool to reflect and guide RECAP in their practice.

Research is needed to assess the manner in which entry-level physical therapy students are trained in providing RECAP both in the classroom and during clinical rotations. Based on this inquiry and the findings from this dissertation, development of educational curricula for entry-level programs and continuing education courses, followed by an examination of effectiveness as perceived by students and practicing clinicians may be useful to guide RECAP clinical practice. Another potential future study to investigate training in entry-level programs would be a qualitative study examining the effects of videotaping student interactions with patients in student service learning clinics, followed by mentoring sessions with academicians/clinicians to review and discuss the videotapes.

Further investigation into the team approach to education in each rehabilitation setting is important, as no one profession can be the educator for everything. Developing and assessing the effectiveness of educational accountability methods, such as team meetings to plan and prioritize education for receivers as a team, just like procedural interventions are coordinated between disciplines, would be a valuable avenue of research. Creating methods to improve inter-provider communication regarding education is needed.

Future research could also include investigations of RECAP by physical therapists for other neurological diagnoses (e.g., Parkinsons, spinal cord injury, multiple sclerosis, traumatic brain injury) to examine similarities and differences in the practice of education for these patient populations compared to stroke.

Potential differences may be found in the content, timing, and delivery of education with RECAP for other diagnoses.

Conclusion

RECAP presents an extensive advancement in the practice of patient and caregiver education in physical therapy in stroke rehabilitation. A theory and theoretical model were generated, depicting not a passive provision of education from the therapist to the receiver, but rather, a continual dynamic educational assessment and interaction between the therapist and receiver within the contexts of professional responsibility, the multidisciplinary team, complex healthcare system, and environmental/socio-cultural context. RECAP is a rehabilitation education model that could theoretically extrapolate to any healthcare provider-receiver educational interaction.

To optimize educational interactions and meet the informational needs of stroke survivors and caregivers, changes are needed at all levels within the model. At the core, physical therapists need to reflect on this critical component of their practice in terms of their role as an educator, how they identify educational needs, the content of education they are providing, how they are delivering it, when they are providing it, and how they assess the outcomes of education. RECAP should be a central component of physical therapy practice and it requires consideration, attention, and reflection at the physical therapist level, healthcare organizational level, and across the profession as a whole. Discussion, at a national level within our profession, to reconceptualize education in the *Guide to Physical Therapy Practice* (Rothstein, 2001), is paramount to

shifting practice to meet the informational needs of patients and caregivers and spur much needed research in this area. The RECAP theory and model provides a springboard to design stroke educational interventions and develop curricula for both entry-level programs and continuing education courses. Multidisciplinary stroke teams need to assess their RECAP practice as a team, develop means of determining educational priorities for patients and caregivers, and communicate with one another to ensure the RECAP plan is implemented and informational needs of the receivers are met. Investment in RECAP by healthcare organizations and third party payers is imperative because the potential cost of not educating patients and caregivers is astronomical. RECAP can inspire the initiation and maintenance of health behavior changes to improve health outcomes, decrease secondary complications from stroke, and reduce the risk of second stroke, avoiding the need for costly hospital readmissions.

RECAP serves to empower, motivate, and engage stroke survivors and their caregivers to put education into action in order to facilitate an optimal recovery and reconstruct a self-identity post-stroke. Through RECAP, rehabilitation professionals can provide stroke survivors and caregivers with the necessary tools to overcome the barriers of disability and achieve a positive quality of life.

Appendix

Content of Stroke-Related Patient and Caregiver Education by Physical Therapists

STROKE KNOWLEDGE

EXAMPLES

- What is stroke (type of stroke, general side/part of brain involved, what caused it)
- Residual deficits (e.g., general R versus L brain characteristics, hemiparesis, cognition, sensation, positional awareness or midline orientation or pushing, neglect, inattention, dysphagia, vision, memory, emotional and personality changes, communication, fatigue/lethargy, tone, spasticity, sensory issues, aphasia, depression)
- Prognosis (e.g., average timelines to achieve goals, typical progression of recovery, the recovery process, influential factors – age, acute versus chronic stage, weight, general health parameters)
- Potential secondary complications
- Stroke prevention and identifying and minimizing risk factors of stroke (e.g., high blood pressure, high cholesterol, sedentary lifestyle, weight management, poor diet, smoking)
- Signs and symptoms of a stroke

SAMPLE QUOTES

<u>What is Stroke</u>

- *what's going on with their body-Elizabeth*
- *what happened to them and why… help them understand the process that occurred in their brain –Zelda*
- *I think they should be educated about their condition -Bertha*
- *I'll stay general…This is happening because of the part of your brain that's been affected -Dan*
- *The area of your brain that was affected –Zelda*
- *You had a stroke in your cerebellum -Demetrius*

<u>Residual Deficits</u>

- *right hemi's and left hemi's and safety awareness and impaired judgment; cognitive changes, vision issues -Zelda*
- *What your stroke did to you; the effects of stroke and what it does to the person –Zelda*
- *everyone's stroke is different –Zelda*
- *the effects of the stroke and how that effects their emotions -Dee*
- *how strength deficits can lead to abnormal gait patterns, balance issues -Jay*
- *educate them that they have neglect, they're ignoring their left side -Jay*
- *how are they with direction-following? How are they with understanding? –Bertha*
- *Because of the stroke, it's hard for your mom to pay attention to all of these different things and lots of different people. -Zelda*
- *after a stroke, this might be affected so I'm testing to see, and here's what I found -Bertha*
- *personality changes, and memory changes, and cognitive changes -Zelda*
- *the side effects and the symptoms of stroke… when their family member starts to act out… it's just because of the stroke -Bertha*
- *[tone] will always be there –Sara*

- *What their deficits are. You've had a stroke. You have right-sided weakness. We're going to work on these things. You need help walking. –Elizabeth*
- *understand its impact, and what it means –Ann*
- *You had a stroke in your cerebellum…I always give the example [of] … sobriety testing, [and why] we're doing a lot of those kinds of tests for ataxia because alcohol really affects the cerebellum and that's the [same area affected by a cerebellar stroke]. That's why you're having issues; and most people, I think, can understand that 'cause they've seen [how intoxicated people have balance deficits] -Demetrius*

<u>Prognosis</u>

- *stroke recovery is hard because it's not an overnight thing -Zelda*
- *things have to change because she's not ever going to be able to do what she did before -Mandy*
- *what's gonna happen in the future –Ann*
- *is isn't like one month and you're done… we're not talking, usually, in terms of weeks… This is going to be an ongoing process and you're going to continue to get better… for years after. -Demetrius*
- *plateaus to occur where we are hopefully still seeing improvements, but they may not be as dramatic after the first couple weeks or months. -Jay*
- *reassurance of… "you're discharged from rehab. You had an intense bout of therapy here where you've been getting at least three hours a day. It's going to be a drop off once… you go to outpatient or homecare." –Demetrius*
- *it's going to take time… how they can expect the recovery process to go –Elizabeth*
- *there's all kinds of stuff that can change and get better... they're gonna get better –Zelda*
- *with a stroke, you might wake up one morning and something moves that didn't move before and you always need to be ready for that and prepared for that. -Zelda*
- *recovery in terms of normalization -Zelda*
- *stroke recover… "Strength usually returns… in your shoulder, then your elbow, then your wrist and hand,"-Elizabeth*
- *We have to take this a day at a time and just see how your body recovers. Everybody recovers differently. It takes time. It's not going to happen overnight… some people recover really quickly, and other people it takes time, and I don't have a crystal ball to tell you 'You're going to be like this or that.' We just have to see how it goes. -Elizabeth*
- *how long it does take [to recover] and that they are making good progress-Dee*
- *as objective measures, what we see in the clinic… this is what we're seeing, the improvements we're seeing -Jay*
- *you are not going to be like you were before… your leg will never be as strong as it was before… I don't want them to think that in therapy, I am going to make them be able to run again… I just have to make it realistic –Sara*
- *most patients, the [hamstrings are the] hardest thing to come back and you've already got them… I can predict and I can say, "I bet you'll be walking with a cane soon," or "I think you'll walk outta here," –Zelda*
- *This is what we're thinking… would like you to be here for this many weeks… going to work on these things. –Elizabeth*
- *the therapist's expectations -Elizabeth*
- *Your leg will never be like it was before. I'm not saying it's not going to get better or your arm's not going to get better, but it will never be as strong as it was before… I've had a nerve injury to my arm… It's not like it was before… it's stronger than it was when I had the injury, but it will never be like that."-Sara*
- *He's never going to walk again, independently. He's just not. He doesn't have any sensory input on that side. It's amazing that he even walks with assist –Dee*
- *as your skills improve… you will be able to do more -Zelda*

<u>Stroke prevention and risk factors</u>

- *risk factors that might've contributed to it…how they can make changes to prevent future strokes.-Bertha*

- *Understanding why this happened, if it's possible to know why, and educating on risk factors and things that you can do to cut down the possibility of it occurring again-Zelda*
- *prevent another stroke… need to be active and you need to really…tax your cardiovascular system as much as is safe…keep active so this doesn't happen again and so… you continue to progress –Demetrius*
- *She needs to move… I don't think that exercising contributed to her seizure. -Maggie*
- *health and wellness and maintaining a healthy lifestyle to prevent anything else -Ann*
- Blood pressure control (Abby, Maggie)
- *the overall healthy lifestyle issue… the weight issue… the obesity issue… diabetes, the blood pressure… "Now that you've had your stroke,"… bring up… preventing it down the road… "Extra body weight is probably… one of the factors." … I'll go through… heart, blood pressure… "You'd be amazed… at what a 10-20 pound difference in weight…will do to some of your ability to move and maybe even to have more energy, to be able to exercise more, and continue down a more healthy road." –Dan*
- Need for smoking cessation
    - *If they're still a smoker, try to talk to them about not smoking. –Sara*
    - *smoking cessation… "your healing's not as good if you're smoking," –Maggie*
    - *I always tell every patient that smokes that they need to quit smoking, and I give about a three minute speech about how it's poor, bad for circulation, -Jay*
- Need for improved nutrition for healthy cholesterol levels and prevent future strokes
    - *Suggestions for foods, and how to cook it -Mandy*
    - *eating right –Maggie*
- Sedentary lifestyle
    - *continuation of homecare and outpatient… activity and doing all the things that they… need to do …decline that comes with just being sedentary after a stroke. –Demetrius*
    - *have to move… exercise… it would help a lot 'cause you're just not moving as much as you used to –Maggie*

<u>Signs and Symptoms of Stroke</u>

- *equating… brain attack… and heart attack as being the same and how it's so important [to get help quickly] -Demetrius*

FUNCTIONAL MOBILITY

EXAMPLES

- Proper technique/mechanics of:
    - Transfers (w/c to/from bed and toilet, car, floor)
    - Bed mobility
    - Stair/curb training (ambulatory and w/c level)
    - Ramp mobility (with device and/or w/c)
    - Gait training (including various surfaces; pre-gait training)
    - In relation to ADL's
    - Wheelchair propulsion/mobility
- How the caregiver can physically assist the patient with functional mobility
- Communication strategies for caregiver to use in directing patient w/ functional mobility (cues they should provide, avoid having too many helpers directing the patient)

SAMPLE QUOTES

<u>Technique/mechanics of mobility items listed</u>

- *return to function -Demetrius*
- *gait mechanics… trying to relearn how to walk -Sara*
- *turn their walker sideways or… step into the bathroom without a walker because the walker won't go –Abby*

How the caregiver can physically assist the patient with functional mobility

- *if you're standing in front of someone and you don't rock your weight or shift far enough back to give the person room to come forward it makes it harder to transfer. –Zelda*
- *how they're moving… how to help them because everybody moves differently…teaching them what works for them specifically with setup -Elizabeth*
- *"transfer training" [for the caregiver]; I know that might be pretty basic, but that's a pretty big deal. –Bertha*
- *[To caregiver]: "We're basically going to be looking at you, how you're doing the transfer, because we don't want both of you to be down. We want you to protect yourself because if you hurt yourself doing this [it's a problem]…So we may critique you a little bit and… don't… take it the wrong way... We're really just trying to make the situation better for everyone involved." –Demetrius*
- *somebody can be an extremely difficult transfer but… really, a lot of it is about their mechanics and how they do it –Demetrius*

Communication strategies for caregiver to use

- *"they have aphasia… so here's what I need you to do when you're helping them do a transfer… You have to demonstrate it first. You have to take a little bit more time… If they definitely didn't get what you said, put the stop signal up." -Dan*
- *"Because of the stroke, it's hard for your mom to pay attention to all of these different things and lots of different people… if you all are doing something tricky or a transfer… get one spokesman to give instructions."-Zelda*

EQUIPMENT OR DEVICES

EXAMPLES

- Need for devices
- Assistive devices (features, how to fold up walker, etc)
- Orthotics and/or proper footwear and where to obtain these
- Braces (how to use, don/doff)
- Gait belt
- Ace wraps
- Wheelchairs (eg, manipulation of parts: lock/unlock brakes, moving anti-tippers for curb, stowing w/c in car, options, design features)
- E-stim use for home (NMES, Bioness)
- Instruction in creating equipment for HEP (eg, bolsters out of towels/pillows, powder boards, standing frames)
- Equipment for recreation

SAMPLE QUOTES

- *"If you don't need this walker anymore, keep it," or "If you need a rolling walker, just ask around the family…. somebody's got one somewhere" as opposed to keep buying this new stuff -Mandy*
- *we send people to the Goodwill…"Look for a walker that's this height." -Abby*
- *"You're really gonna be better off without that bedrail." -Zelda*
- *getting leg straps, leg lifters so that the caregiver's not having to lift the legs every time… the patient can do more. -Maggie*
- *[a power wheelchair] would give him so much more mobility, I think he would just light up if he could get himself around -Dee*
- *"They could get the wheelchair around in the home"… "but I want a Hoveround for her to*

be independent in the community," … "we don't feel that that's… necessary… in this setting, we just don't know what her recovery's going to be and I don't want to… limit her recovery." -Elizabeth

- *I recently told somebody to try John's Run/Walk Shop for more of a diabetic-type shoe – Molly*
- *for the caregiver, I always show them how to appropriately hold the gait belt -Molly*
- *putting the sling on, folding up the wheelchair, putting on the gait belt -Dan*
- *Equipment use is something I go over a lot with them… anything from an assistive devices to braces to how to use the wheelchair, how to lock the brakes, how to flip up the anti-tippers before you go up a curb and always remember to put them down when you come up. –Molly*
- *What you can do is just take off the cushion, the seat cushion cover, put it in the washer, have it washed –Jay*

PSYCHOLOGICAL & EMOTIONAL ISSUES

EXAMPLES

- Need for caregiver support and self care
  - Respite services
  - Establishing/planning day-to-day routines (balancing role as caregiver with other life roles)
- Stroke journey
  - Recommendation to keep a recovery journal to track progress, set new goals, document when goals are met (reinforce hope, optimism, engagement, motivation)
  - Reassurance of future gains
  - Redefining goals and expectations; Addressing pt/CG expectations in establishment of goals
  - Coping strategies
    - We don't say "I can't" (avoiding negative thought processing)
- Depression can be common post stroke; benefits of psychological support or counseling, discussing anti-depressants with MD
  - Need for monitoring depression and why (that it's common and can impede progress with PT)
- Sexuality/sexual function
- Support groups available (for patient and caregiver)
- Return to hobbies/leisure, finding meaningful activities

SAMPLE QUOTES

<u>Caregiver support and self-care</u>

- What their role is (and they are an integral component of the person's rehabilitation team), how to help, how to be involved (e.g., what to observe while they're in inpatient), what their goals as caregivers are (Dan)
- *very important for them to have… breaks… so they don't get burnt out. –Demetrius*
- *Caregiver support and self-care. –Dee*
- *we do a lot with the caregivers on… getting out and doing their own thing so they have a break because there's a lot of burnout. –Mandy*
- *learning the importance of taking care of yourself so you can take care of your person… if you run yourself ragged to where you get the flu and you can't take care… giving yourself a break and… helping them understand that it's ok to have someone come and sit with*

Dad while you go shopping, or get a pedicure… to balance it out so you don't get burnt out. –Zelda

- *support group… that it's not just for patients, but for their family members -Zelda*
- *what can they do, what's their own balance… you have to make sure the caregivers don't get burnt out…There has to be that right balance.-Abby*
- *their overall day-to-day management, how are they gonna get their routine in, how are they gonna get their medicines… meals… standing time… exercise time in… the caregiver's got to take care of [the stroke survivor] but that doesn't stop the caregiver from still having to do the 500 other things that they do… has to be some structure to all that… has to be some time to themselves… times just dedicated to caregiving… times that's a mixture of both… and how to get the others to help. –Abby*
- *if the parent was doing a Silver Sneakers class, then the caregiver could get some exercise at the Y[MCA] at the same time… something where mentally, they could keep healthy. –Demetrius*
- *"You have got to be with him… you're spending his last weeks running around, managing his life… Call hospice in, and you sit there, read to him, talk to him, look through old pictures, watch TV, do a puzzle… just be with him… Stop managing… Go sit there with him." –Mandy*

<u>Stroke journey</u>

- *Even when the recovery's good, it's still way too slow for the patient. So just educating them on how long it does take, and that they are making good progress. -Dee*
- *Recovery in general, I think it's almost better to think in longer terms just so you're not disappointed if it doesn't happen quicker, but… not saying "Oh, this is going to be years and years" 'cause that can be really discouraging -Demetrius*
- *remaining motivated –Jay*
- *reassurance of future gains -Demetrius*
- *"Did you know it took two people to help you from the chair to the bed when you first got here?"-Zelda*
- *Educating on… how far that they've come…reminding them about where they were when they started and where they are now, to encourage them that they are making progress and we just have to keep pushing forward. –Elizabeth*
- *"You were making this much progress in the last month" -Dee*
- *I suggest they keep a journal…"Write down 'here's what I'm good at, and here's what I can do, and here's what I'm still struggling with,'"…to see that they're still making changes… "writing your goals and keeping track from the very beginning of your… stroke recovery" -Zelda*
- *Those little kernels of improvement and celebrating that: "You couldn't do that last week!" –Zelda [celebrating improvements and milestones]*
- *This is your life, your body, your existence. So it's really up to you how far you want to progress –Demetrius*
- *[To caregivers]… encouragement… just that they can do it with training. –Demetrius*
- *it's their body, their life to live…So two years down the line, you can either be here, you know, where you would like to be, or you can sit around and not do much and you may not be much better than where you are right now, or even worse-Demetrius*
- *Part of the education was to say "You think that things are not so good, but look at what you are doing." And the big issue as it came down to it was she doesn't go to the mall anymore like she did… She can't quite walk down the street like she normally did. And so there, the education for that was to try to say "But you're looking at what you can't do and here's all the things that you can do." And what she could do was pretty good, still. –Dan*
- Coping, staying positive, optimistic
    - stay positive, optimistic: *part of it is the understanding. Like, I've asked people, you know, "Can you move your leg?" "No, I can't." And I try from early on to say "Don't say 'I can't.'" You know? Say "I'll try,"-Zelda*
- *"It's ok. You're not at a good place in your life. There's a lot of other things goin' on that are taking precedence over being able to be in therapy, but if you're not here, we can't*

help you… Let's look at discharging now and then when you are better able to, like, commit to coming to therapy and you feel like you're at a good place, then come back and we'll be happy to see ya." –Dee

Depression

- Priority education for Sara: *one lady I just recently talked to, she's "I've been off of it for two weeks. The doctor told me not to be on it because I needed to see the neurologist first," and I said "You need to get on your antidepressant now. You need to call the doctor and get a prescription filled now," because she was at the point where she was like "I just can't do this. I cannot do this."*
- *"I really think you might want to be on an antidepressant. You know, you wouldn't have to be on it forever. You know, but this is something to help get you through so, maybe, you feel more motivated 'cause if you're not motivated to do anything at the house, you're not going to get any better," you know. So I do touch on that quite a bit.-Sara*
- *they'll talk about the depression, like "Depression is very common with stroke. That's not unusual at all. Have you considered talking to someone? Here's a list of people that you could go to." –Dee*
- *I have educated why I would like them to speak to a case manager, but I've told them I'm not comfortable speaking about depression with the patients because it's just beyond the scope of what I'm familiar with. -Jay*
- *depression is not really my thing. I would refer out. –Jay*
- *It's stuff I feel more comfortable referring… I still ask them about how they feel like they're responding to their medications, or if they feel like stroke support group is beneficial, or if they feel like they want to talk to a psychologist. How they coped with things before, just how they're feeling. –Ann*

Sexuality and sexual function

- *I've never had the sexual activity talk with anybody –Dan*
- *I haven't done, haven't had to do much sexual positioning stuff or anything. I know I did that in Inpatient, but I haven't really had to do…I mean, I don't know if I'd be, I wouldn't know what to tell them. -Sara*
- *Never cover sexuality and sexual function-Dee*
- *I've not actually gone over that with anybody… The sexuality and sexual function like I said, most of mine are elderly and even the younger ones, I can't remember anybody bringing it up. And I've just never brought it up. –Mandy*
- *sexuality and sexual function, that's something that I don't cover-Jay*
- *I don't really talk about, a lot about sexual function. -Maggie*
- Discussed this during an all male support group –Demetrius

Support groups available/needed

- *I do encourage my clients to go to stroke support group while they're here. I'm probably not as good at encouraging them to come back once they go home. –Elizabeth*
- *a lot of referring to senior citizen centers in Frankfort and Versailles, and support groups back here, -Mandy*

Hobbies/leisure/return to meaningful activities

- *returning to what they like to do. –Demetrius*
- *how do we get them to understand that they may not be going back to those hobbies, which might be just as important for them to start coping and no longer be in denial. It's important to, kind of, get through those stages, I imagine. –Jay*
- *Return to hobbies and leisure, you know, just trying to get, you know, that's a great example of what we should be doing, but I've never gone out with someone and swung a golf club, for instance.-Jay*

PROMOTING OPTIMAL RECOVERY

EXAMPLES

- Treatment interventions
  - Purpose/rationale/benefits/risks
  - options eg Lokomat, Bioness, aquatics
  - Research and interventions
  - Mental practice, imagery, visualization for motor control with functional movements
  - Managing tone/spasticity
  - Overcoming neglect/inattention
  - Pain management
- HEP/exercise routine
  - Incorporating HEP into functional daily tasks/routines
  - how caregiver can assist with HEP
  - Using exercise log to increase HEP compliance
  - Continuing activity upon d/c from PT (eg wellness program, gym memberships)
  - Relation of HEP to functional mobility
  - Monitoring CV response to exercise (eg how to take their HR)
- Concept of recovery versus compensation
  - eg involving affected/hemiplegic limbs w/ functional tasks like transfers, gait, w/c propulsion, with weight bearing, optimal mechanics
  - Neuroplasticity principles (e.g. need for increased repetitions, intensity of training)
- Preventing secondary complications
- How family can promote optimal recovery
  - sit by hemiparetic side to help them overcome neglect/inattention
  - attend PT sessions with the patient; need for CG to practice/observe mobility/HEP with patient
- Online resources (eg, youtube, stroke education sites)

SAMPLE QUOTES

<u>Treatment interventions</u>

- *explanation of skilled PT interventions, why I'm doing what I'm doing. –Jay*
- *purposes of exercises. -Demetrius*
- *why we're doing what we're doing -Bertha*
- *explain how this helps to reconnect the pathways in the brain –Bertha*
- *overcoming neglect -Bertha*
- *recommending a low dosage anti-spastic medicine -Jay*
- *why we're doing this… the benefits of performing those in terms of function -Jay*
- *"Your brain is getting better and this is the time to make use of this intense rehab… you're here because you wouldn't do this for yourself at home" -Zelda*
- *purpose or goal of the treatment… "This is how it works. This is the purpose and there's lots of good research that shows that it's proven to be effective." -Bertha*
- *incorporating research… whenever I get a patient on the Lokomat, I try to get them to close their eyes and think about what it feels like, and I talk to them about mental imagery and mental practice… tell them about the research study with the free throw shooters who actually did it or who just thought about it… the Olympic divers and how you see them going through it in their head, and that ultimately, that can help. -Zelda*
- *We can do things… to help make you get better. If you start getting something weight-*

bearing… stand on it and help loosen it up, constantly stretch. –Sara

- *We want to keep you moving and improving and do the very best that you can –Zelda*
- *what the process is for getting better… why we do things … "This is the same muscle that you use when you climb the stairs and this is why we're doing this slow stand-to-sit with control because this will prepare you for stairs or sittin' on the commode"… Trying to help them understand how it all ties in together and making those connections for them. -Zelda*
- *"I want to drive again." "Well, let's work on your attention. Let's work on attending to this side of your body." –Zelda*

<u>HEP/exercise routine</u>

- how the caregiver can assist with the home exercise program
- What they can be doing on their own (even while in the hospital); PT time is limited and they will get better outcomes if they integrate principles enforced in therapy throughout their day (Dan)
- *"Instead of coming to PT from 9-10, you need to do your exercises from 9-10 at home". -Maggie*
- *"Your son comes to visit, get out with him and walk a pretty good stretch. And you've got your rollator so you've got your seat built right there so you can stop and rest." -Demetrius*
- *"This week, transfer to the right. Only do a squat, pivot. Focus on putting weight on that right side." -Dee*
- *keep some type of daily log or a check-off sheet. -Abby*
- *pick a regular time… to do your exercise program, just incorporate it into your routine. -Zelda*
- *they don't have to sit and do all their exercises straight in a row for 30 minutes. –Abby*
- *Remain physically active even after you're discharged -Ann*
- *"these are the exercise programs they offer. You need to go every Tuesday and Thursday, like when you were coming to PT. Instead of coming to PT, you're going to go to the Y now from 10-11 for this aquatic exercise program" –Maggie*
- *the Silver Sneakers program, and that would come back to promoting optimal recovery –Demetrius*
- *You really need to work this hip muscle. This exercise is so important for this hip muscle when you're in stance –Dee*
- *"But you have time to leave your house and come to therapy and then get back in your car and drive home. So when you're discharged from therapy, take an hour 'cause it takes you more than an hour to do all that to get here, so it's actually going to take you less time. Just use that hour that you were taking to come in to therapy and do your home exercise program." -Maggie*

<u>Neuroplasticity (recovery versus compensation, repetitions, active participation)</u>

- *I try to communicate to them the tendency for our patients that have hemiparesis is they learn really quick that they can do things, but they don't do them the right way. They do them the way that their dominating side can do things, and so I want to make them aware that "In order for you to recover optimally based on what I know, then you have to purpose yourself to try to use the affected side. –Dan*
- Provides tips on how to involve hemiplegic side, avoiding substitutions and compensations (Dan)
- *we can describe compensations, you know, and that we want to minimize those-Demetrius*
- *using appropriate equipment/techniques; what they get early on in the beginning may be detrimental in the long run. So explaining the investment, you know, and why you want to do it this way and trying to educate people. And that's something you fight against too 'cause, you know, you say "Now, when you go home, I want you to walk on this walker." –Zelda*
- *what the way to get better is, and good ways and bad ways to get better-Zelda*

- *Every time you learned a new skill, it required a lot of practice. A lot of trial and error, a lot of practice." -Dee*
- *don't walk for a point; walk to learn to walk better." Jay*
- *"Now is your window of opportunity, you know. This is the time that your brain, I mean, you're going to still make gains in the future, but this is the time to get it right," –Zelda*
- *explain how this helps to reconnect the pathways in the brain and things like that, "So that will help you move better." -Bertha*
- *encouraging them to try to move. Even if their arm doesn't move or their leg doesn't move, trying to get that…making them engaged, you know, in that process and reconnecting pathways even if they're not in therapy, just working on that.-Elizabeth*
- *it's really important that you continue not just twice a week or three times a week for an hour with your therapist, 'cause it's really up to you to be the majority part of the team." –Demetrius* [repetitions]
- *I'll always do a lot of education on: "There's only so much we can do two days a week in Outpatient, you know, you really need to be doing something every day and you're going to progress a lot faster than you would just sitting around on the days in between. Like, "I'm not going to do these exercises with you anymore, but you need to do them. I'm giving them to you to do on your own and then we're gonna progress to some other things here while you do those at home on your own because you can do those by yourselves without me now.-Maggie*
- *their active participation in their recovery -Elizabeth*
- *Dee: Yeah. And so they have to have that amount of practice every single day, that this one hour won't cut it. Like, trying to drive home that point that this, "You coming to see me is not the fix. I am not going to fix you. You are going to fix yourself. You are going to do the work. You have to be committed to do this much work. Like, it's a huge commitment."*
- *I've really come to realize is the importance of normalized movement as opposed to just get 'er done kind of things, you know? –Zelda*
- *a lot of times, what I hear is "Oh, well we need therapy." And yes, they need…What they mean is "I need a therapist to come in and do all this." And the word for, sometimes, therapy is "Someone is doing therapy on me." And I try to get it across to them that "You're doing therapy when I'm not there, as well. And you and your family member are doing therapy, you know, after hours when you take your leg rest off on your affected side and you try to mobilize another 100, 150 feet, or 200 feet, or…until it fatigues," you know? "Or when you do your transfer and nursing is doing your transfer with you and you direct them in how I've shown you here, and how we've practiced here, and how it's working here." Things like that. – Dan*
- *"You need to be directing your nurses to how we have just done this, and so you have more therapy in the evening when you do more transfers or more walking. Um, I want you walking tonight, with the nurses on the night shift, once up the hall." –Dan*
- *just reassurance of…that "Hey, you're discharged from rehab. You know, you had, kind of, an intense bout of therapy here where you've been getting at least three hours a day. It's going to be a drop off once you, whether you go to outpatient or homecare, so, I mean, it's really important that you continue not just twice a week or three times a week for an hour with your therapist, 'cause it's really up to you to be the majority part of the team." -Demetrius*
- *Give a percentage… "I'm maybe 10% of this… I can try to help guide and I can give you some things that will help, but really, it's up to you… if you do these things, you will continue to make gains." –Demetrius*
- *"You have to ask this leg to do the work, you don't want it to just be a kickstand. You want to bear your weight on it, you want it to hold you, you want to learn to trust it." –Zelda*
- *"Your brain is getting better and this is the time to make use of this intense rehab… Now is your window of opportunity. This is the time that your brain, I mean, you're going to still make gains in the future, but this is the time to get it right," –Zelda*

Preventing secondary complications

- *just give them the repercussions. "What can happen if you don't take care of yourself, and that would set you back and we don't want that." –Maggie*
- *"If you sit in a recliner all day, this is the posture you end up with. -Mandy*

How CG can optimize recovery

- *if someone has left neglect and you can educate family on "OK, if you can start in their visual field and then really get them to attend to the side that they're not aware of,"- Demetrius*
- Teaching the caregiver how to provide the right amount of assistance – not just do everything for the patient (Dan)
- *'cause so many families are so willing to help, and provide too much care, and you, kind of, educate the family that "Hey, this…As we continue to progress and recover, you want to do less and less."…possibly progress to and that means they need to be doing more, you need to be doing less." –Demetrius*
- *to CG's: , if you don't do everything for them now, you know, and allow them more independence and to take over more of those tasks, it's better for them-Zelda*
- *you're sitting in the room, you want them to have to attend to that side so, you know, sometimes we'll say "OK, start at midline where they can see and then get them, even if it's turning the head, scanning, you know, and whatever, let's get them to recognize that they have…that there's a world out there on whichever side is, you know…there's a deficit.-Demetrius*
- *I was telling the family "I want her up. I want her walking. I know it seems like she, it seems like the patient is at a high fall risk, but she has not fallen. She's hasn't shown any indication that she's falling. She's slower, but this is what we're trying to improve."-Jay*
- [To a caregiver]: "*instead of jumping in there, and picking up both their legs, and flinging 'em in the bed, just let them struggle [at first]… It's just like a baby. When they learn to walk again, if they don't get the experience, they're never going to do it." –Zelda*

HEALTHCARE CONTINUUM AND TEAM

EXAMPLES

- PT goals and POC for current setting/level of care (ELOS/duration of therapy)
- Rationale for discharge from PT in current setting
- Next level of care (eg, HH, OP, SNF, wellness/community gym memberships) needed, expectations there, goals
- Expectations of current setting (eg, in IP rehab there will be greater intensity of therapy than acute care – may be more sore/tired initially)
  Referral to other disciplines for questions outside realm/expertise of PT

SAMPLE QUOTES

PT goals and POC and d/c plans

- *I think you'll be here about this long –Elizabeth*
- *really anticipate this much more therapy time before you continue on your wellness program –Jay*
- *"This is what I'm thinking…I think you'll be here about this long and these are the things we're going to work on." –Elizabeth*
- *I actually start bringing up discharge planning -Jay*
- What is PT and when PT is and is not indicated
  - *"Why are you all going through all this over and over and over again?" And I*

remember asking them the question…I said "You mean you went through home health therapy or outpatient therapy for three months and nothing changed and you still want to go back?"…I said "If nothing else, I'd have fired those people and I'd have found another to try. But to say you're going to do the same over and over and over again and nothing's changing…" –Dan

- *And the other thing that we have to educate a lot about is home health, what we do, versus paid caregivers. They think we're coming in to stay with them –Mandy*

Expectations of current setting

- *educating them on what's going on, the process, what they can expect, where they go from here, -Elizabeth*
- *what to expect from inpatient rehab,-Elizabeth*
- *"This is what you can expect. You're going to get three hours of therapy a day," –Elizabeth*
- *"OK, well, you know, for inpatient, here's, you know, what we're definitely trying to get to and it's great to have that…" –Demetrius* [educating about about realistic goals and what can be expected as time passes or in each setting]
- *the point of homecare isn't so we restrict you to the house. We want to get you to the point where you don't need to be restricted to the house anymore. And really, when you're getting to that point where you're like "Gosh, I really feel like, because of this, I'm having to stay home when I could get out," then that's probably a pretty go indicator that you're ready to move on to outpatient –Demetrius*
- *if you're homebound status… you can still go to church… get a haircut… go to your doctor's appointments -Demetrius*
- *"You make sure you tell your outpatient therapist this is your goal so you can work towards that. But right now, we're still not at that point." –Bertha* [educating them about the healthcare continuum, settings, and goals for each setting]
- *make use of this intense rehab. And you're here because you wouldn't do this for yourself at home –Zelda*

Next level of care

- *the next level of care would be like a subacute -Bertha*
- *when discharging, I usually say that about six months would be an appropriate time to get back in if they're continuing with their therapy program, the wellness program. –Jay*
- *how it is really a continuum… you go from the hospital acute care to inpatient rehab, to homecare, to outpatient, to a continued wellness-type program –Demetrius*
- *mentioned just homecare, outpatient, kind of like we talked about in the continuum-Demetrius*
- *"This is what we're doing to prepare and in the next setting -Zelda* [goal setting and expectations for each setting; what next setting can work on with them]
- *bringing hospice in –Mandy*
- *we tell them right off, "And then the next step is to go to Outpatient" -Mandy*
- *you can't send someone to home health after they've been in Outpatient. -Abby*
- *wellness gym as a continuum…-Jay*
- seek out services/providers that are going to best help you
    - *doing home care initially, usually, and this may come across as a little bit of a bias, but I usually will say "OK. As far as outpatient continuing on," I was like "You know you want to get somewhere. It's your decision where you want to go, but you want to get somewhere." Or they…Not just in general clinic, where they don't deal with neurological-type issues…"If you've had your hip replaced, or knee, or whatever, you can go to any clinic, but really to continue to focus on the deficits that you have that you want to overcome, then it's good to work with people that work with stroke patients-Demetrius*
    - *we usually encourage them to come here to outpatient because it's very neuro-based and so they get the better benefits of all the technology and that sort of thing. –Elizabeth*

Referrals (who is on the team, what role does each profession serve)

- *say "Let me get you someone who can come talk to you." –Dan (regarding sexuality content)*
- *get to their primary care physician.. they're told to go to their primary care physician. We reiterate that. "Take them to…Take all your meds and then let them sort it out." -Mandy*
- *what the options are when you're, you know, referrals to other disciplines. –Abby*
- *but if there's a rationale for a referral to other services. Just, for instance, I've had a patient that had a stroke that appeared to also have Parkinson's, so trying to educate the family as far as why I believe that they should seek, you know, a neurological consultation from a physician-Jay*
- *I have educated why I would like them to speak to a case manager, but I've told them I'm not comfortable speaking about depression with the patients because it's just beyond the scope of what I'm familiar with. -Jay*
- *and I think it's really important for them to know, kind of, what their benefits are and that sort of thing as far as that goes. And I cover it in little bits and then refer them on to case management...-Elizabeth*
- *any medical problems, they need to follow up with their primary doctor here. –Demetrius*

ADVOCACY

EXAMPLES

- Raising public awareness of stroke (eg, educating patients/caregivers regarding benefits of speaking at stroke support groups, schools, health fairs, CHRH telethon)
- How/what to educate family/friends about regarding stroke
- Resources/organizations that advocate for people with stroke and caregivers they could connect with
- Advocating for oneself (eg, advocating to healthcare team for more therapy, services, needs, supports; expressing goals)

SAMPLE QUOTES

Advocating for oneself

- *Ann: I like to talk to people about, like, advocating for themselves, you know, pushing to continue services or receiving services, and, you know, speak up to their doctors and any healthcare professionals about their needs and their goals.*

Advocacy in general

- *The things that are in this category are ones that I don't typically cover at all. –Elizabeth*
- *we're missing that piece –Dee*
- *Raising public awareness… we have a responsibility, but that's not the primary thing in my job description. -Zelda*

SAFETY & PRECAUTIONS

EXAMPLES

- Impact of residual deficits on safety (eg, memory, cognition, vision (hemianopsia, field cuts, diplopia), neglect, inattention, personality, sensory issues, tone, spasticity)
- Secondary complications (prevention and management of)
    - Fall prevention
        - How fear of falling can increase chances of falling

        - Increased risk of falls with polypharmacy (4+ meds)
    - Musculoskeletal injuries
        - Awareness, care, and protection of hemiparetic side for protection due to decreased sensation, vision impairments, proprioception, neglect, inattention (eg, knee control to prevent hyperextension, proper positioning of UE to avoid shld subluxation)
    - UTI
    - Pressure relief and doing skin checks
        - Due to risks from immobility, poor positioning, TED hose, braces, diabetes, etc
        - Safely wrapping BLE for edema reduction
- Medication precautions
    - eg, risk of bleeding while on Coumadin, monitoring BP and glucose; how medications impact mobility
- Supervision needs
    - 24/7 or for specific activities like long distance walking, stairs
    - Ability/inability to safely remain at home, need for institutional living, role of adult protective services
- Safety with functional mobility
    - CG safety (body mechanics, how to safely guard and handle the person)
    - How to properly use and grip gait belt
    - Safe use of home oxygen/management of oxygen tubing with mobility
    - Floor transfers
- Home modifications for safety
    - eg, throw rugs, night lights, bedside commode, tub bench, decluttering, optimal furniture arrangement
    - Use of life-line technology in the home

SAMPLE QUOTES

<u>Impact of residual deficits on safety</u>

- *risk of falling –Jay*
- *have to be a lot more specific about do's and don'ts, and things that aren't safe right away, and things like that. –Bertha*
- *Safety with mobility-Bertha* [especially with those with R lesions
- *If they've got visual neglect or … visual deficits, those are going to have to be strategies that …We're going to have to work…to help them be safer with their walking or their mobility and to compensate for those visual deficits. –Dee*

<u>Secondary complications</u>

- Positioning (Ann, Bertha)
    - UE management
        - shoulder is a big thing –Zelda
        - *CG: not pulling, transferring using the … hemiparetic arm… protecting the arm if it's, you know, if it hasn't had any return, really, if the muscles aren't activated, if they're, you know…have a subluxation –Demetrius*
- Fall prevention (Ann)
    - *Abby: fall prevention's always one 'cause that's required, you know, for us in home care.*
    - *watching for the dog that's going to run through and trip them-Molly*
    - Home modifications and safety with functional mobility for fall prevention (see home mod section)
- Skin: Pressure relief/ulcers (Ann)
    - *Increased swelling, any signs of a pressure sore-Ann*
    - *wound prevention-Zelda*

- *"This is so unsafe for your dad to be laying in urine and, you know, he can't get to the bedside commode because you have it across the room, and the house is filthy, and stuff like that." –Mandy*
- *people with diabetes, you want to go through, like, foot care, and more about skin breakdown, -Maggie*
- *blood sugar-Maggie*
- *hot surfaces if they have decreased sensation -Molly*

- UTI:
  - *prevention of UTI, signs and symptoms, what to look for -Abby*
  - *We do bowel and bladder-Abby*

Medication precautions

- *if you are on certain blood thinners Coumadin… Let's say you fall and you whack your head pretty hard on the way down… that's just not something you want to mess around with. You want to call…You want to get in, get scanned, make sure that you don't have an active bleed. –Demetrius*
- *medications -Mandy*
- *how their medications, new and old, might interact, you know, if they've got any new medications. Most clients don't realize that anytime you take four or more medications, it increases their risk for a fall. –Abby*

Supervision needs

- *on not trying to do too much, like self-transfer when they need assistance or walk without assistance when they definitely need a hand on them, -Elizabeth*
- *always go over safety: not getting up on their own, and using the call light,-Elizabeth*
- *how the call light works and, you know, making sure that they know how to get help if they need help so that they don't feel stranded in their room, -Elizabeth*
- *So educating them on "I know that you want to get up on your own and you want to do things for yourself," but really encouraging them to call for nursing and, you know, tell them it's for their safety, and educating them about why we don't, and that we're going to work toward their independence, but for them to be patient and be safe in the meantime. –Elizabeth*
- *We don't want to call APS, but legally we're required because if you're not safe,-abby*
- use and purpose of alarms… *"This will help you remember and keep you safe,"-Zelda*
- *'cause if they tell me they want to walk the dog, ok, "Well, ok, we can walk the dog, but I don't want you walking the dog when I'm not here or when your daughter's not here. So if you want to be able to get to the point where you can walk your dog, then this is what I need you to do here at home to get us to that point." –Abby*
- [education about the need for restraints and/or seat belts]: *I've learned ways to… explain it to them in a way that isn't degrading. It's not like "I'm going to tie you to this chair 'cause you're bad." That's not the message you want to give. It's like "This will help you remember and keep you safe," explaining why we use it and "Our goal is to get away from this," and make them more responsible, like "Do you think you would call the nurse?" –Zelda*

Safety with functional mobility

- safety with assisting with functional mobility; safe guarding (Ann, Molly, Maggie, Elizabeth, Demetrius)
  - *CG: you're going to have to block the knee because it will give out, you know, on the transfer,"-Demetrius*
  - *setup, and just how they can make it the easiest way possible. –Bertha*
  - *with caregiver education. "OK, which side do you want to be on?" you know, if you're…if the person, you know, is neglectful on the left side or whatever or if their proprioception, or sensation, or whatever are off, we want to be on that side.-Demetrius*
  - How to don/doff and use a gait belt (Dan, Molly)

- *like ways to actually guard the patient for gait, like where to stand, like to stand on their weak side for walking or to be more below them during stairs.-Molly*
- *how to be safe, how to wait, how to, you know, pause between transitions from supine to sitting on the edge of the bed, to sitting on the chair and standing up, all those little things.-Abby*
- *how to be able to stabilize themselves –Abby* [how to stabilize themselves given environmental restrictions of the home – how to problem solve if they can't use their assistive device]
- *but it just needs to be a little different for it to be safe.* –Abby [Edu re: functional mobility adaptations required for safety and to enable independence in home environment]

- Floor transfers and safety (Demetrius)
  - *getting back up and not just standing in the middle of the floor and then falling back down. You know, getting to a stable object where you can just hop on over to a couch or whatever. –Demetrius*
  - *teaching floor transfers …"There's a… pretty good chance that you may take a spill, you may fall, and of course you don't plan for that. It's great to train on how to fall, … "you want to protect your head… roll into it. Hit as much surface area as you can," 'cause a lot of times, if you just stick out a hand, you're going to break a wrist. -Demetrius*
- Proper body mechanics for CG's (Molly, Elizabeth, Maggie, Bertha, Abby)
  - *We want the caregiver's back to be protected and all that kind of stuff so that they don't end up getting hurt and aren't able to provide care to the client.-Demetrius*
  - *with caregivers is just body mechanics. You see so many caregivers that have back pain and, so just education on keeping a neutral spine and not, you know, pivoting your feet, and not twisting your back, and all those things 'cause you have so many people that end up with injuries, caregiver injuries just from repetition… why, you know, why it's important. –Maggie*

<u>Home modifications</u>

- *settin' up a therapeutic rehab environment in the home or after discharge is a high priority for me. –Zelda*
- Calling for help
  - Lifeline/LifeAlert systems (Abby, Demetrius)
  - Phone safety
    - *have a cell phone and you'd like to have it on you where you can get to it." –Demetrius*
    - *if you have a cordless phone, then have it low where you can get to it, like on a coffee table or something and not way up on a big counter, you know." –Demetrius*
  - *examples of what happened to so-and-so when they didn't have their phone with them, and fell, and they laid in the bathroom floor for 12 hours until somebody came -Mandy*
  - *if they're home alone… need to call for help, well if the phone's not on this side, they fall off the bed tryin' to reach for the phone, or they fall tryin' to race to get to the phone, or just how's their overall setup of, and not just of their body, but a setup for safety in their home. It's not just removing rugs. -Abby*
- *home modification, which we really can't do a lot of, but just talking maybe about different things that might make their situation easier just to be, whether it's, like, transfers, showering, and all that. –Maggie*
- *Take a box spring out and put a board in -Mandy*
- To reduce fall risk
  - *If they're going to go home, they have to be safe at home, so you have to talk about the patient's awareness of their surroundings, safety and the kind of guide that they might need, modifications to the home to, kind of, reduce the risk of*

falling and things like that. –Bertha
    - *"Clear the walkways and stuff," –Mandy*
    - *That why are we removing them [rugs], what does this mean, how are we doing it the safest? You know, "No, you've never used a nightlight before, but now we might need one.".-Abby*
    - *home safety… includes everything from picking up throw rugs if they have hardwood floors and having all the rugs out to watching for, you know –Molly*
    - *Just overall stability in their home, safety, clutter, open pathways, all that stuff. Lighting-Abby*

COMMUNITY REINTEGRATION

EXAMPLES

- Going out in the community; community mobility
    - Driving
    - Transportation
    - Recommendations for home modifications to get in/out of house
    - Devices/equipment needed for community mobility
- Return to hobbies/leisure
- Return to work

SAMPLE QUOTES

Community Mobility

- *Driving… "Your doctor has to give you approval to be able to drive" and also, I usually make them aware… that there are driving evals, and we've got some OT's that do that…Your vision needs to be back to normal" –Demetrius*
- *"It's a process and… it's usually not weeks. It's usually months… averages, like six months, or at least… where you return to driving, and that's just an average… For some people it's never, and some people, a few weeks, if they're very mild-Demetrius*
- *Where to refer people [to get] someone back to driving… first off, their physician and then second off, if you want to participate in that as far as therapy goes and provide the physician a little bit more insight, you've really got to refer them to someone with driving evaluation specialty. -Jay*
- *[How to] get in and out of their house so they can get to outpatient –Abby*
- *We talked to the lady that owns the building about putting in a ramp for her. –Maggie*

Return to hobbies/leisure

- *I've referred people… to people who will give [horseback] riding lessons. -Maggie*
- *People that have had strokes that used to ride before, we've done some adaptive reins… talk to them about… making some modifications on their riding equipment. –Maggie*
- *I had one guy that we did work with Agrability to modify his tractor because he was having some falls getting up and down off his tractor, so they came out and did some modifications, like his fencing to make it more accessible, to switch his tractor around… he was having some cattle dying because he couldn't get to 'em. -Maggie*
- *I've done fishing rods… people who… fished before and it's just difficult to cast and reel with one hand… adaptation for a fishing rod where you can cast and then put it, it's almost like a belt, and reel that way. –Maggie*

INSTITUTIONAL SUPPORT & RESOURCES

EXAMPLES

- Insurance as it pertains to Physical Therapy (e.g., Medicare regulations, cap on therapy services) and Equipment Coverage
- Resources
    - To get equipment paid for
    - Local community services/programs
    - Government services
    - Disability

SAMPLE QUOTES

Insurance-related topics

- *Paying out of pocket is what you have to do to get somebody to come and sit and do the laundry or do your meds, and help you walk around. -Mandy*
- *None of that stuff gets paid for by insurance. [e.g. bathroom equipment] – Mandy*
- *If you're going to give them [equipment], you should tell them where you think the money will come from -Bertha*
- *if we think you're going to need both a walker and a wheelchair, then if you can come up with one of these… it really helps out from a financial standpoint… Insurance will probably cover the other one, potentially. –Demetrius*
- *When people find out they have to pay…Like if the husband has to get back to work and he's got to pay out of pocket for somebody to stay with his wife. -Mandy*
- *I just tell them that if they have that Medicare/Humana… replacement plan, then they're either going to be limited on visits or they're going to have these high co-pays… it's going to be less per month and they're going to have pharmaceutical coverage but if they have some sort of chronic, neurological disorder… they've got to really lay out how much it's going to cost to have this plan versus how much it's going to cost to have Medicare and they need to sit down with someone who can really help them figure that out because even though this one upfront looks like it's a lot cheaper, in the long run, that Humana/Medicare replacement plan may be more expensive because they're not going to get the therapy they need, they're going to have secondary complications, they're going to need more medication to combat all the other stuff -Dee*
- *Orthonet says "you're going to have 4 visits after your stroke and then we'll reassess" – Dee*
- *"I would like to stay here until I can walk" … "Well, that's not what your insurance is going to allow." –Zelda*
- *"Sometimes they pay for things, sometimes they don't. Sometimes you can do this for money." –Bertha*
- *we give out names and numbers, we tell them where to go, "You can get this at Lowe's, you've got this available here… [order out of] catalogs because it's cheaper." –Abby*

Resources

- *"We have wheelchair seating mobility clinic if there ever was a need for power mobility" – Demetrius*
- *People are worried about money and they don't want to have a huge bill that's going to bankrupt them when they get done, so they want to be wise from that perspective - Demetrius*

References

Alkadry, M., Wilson, C., & Nicholas, D. (2006). Stroke Awareness Among Rural Residents. *Social Work in Health Care,* 42(2), 73-92.

Anderson, S. & Marlett, N. (2004). Communication in stroke: the overlooked rehabilitation tool. *Age and Ageing*, 33(5), 440-443.

Asselin, M. (2003). Insider research: issues to consider when doing qualitative research in your own setting. *Journal for Nurses in Staff Development*, 19(2), 99-103.

Avent, J., Glista, S., Wallace, S., Jackson, J., Nishioka, J., & Yip, W. (2005). Family information needs about aphasia. *Aphasiology, 1*9, 365-375.

Behringer, B. & Friedell, G. (2006). Appalachia: where place matters in health. *Preventing Chronic Disease,* 3(4), A113.

Brereton, L. & Nolan, M. (2000). 'You do know he's had a stroke, don't you?' Preparation for family care-giving: the neglected dimension. *Journal of Clinical Nursing,* 9, 498-506.

Britten, N. (1995). Qualitative interviews in medical research. *BMJ*, 311, 251-253.

Bulley, C., Shiels, J., Wilkie, K., & Salisbury, L. (2010). Carer experiences of life after stroke - a qualitative analysis. *Disability and Rehabilitation,* 32(17), 1406-1413.

Cameron, J. & Gignac, M. (2008). “Timing it Right”: a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Education and Counseling,* 70, 305-314.

Casper, M., Nwaise, I., Croft, J., & Nilasena, D. (2008). Atlas of Stroke Hospitalizations Among Medicare Beneficiaries (Appendix A - State Tables). Retrieved December 31, 2012, from http://www.cdc.gov/dhdsp/atlas/2008_stroke_atlas/docs/2008_Stroke_Atlas_Appendix_A.pdf.

Charmaz, K. (2006). *Constructing grounded theory*. London: Sage.

Cheek, J. (2008). Researching collaboratively: implications for qualitative research and researchers. *Qualitative Health Research,* 18(11), 1599-1603.

Coghlan, D. & Casey, M. (2001). Action research from the inside: issues and challenges in doing action research in your own hospital. *Journal of Advanced Nursing*, 35(5), 674-682.

Counties in Appalachia. Appalachian Regional Commission. Retrieved December 31, 2012, from http://www.arc.gov/counties.

County Economic Status and Distressed Areas in the Appalachian Region, Fiscal Year 2011. (2010). Retrieved November 20, 2012, from http://www.arc.gov/appalachian_region/CountyEconomicStatusandDistressedAreasinAppalachia.asp.

Creswell, J. (2007). *Qualitative inquiry and research design: choosing among five approaches*. Second ed. Thousand Oaks, CA: Sage.

Creswell, J. (2009). *Research design: qualitative, quantitative, and mixed methods approaches*. Third ed. Thousand Oaks, CA: Sage.

Dancause, N., Barbay, S., Frost, S., et al. (2005). Extensive cortical rewiring after brain injury. *The Journal of Neuroscience, 25*(44), 10167-10179.

Danzl, M., Hunter, E., Campbell, S., Sylvia, V., Kuperstein, J., Maddy, K., & Harrison, A. (2013). "Living with a ball and chain": The experience of stroke for individuals and their caregivers in rural Appalachian Kentucky. *The Journal of Rural Health*, in press.

Denby, F. & Harvey, R. (2003). An educational intervention for stroke rehabilitation patients and their families: healthy living after stroke. *Topics In Stroke Rehabilitation,* 9, 34-35.

Dicicco-Bloom, B. & Crabtree, B. (2006). The qualitative research interview. *Medical Education,* 40(4), 314-321.

Duncan, P., Zorowitz, R., Bates, B., Choi, J., Glasberg, J., Graham, G., Katz, R., Lambert, K., & Reker, D. (2005). Management of adult stroke rehabilitation care: a clinical practice guideline. *Stroke,* 36, e100-e143.

Dwyer, S. & Buckle, J. (2009). The space between: on being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8, 54-63.

Eames, S., Hoffman, T., Worrall, L., & Read, S. (2010) Stroke Patients' and Carers' Perception of Barriers to Accessing Stroke Information. *Topics in Stroke Rehabilitation*, 17(2), 69-78.

Eames, S., Hoffmann, T., Worrall, L., & Read, S. (2011). Delivery styles and formats for different stroke information topics: Patient and carer preferences. *Patient Education and Counseling,* 84, e18-e23.

Ellis, J., Amjad, A., & Deng, J. (2011). Using pre-interview activities to support participants' recall and analysis of past events. *In education*, 17(2), 1-14.

Eries, J. & McShane, D. (1998). Reducing the need and demand for medical services in high-risk persons: A health education approach. *Western Journal of Medicine,* 169, 201-207.

Fruth, S., Ryan, J., & Gahimer, J. (1998). The prevalence of health promotion and disease prevention education within physical therapy treatment sessions. *Journal of Physical Therapy Education,* 12(1), 10-16.

Gahimer, J. & Domholdt, E. (1996). Amount of patient education in physical therapy practice and perceived effects. *Physical Therapy,* 76(10), 1089-1096.

Garrett, D. & Cowdell, F. (2005). Information needs of patients and carers following stroke. *Nursing Older People,* 17(6), 14-16.

Gillum, R. & Mussolino, M. (2003). Education, poverty, and stroke incidence in whites and blacks: the NHANES I Epidemiologic Follow-up Study. *Journal of Clinical Epidemiology,* 56, 188-195.

Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Green, T., Haley, E., Eliasziew, M., & Hoyte, K. (2007). Education in stroke prevention: Efficacy of an educational counselling intervention to increase knowledge in stroke survivors. *Canadian Journal of Neuroscience Nursing,* 29(2), 13-20.

Greenwood, N., Mackenzie, A., Cloud, G., & Wilson, N. (2009). Informal primary carers of stroke survivors living at home – challenges, satisfactions and coping: A systematic review of qualitative studies. *Disability and Rehabilitation*, 31(5), 337-351.

Gresham, G., Duncan, P., Stason, W., et al. (1995). Post-stroke Rehabilitation. Clinical Practice Guideline, No. 16. Rockville, MD: U.S. Department of Health and Human Services. Public Health Service, Agency for Health Care Policy and Research. AHCPR Publication No. 95-0662. Retrieved March 17, 2012, from http:///www.ncbi.nlm.nih.gov/books/NBK52428/.

Hafsteinsdottir, T., Vergunst, M., Lindeman, E., & Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: A systematic review of the literature. *Patient Education and Counseling*, 85, 14-25.

Halverson, J., Barnett, E., & Casper, M. (2002). Geographic disparities in heart disease and stroke mortality among black and white populations in the Appalachian region. *Ethnicity & Disease,* 12(4), S3-82-91.

Hanger, H., Walker, G., Paterson, L., McBride, S., & Sainsbury, R. (1998). What do patients and their carers want to know about stroke? A two-year follow-up study. *Clinical Rehabilitation,* 12, 45-52.

Hoffman, T. & McKenna, K. (2006). Analysis of stroke patients' and carers' reading ability and the content and design of written materials: Recommendations for improving written stroke information. *Patient Education and Counseling*, 60, 286-293.

Hoffman, T., McKenna, K., Worrall, L., & Read, S. (2007). Randomised trial of a computer-generated tailored written education package for patients following stroke. *Age and Ageing*, 36, 280-286.

Hofgren, C., Bjorkdahl, A., Esbjornsson, E., & Sunnerhagen, K. (2007). Recovery after stroke: cognition, ADL function and return to work. *Acta Neurologica Scandinavica,* 115(2), 73-80.

Jahrami, H., Marnoch, G., & Gray, A. (2009). Use of card sort methodology in the testing of clinical leadership competencies model. *Health Services Management Research*, 22, 176-183.

Jette, D., Latham, N., Smouth, R., Gassaway, J., Slavin, M., & Horn, S. (2005). Physical therapy interventions for patients with stroke in inpatient rehabilitation facilities. *Physical Therapy,* 85, 238-248.

Johansson, B. (2000). Brain plasticity and stroke rehabilitation. The Willis lecture. *Stroke, 31*(1), 223-230.

Johnson, J. & Pearson, V. (2000). The effects of a structured education course on stroke survivors living in the community. *Rehabilitation Nursing*, 25(2), 59-65.

Joubert, J., Prentice, L., Moulin, T., Liaw, S., Joubert, L., Preux, P., Ware, D., Madeiros de Bustos, E., & McLean, A. (2008). Stroke in rural areas and small communities. *Stroke,* 39(6), 1920-1928.

Kanuha, V. (1999). Being native versus going native: conducting social work research as an insider. *Social Work*, 45, 439-447.

Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power relations in qualitative research. *Qualitative Health Research*, 19, 279-289.

Keaton, L., Pierce, L., Steiner, V., Lance, K., Masterson, M., Rice, M., & Smith, J. (2004). An E-rehabilitation team helps caregivers deal with stroke. *The Internet Journal of Allied Health Sciences and Practice,* 2(4), 1-9.

Kerr, J., Hilari, K., & Litosseliti, L. (2010). Information needs after stroke: What to include and how to structure it on a website. *Aphasiology*, 24(10), 1170-1196.

King, R. & Semik, P. (2006). Stroke Caregiving: difficult times, resource use, and needs during the first 2 years. *Journal of Gerontological Nursing*, 32(4), 37-44.

King, R., Ainsworth, C., Ronen, M., & Hartke, R. (2010). Stroke caregivers: pressing problems reported during the first months of caregiving. *Journal of Neuroscience Nursing,* 42(6), 302-311.

Kopp, B., Kunkel, A., Muhlnickel, W., Villringer, K., Taub, E., & Flor, H. (1999). Plasticity in the motor system related to therapy-induced improvement of movement after stroke. *Neuroreport, 10*(4), 807-810.

Korner-Bitensky, N., Roy, M., Teasell, R., Kloda, L., Storr, C., Asseraf-Pasin, L., & Menon, A. (2008). Creation and pilot testing of Strokengine: A stroke rehabilitation intervention website for clinicians and families. *Journal of Rehabilitation Medicine*, 40, 239-333.

Laver, K., Halbert, J., Stewart, M., & Crotty, M. (2010). Patient readiness and ability to set recovery goals during the first 6 months after stroke. *Journal of Allied Health,* 39(4), e149-e154.

Lincoln, Y. & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lowe, D., Sharma, A., & Leathley, M. (2007). The CareFile Project: a feasibility study to examine the effects of an individualized information booklet on patients after stroke. *Age and Ageing*, 36, 83-89.

Marsden, D., Quinn, R., Pond, N., Golledge, R., Neilson, C., White, J., McElduff, P., & Pollack, M. (2010) A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial. *Clinical Rehabilitation*, 24, 328-341.

Mellion, L. & Tovin, M. (2002). Grounded theory: a qualitative research methodology for physical therapy. *Physiotherapy Theory and Practice*, 18, 109-120.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods 1* (2), Article 2. Retrieved March 31, 2013, from http://www.ualberta.ca/~ijqm/.

Norum, K. (2008) *Artifacts*. In L. Given (Ed.). The SAGE Encyclopedia of Qualitative Research Methods (Volume 2). Thousand Oaks, CA: Sage, 24-26.

Nudo, R. J., Plautz, E. J., & Frost, S. B. (2001). Role of adaptive plasticity in recovery of function after damage to motor cortex. *Muscle Nerve, 24*(8), 1000-1019.

O'Connell, B., Baker, L., & Prosser, A. (2003). The educational needs of caregivers of stroke survivors in acute and community settings. *Journal of Neuroscience Nursing,* 35, 21-28.

O'Connell, B., Hawkins, M., Botti, M., Buchbinder, R., & Baker, L. (2009). Providing information to stroke survivors: Lessons from a failed randomized controlled trial. *JARNA*, 12(3), 4-6.

O'Farrell, B. & Evans, D. (1998). The continuum of care: The process and development of a nursing model for stroke education. *Axone*, 20(1), 16-18.

O'Halloran, R., Worrall, L., & Hickson, L. (2011). Environmental factors that influence communication between patients and their healthcare providers in acute hospital stroke units: an observational study. *International Journal of Language and Communication Disorders*, 46(1), 30-47.

O'Mahoney, P., Rodgers, H., Thomson, R., Dobson, R., & James, O. (1997). Satisfaction with information and advice received by stroke patients. *Clinical Rehabilitation,* 11, 68-72.

Pearson, T. (2010). Cardiovascular risk in minority and underserved women in Appalachian Tennessee: a descriptive study. *Journal of the American Academy of Nurse Practitioners,* 22, 210-216.

Pierce, C., Fahs, P., Dura, A., Fronczek, A., Morgan, L., Leppert, T., Srnka-Debnar, F., Terriquez-Kasey, L., Hamilton, B., & Buel, V. (2011). Raising

stroke awareness among rural dwellers with a Facts for Action to Stroke Treatment-based educational program. *Applied Nursing Research*, 24, 82-87.

Pollard, K. & Jacobsen, L. (2011). The Appalachian Region in 2010: A Census Data Overview Chartbook. Appalachian Regional Commission. Retrieved December 2, 2012, from http://www.arc.gov/research/researchreportdetails.asp?REPORT_ID=94.

Rindflesh, A. (2009). A grounded-theory investigation of patient education in physical therapy practice. *Physiotherapy Theory and Practice,* 25, 193-202.

Rittman, M. (2007). *Giving hope: A guidebook for caregivers of veterans with stroke.* Department of Veterans Affairs. Retrieved April 22, 2013, from http://www.queri.research.va.gov/tools/stroke-quality/patient-edu.cfm.

Rochette, A., Korner-Bitensky, N., Tremblay, V., & Kloda, L. (2008). Stroke rehabilitation information for clients and families: Assessing the quality of the StrokEngine-Family website. *Disability and Rehabilitation*, 30(19), 1506-1512.

Rodgers, H., Bond, S., & Curless, R. (2001). Inadequacies in the provision of information to stroke patients and their families. *Age and Ageing,* 30, 129-133.

Roger, V., Go, A., Lloyd-Jones, D., et al. (2011). Heart disease and stroke statistics-2011 update: a report from the American Heart Association. *Circulation,* 123(4), e18-e209.

Rose, T., Worrall, L., & McKenna, K. (2003). The effectiveness of aphasia-friendly principles for printed health education materials for people with aphasia following stroke. *Aphasiology*, 17(10), 947-963.

Rose, T., Worrall, L., Hickson, L., & Hoffmann, T. (2011). Aphasia friendly written health information: Content and design characteristics. *International Journal of Speech-Language Pathology*, 13(4), 335-347.

Rothstein, J. (Ed.) (2001). *Guide to Physical Therapist Practice.* Vol 81. Second edition ed. Alexandria, VA: American Physical Therapy Association.

Royal College of Physicians. National Clinical Guideline for Stroke. Retrieved March 17, 2012, from http://www.rcplondon.ac.uk/resources/stroke-guidelines.

Rubinstein, R. (2002). *The qualitative interview with older informants: some key questions*. In G.D. Rowles & N.E. Schoenberg (Eds.). Qualitative Gerontology (Second Edition). New York, NY: Springer Publishing Company, 138-153.

Rural-Urban Continuum Codes. (2003). United States Department of Agriculture, Economic Research Service. Retrieved November 28, 2012, from http://www.ers.usda.gov/data-products/rural-urban-continuum-codes.aspx.

Salisbury, L., Wilkie, K., Bulley, C., & Shiels, J. (2010). 'After the stroke': patients' and carers' experiences of healthcare after stroke in Scotland. *Health and Social Care in the Community,* 18, 424-432.

Sandelowski, M. (1995). Sample Size in Qualitative Research. *Research in Nursing and Health*, 18, 179-183.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334-340.

Scheets, P., Sahrmann, S., & Norton, B. (1999). Diagnosis for Physical Therapy for Patients with Neuromuscular Conditions. *Neurology Report*, 23(4), 158-169.

Sluijs, E. (1991). Patient education in physiotherapy: Towards a planned approach. *Physiotherapy,* 17, 14-16.

Smith. J., Forster. A., House. A., Knapp. P., Wright. J., & Young, J. (2008). Information provision for stroke patients and their caregivers. *Cochrane Database of Systematic Reviews,* 2.

Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Sullivan, K., White, K., Young, R., Scott, C., & Mulgrew, K. (2008). Developing a stroke intervention program: What do people at risk of stroke want? *Patient Education and Counseling*, 70, 126-134.

Teasell, R., Foley, N., Salter, K., Bhogal, S., Jutai, J., & Speechley, M. (2011). Evidence-based review of stroke rehabilitation: Executive Summary, 14th edition. Retrieved March 17, 2012, from www.ebrsr.com.

Tickamyer. A. & Duncan, C. (1990). Poverty and opportunity structure in rural America. *Annual Review of Sociology,* 16, 67-86.

van Veenendaal, H., Grinspun, D., & Adriaanse, H. (1996). Educational needs of stroke survivors and their family members, as perceived by themselves

and by health professionals. *Patient Education and Counseling,* 28, 265-276.

Vanetzian, E. (1997). Learning readiness for patient teaching in stroke rehabilitation. *Journal of Advanced Nursing,* 26, 14-25.

Wellwood, I., Dennis, M., & Warlow, C. (1994). Perceptions and knowledge of stroke among surviving patients with stroke and their carers. *Age and Ageing*, 23(4), 293-298.

Whyte, E., Mulsant, B., Vanderbilt, J., Dodge, H., & Ganguli, M. (2004). Depression after stroke: a prospective epidemiological study. *Journal of the American Geriatrics Society,* 52(5), 774-778.

Wiles, R., Pain, H., Buckland, S., & McLellan. (1998). Providing appropriate information to patients and carers following a stroke. *Journal of Advanced Nursing,* 28, 794-801.

Wood, J., Connelly, D., Maly, M. (2010). 'Getting back to real living': A qualitative study of the process of community reintegration after stroke. *Clinical Rehabilitation,* 24(11), 1045-1056.

Zahnd, W., Scaite, S., & Frances, M. (2009) Health literacy in rural and urban populations. *American Journal of Health Behavior*, 33(5), 550-7.

Vita

Megan Marie Danzl, PT, DPT, NCS

GENERAL INFORMATION

Licensure and Certifications:

Present	Licensed Physical Therapist Kentucky (004904) and Indiana (05008894A)
2011	Board Certified Neurologic Specialist; American Board of Physical Therapy Specialties
2007	Credentialed Physical Therapy Clinical Instructor; American Physical Therapy Association
2006	Certified Kinesio Taping Practitioner; Progressive Rehab Concepts

EDUCATION

2008-present	University of Kentucky, Lexington, KY College of Health Sciences
2002-2005	Bellarmine University, Louisville, KY Lansing School of Nursing and Health Sciences Bachelor of Health Science Doctor of Physical Therapy
2001-2002	University of Louisville, Louisville, KY College of Arts and Sciences

PROFESSIONAL EXPERIENCES

Dates	Position/Title	Institution
2009-2012	Physical Therapist Doctoral Fellowship	Cardinal Hill Rehabilitation Hospital, Lexington, KY
2006-present	Inpatient Rehabilitation Physical Therapist	Southern Indiana Rehab Hospital New Albany, IN
2006-2012	Acute Care Pediatric Physical Therapist	Kosair Children's Hospital, Louisville, KY
2006-2007	Acute Care Physical Therapist	Norton Hospital, Louisville, KY

TEACHING ACTIVITY

2012 University of Kentucky, Guest Laboratory Instructor, Neurologic Rehabilitation, Physical Therapy Department
2011 University of Kentucky, Graduate Teaching Apprenticeship in Neurologic Rehabilitation, Physical Therapy Department. Advisor Dr. Lynn English
2006-2009 Bellarmine University, Clinical Laboratory Instructor and Lecturer Courses: Neurologic Rehabilitation, Basic Patient Care, Spine, Human Performance and Health Promotion, Gross Anatomy

SCHOLASTIC AND PROFESSIONAL HONORS AND AWARDS

2012 Elected to Omicron Delta Kappa, Leadership Honor Society, University of Kentucky
2012 American Congress of Rehabilitation Medicine, 89th Annual Conference, Vancouver, BC, Outstanding Poster Presentation
2012 University of Kentucky Physical Medicine and Rehabilitation 24th Annual Research Day, Lexington, KY, Best Poster Presentation
2011 Elected to Phi Kappa Phi Honor Society, University of Kentucky
2011 Elected to Delta Epsilon Iota Honor Society, University of Kentucky
2011 Elected to Golden Key International Honour Society, University of Kentucky
2003 Great Lakes Valley Conference All-Academic NCAA Volleyball
2003 Elected to Chi Alpha Sigma Honor Society, Bellarmine University
2001 Southern Indiana Academic Scholarship, University of Louisville

PROFESSIONAL PUBLICATIONS AND PRESENTATIONS

Peer-Reviewed Publications

Danzl M, Etter N, Andreatta R, & Kitzman P (2012) Facilitating neurorehabilitation through principles of engagement**.** *Journal of Allied Health*. 41(1):35-41.

Danzl M, Hunter E. Perceived value of stroke outcome measures across the post-acute care continuum: A qualitative case study. *Physiotherapy Theory and Practice.* Available early online: October, 2012.

Danzl M, Hunter E, Harrison A, Campbell S, Sylvia V, Kuperstein J, Maddy K. "Living with a ball and chain": The experience of stroke for individuals and their caregivers in rural Appalachian Kentucky. *Journal of Rural Health*. In press.

Danzl M, Chelette K, Lee K, Lykins D, Sawaki L. Non-invasive brain stimulation paired with novel locomotor training in chronic stroke: A feasibility study. *NeuroRehabilitation*. In press.

Non-Reviewed Publications

Danzl M. For Reasons Real and Reel: Inspired More by Home than Hollywood. *PT in Motion*, “This is Why” segment. February, 2011.

Refereed Abstract Presentations

2013 **Danzl M**, Hunter E, Campbell S, Sylvia V, Kuperstein J, Maddy K, Harrison A. "Living with a ball and chain": The lived experience of stroke for individuals and their caregivers in rural Appalachian Kentucky. *American Physical Therapy Association Annual Combined Sections Meeting*. Poster Presentation. San Diego, CA.

2013 Harrison A, Kuperstein J, **Danzl M**, Hunter E, Campbell S, Sylvia V, Maddy K. The lived experience of stroke across the continuum of care in rural Appalachian Kentucky: Theoretical frameworks. *American Physical Therapy Association Annual Combined Sections Meeting*. Poster Presentation. San Diego, CA.

2012 **Danzl M**, Chelette K, Lee K, Lykins D, Sawaki L. Non-invasive Brain Stimulation Paired with a Novel Locomotor Training in Chronic Stroke: a Feasibility Study. *American Congress of Rehabilitation Medicine-American Society for Neurorehabilitation Annual Conference, ‘Progress in Rehabilitation Research’*. Poster Presentation. Vancouver, BC.

2012 **Danzl M**, Hunter E, Campbell S, Sylvia V, Kuperstein J, Maddy K, Harrison A. "Living with a ball and chain": The lived experience of stroke for individuals and their caregivers in rural Appalachian Kentucky. *Kentucky Appalachian Rural Rehabilitation Network Annual Conference.* Poster Presentation. Richmond, KY.

2012 **Danzl M**, Harrison A, Hunter EG, Rowles G. The use of teams in qualitative research. *University of Kentucky Center for Clinical and Translational Science Spring Conference – Appalachian Health Summit.* Poster Presentation. Lexington KY.

2012 **Danzl M**, Chelette K, Lee K, Lykins D, Sawaki L. Brain stimulation and robotic gait orthosis in chronic stroke: a feasibility study. *University of Kentucky Center for Clinical and Translational Science Spring Conference – Spring Neuroscience Research Day: Bluegrass Chapter of the Society for Neuroscience*. Poster Presentation. Lexington KY.

2012 Campbell S, **Danzl M**, Maddy K, Hunter E, Sylvia V, Kuperstein J, Harrison A. Needs assessment of people with stroke in Appalachian Kentucky: a theoretical model. *University of Kentucky Center for Clinical and Translational Science Spring Conference – Appalachian Health Summit.* Poster Presentation. Lexington KY.

2012 **Danzl M** and Hunter EG. The experience of implementing and using stroke outcome measures across the post-acute care continuum. *American Physical Therapy Association Combined Sections Meeting*. Poster Presentation. Chicago, IL.

2012 **Danzl M**, Harrison A, Hunter EG, Rowles G. The use of teams in qualitative research. *American Physical Therapy Association Combined Sections Meeting*. Poster Presentation. Chicago, IL.

2012 Campbell S, Harrison A, **Danzl M**, Hunter E, Sylvia V, Kuperstein J, Maddy K. Social networks after stroke in rural Appalachia: a qualitative study. *American Speech Language Hearing Association Annual Convention*. Oral Presentation. Atlanta, GA.

2011 **Danzl M**, McKeon, PO. Interventions for drop foot in those with sub-acute cerebrovascular accident: A systematic review. *American Physical Therapy Association Combined Sections Meeting*. Poster Presentation. New Orleans, LA.

2011 **Danzl M**, Chelette K, Lykins D, Lee K, Sawaki L. Transcranial direct current stimulation and Lokomat for gait recovery in chronic stroke. *Kentucky Appalachian Rural Rehabilitation Network Conference.* Poster Presentation. Somerset, KY.

2011 **Danzl M** and Hunter EG. The experience of implementing and using stroke outcome measures across the post-acute care continuum. *Kentucky Appalachian Rural Rehabilitation Network Conference.* Poster Presentation. Somerset, KY.

2010 **Danzl M**, McKeon, PO. Interventions for drop foot in those with sub-acute cerebrovascular accident: A systematic review. *Kentucky Physical Therapy Association Summer Conference.* Poster Presentation. Louisville, KY.

2008 **Danzl M**, Lonnemann E, Boyce D, Brosky, T. Examining Oral Contraceptive Use as a Contraindication for Spinal Manipulations (High Velocity Thrusts): a Literature Review. *International Federation of Orthopedic and Manipulative Therapists Annual Conference.* Oral Presentation. Rotterdam, The Netherlands.

2006 **Danzl M**, Boyce D, Lonnemann E, Brosky T. Examining Oral Contraceptive Use as a Contraindication for Spinal Manipulations (High Velocity Thrusts): a Literature Review. *Kentucky Physical Therapy Association Spring Conference.* Oral Presentation. Lexington, KY.

2006 **Danzl M**, Boyce D, Lonnemann E, Brosky T. Examining Oral Contraceptive Use as a Contraindication for Spinal Manipulations (High Velocity Thrusts): a Literature Review. *American Physical Therapy Association Combined Sections Meeting.* Oral Presentation. San Diego, CA.

2005 **Danzl M**, Boyce D. Examining the Effects of Vitamin B6 (Pyridoxine) in Treating Carpal Tunnel Syndrome: a Literature Review. *American Physical Therapy Association Combined Sections Meeting.* Oral Presentation. New Orleans, LA.

Invited Speaking Engagements/Presentations

2013 Ulanowski L, **Danzl M**, Brosky T. *Outcome Measures for the Neurological Population*. Physical Therapy Neuroresidency Program. Norton Neuroscience Institute. Lexington, KY.

2012 **Danzl M**, Etter N. *The Role of Rehabilitation in Neuroplasticity*. Neuroplasticity for the Speech Language Pathologist, Masters in Speech Language Pathology program. University of Kentucky. Lexington, KY

2012 **Danzl M**, Etter N. *Facilitating Neurorehabilitation through Principles of Engagement*. Research Lunch and Learn program. Cardinal Hill Rehabilitation Hospital. Lexington, KY.

2012 Ulanowski L, **Danzl M**, Brosky T. *Outcome Measures for the Neurological Population*. Physical Therapy Neuroresidency Program. Norton Neuroscience Institute. Lexington, KY.

2011 **Danzl M**, Chelette K, Lee K, Lykins D, Sawaki L. *Neuroplasticity and Stroke Locomotor Rehabilitation*. Research Lunch and Learn program. Cardinal Hill Rehabilitation Hospital. Lexington, KY.

2011 **Danzl M**, Hunter E. *Implementing a Stroke Outcomes Assessment Program for Post Acute Care: A Qualitative Case Study*. Research Lunch and Learn program. Cardinal Hill Rehabilitation Hospital. Lexington, KY.

2006 **Danzl M**. *A Former Student's Perspective on the Doctoral Program at Bellarmine University*. Physical Therapy Class of 2008 Incoming Professional Invocation. Bellarmine University. Louisville, KY

2006 **Danzl M**. *Evidence Based Research During Clinical Rotations: a Student's Perspective*. Partners in the Future of Physical Therapy: Academic, Clinician, and Student Collaboration. The Ohio Consortium of Physical Therapy Programs 17th Annual Workshop. Kings Island, OH.