

Using the Preparedness Assessment for the Transition Home After Stroke Instrument to Identify Stroke Caregiver Concerns Predischarge: Uncertainty, Anticipation, and Cues to Action

Michelle Camicia¹, PhD, RN, CRRN, CCM, NEA-BC, FAHA, FARN,
Barbara J. Lutz², PhD, RN, CRRN PHNA-BC, FAHA, FAAN, Theresa A. Harvath³, PhD, RN, FAAN, FGSA &
Jill G. Joseph³, MD, PhD, MPH

Abstract

Purpose: The aim of the study was to better understand caregivers' concerns about long-term implications of stroke and the caregiving role after completing the Preparedness Assessment for the Transition Home After Stroke (PATH-s).

Design/Methods: In this qualitative study, cognitive interviews were conducted with 20 stroke caregivers who completed the PATH-s tool as part of an instrument validation study. Data were analyzed for salient themes related to their perceptions about stroke and the caregiving role.

Findings: Interviews yielded robust narrative data describing how the PATH-s items aided caregivers in recognizing potential issues and concerns about stroke and the caregiving role. Caregivers experienced uncertainty about the long-term stroke prognosis, which provoked anticipation and cues to action to begin addressing their concerns.

Conclusions/Clinical Relevance: Completing the PATH-s helped caregivers identify concerns regarding the long-term implications of stroke and their caregiving role. It may serve as an important assessment tool to assist rehabilitation nurses to better understand and address caregiver needs predischarge.

Keywords: Caregiver; discharge planning; patient- and family-centered care; stroke; transitions.

Stroke is a leading cause of major disability in the United States and globally (Benjamin et al., 2019). Of the estimated 6.6 million stroke survivors living in the United States, more than 4.5 million have some level of disability following stroke (Mozaffarian et al., 2016). When stroke survivors return home, they frequently require assistance with activities of daily living (ADLs) and instrumental ADLs, usually provided by family members. Stroke is often a crisis for the

family system (Lutz, Young, Cox, Martz, & Creasy, 2011). There are approximately 4 million family members in the United States who provide care for stroke survivors at home (National Alliance for Caregiving, 2015).

Stroke survivors usually receive care in the emergency department and acute care hospital, with an average length of stay of 5.7 days (Steiner & Weiss, 2016). Those who have functional impairments that require ongoing hospitalization and rehabilitation are often admitted to an inpatient rehabilitation facility (IRF) for treatment and family caregiver training, as recommended by the American Heart/Stroke Association (Winstein et al., 2016). The discharge from the IRF is where the caregiver, often a family member, assumes the caregiving role, participating in the patient's nursing care and rehabilitation therapies to learn the skills required upon discharge.

Correspondence: Michelle Camicia, Kaiser Foundation Rehabilitation Center, Kaiser Permanente Vallejo Medical Center, 975 Sereno Drive, Vallejo, CA 94589.
E-mail: Michelle.Camicia@KP.org

1 Kaiser Foundation Rehabilitation Center, Kaiser Permanente Vallejo Medical Center, Vallejo, CA, USA

2 School of Nursing, University of North Carolina-Wilmington, Wilmington, NC, USA

3 The Betty Irene Moore School of Nursing, University of California-Davis, Davis, CA, USA

Copyright © 2020 Association of Rehabilitation Nurses.

Cite this article as:

Camicia, M., Lutz, B. J., A. Harvath, T. A., & Joseph, J. G (2021). Using the preparedness assessment for the transition home after stroke instrument to identify stroke caregiver concerns predischarge. *Rehabilitation Nursing*, 46(1), 33-42. doi: 10.1097/mj.0000000000000267

Background

Stroke survivors and their family caregivers face enormous challenges as they transition through the stroke care continuum from acute care to the IRF to home (Camicia et al., 2014; Lutz et al., 2011). Caregivers' needs for emotional support

and attentiveness to their well-being, preparation for discharge, and reassurance regarding their ability to care for the stroke survivor at home are often not met during the IRF stay (Camicia, Lutz, Markoff, & Catlin, 2019; Lutz & Camicia, 2016). Caregivers often do not have a good understanding of the role to which they are committing. The needs and concerns of caregivers are overlooked, and they are underprepared to take on even the basic tasks to meet the patients' needs postdischarge (Lutz et al., 2011, 2017). Stroke caregivers often do not possess the requisite knowledge to determine if they are prepared to provide care at home; in short, they do not know what they do not know.

The patient's physical and cognitive status at discharge as well as preexisting caregiver factors, such as the caregivers' health concerns and prestroke responsibilities; informal, formal, and financial resources; home accessibility; plans for self-care; and relationship with the stroke survivor, can influence the caregiver's ability to assume the caregiving role (Lutz et al., 2011, 2017). Each individual's experience and meaning derived from the caregiving experience are dynamic and may change over time, requiring careful nursing assessment (Nettina, 2019; Zhang & Lee, 2017). In particular, it is important to assess the caregiver's readiness for the caregiving role so that a plan of care can be tailored to address gaps in preparedness (Lutz et al., 2017).

The Preparedness Assessment for the Transition Home After Stroke (PATH-s) is a 25-item instrument designed to assess caregiver readiness to care for a stroke survivor following discharge from an IRF and is based on the *Improving Stroke Caregiver Readiness Model* (Lutz et al., 2017). The data underlying this model suggest that, as caregivers move from IRF to home, they do not have a good understanding of the role to which they are committing and are often underprepared to take on even the necessary basic tasks on discharge (Lutz et al., 2017). Furthermore, the model illustrates that the caregiver assessment is essential to develop an individualized plan to address the gaps in caregiver preparedness. The theoretical model was developed from caregiver perspectives and identifies the important assessment domains of caregiver commitment and caregiver capacity (Lutz et al., 2017). The model domains are included in Table 1. The PATH-s instrument was developed to assess each of these domains. The purpose of this study was to better understand caregivers' concerns about long-term implications of stroke and the caregiving role after completing the PATH-s.

Methods

Overview

This study was conducted as part of a larger study to develop and validate the (PATH-s) instrument (Camicia et al., 2018; Camicia, Lutz, Harvath, et al., 2019). In the

Table 1 Improving Stroke Caregiver Readiness Model: Assessment Domains

Commitment	Strength of relationship
	Willingness to perform caregiver role
Capacity	Preexisting factors
	Health problems
	Prestroke roles/responsibilities
	Prestroke caregiver experience
	Home and transportation accessibility
	Internal and external resources
	Informal support
	Formal support
	Financial
Ability to sustain	Responding to stroke
	Dealing with crisis of stroke
	Long-term implications

Note. Adapted from Lutz et al. (2017).

larger study, the PATH-s instrument was developed in a three-stage sequential, multimethod approach, which included the following:

Stage 1: Item generation for each of the concepts in the *improving stroke caregiver readiness model* and review of items by expert clinicians;

Stage 2: Cognitive interviews of stroke caregivers to improve item clarity and to generate new items based on the results; and

Stage 3: Pilot testing to evaluate respondent burden to complete the PATH-s.

The data in the study described here reflects Stage 2 and is reported as a subset of this larger project.

Research Design

Cognitive interviewing techniques (Knafl et al., 2007; Willis, 1999) were used to develop and establish the validity of the PATH-s instrument (Camicia, Lutz, Harvath, et al., 2019). Cognitive interviewing is an evidence-based, qualitative method specifically designed to investigate if the questions in a survey fulfill the intended purpose (Willis & Artino, 2013). Large volumes of narrative data are generated through cognitive interviews (CIs), including information about the participant's thoughts, concerns, or anxieties while responding to the items (Goodwin, 2002). Cognitive interviews are designed to improve the content validity and reliability of an instrument by assessing the clarity and relevance of items for the target population (Knafl et al., 2007). Cognitive interviews also can be used to determine how a participant comprehends an item and what the respondent thinks about during the formulation of a response to the question (Collins,

2003). Therefore, in addition to improving item validity and relevance, CIs may also ascertain important information about the impact that instrument items have on the individual's perceptions about the constructs being assessed. This is especially relevant when assessing individuals about topics that they have not otherwise considered.

Sampling

Following approval of the organization's institutional review board, CIs with 20 stroke caregivers of patients admitted to an IRF within an integrated care delivery system were conducted. Caregivers were identified as the persons who would provide assistance to the stroke survivor with ADLs (e.g., bathing, dressing, toileting, mobility) and instrumental ADLs (e.g., shopping, cooking) upon discharge. Participants met the following criteria: caring for a stroke survivor who was admitted following first stroke with planned discharge to home, the ability to speak and read English, 18 years of age or older, and cognitively able to consent. Potential participants were identified through review of the facility census. Caregivers of stroke survivors who were present at the facility were screened by the principal investigator (PI) according to the above criteria and invited to participate if they met the criteria. Demographic characteristics of the participants were tracked. Participants were purposefully recruited to include diverse representation of age, gender, race, income level, and relationship to the stroke survivor.

Data Collection

Data collection began in the spring of 2017 and continued for 2 months. The PI approached eligible caregivers visiting stroke survivors to explain the study. Caregivers who indicated an interest in participating were given an institutional review board-approved consent form and a *research participant's bill of rights*. Once consent was obtained, the PI scheduled an appointment to conduct the interview and provided the participant a copy of the signed consent.

The PATH-s instrument was administered in person to 20 caregivers. Each of the PATH-s 25 items has four response options that are ordinally ranked and written in the first person. The PATH-s is self-administered on an iPad or other electronic device. These items have been previously reported (Camicia, Lutz, Harvath, et al. 2019).

Study participants were asked to enter their responses to items directly into Qualtrics using an iPad. Qualtrics (Qualtrics, Provo, UT) is an online web-based survey tool that allows for the distribution, collection, and analysis of survey items. Basic demographic information was entered into Qualtrics by each participant, including age, gender, race/ethnicity, relationship to stroke survivor, educational attainment, and household income.

After each participant completed the instrument, the PI conducted item-by-item, semistructured CIs, with open-ended questions, to elicit participants' understanding of the items and identify what they were thinking when they read and answered each question in an effort to evaluate how each of the PATH-s items was interpreted and understood (Knafl et al., 2007). Participants were asked open-ended questions about each PATH-s item following a script. Questions included, "What did you understand this question is asking?" and "What were you thinking when you answered the question?" These questions were asked item-by-item for each item of the PATH-s instrument. Verbal probing was used to elicit participants' understanding of the items and what they were thinking when they answered each question to obtain insights into their responses. The interviews were conducted in a private room at the IRF. Participant interviews were audio-recorded and transcribed verbatim. Findings from the item analysis are reported elsewhere (Camicia Lutz, Harvath, et al., 2019a).

During the CIs, participants were asked to "think aloud" and describe what they thought about as they responded to each item. The caregivers reflected on how responding to the items raised their awareness about their caregiving role. They provided rich and detailed descriptions of issues and concerns about caring for the stroke survivor that they had not considered prior to completing the PATH-s. So, in addition to providing information about item clarity, relevance, and validity, participants also discussed how certain items made them aware of concerns they had about assuming the caregiving role. These descriptions were unexpected, but important, in understanding the impact of the tool on raising caregiver awareness about potential issues and concerns.

Data Analysis

Two certified registered rehabilitation nurses on the research team (M. C. and B. L.) with experience in qualitative research independently coded the interviews using thematic analysis (Guest, MacQueen, & Namey, 2012; Ryan, & Bernard, 2003). Data were entered into an Excel spreadsheet with one column for the verbatim quotes and one column for the associated themes. Salient themes related to caregivers' responses to each item on the PATH-s were manually coded. The identified theme was entered into the column corresponding to the verbatim quote. As themes were identified in early interviews, they were verified in later interviews, substantiating their relevance. The researchers met in person and by video conferencing to discuss themes identified in their independent review of the transcripts. Comparisons of themes were made within and across interviews and compared for similarities and differences in caregivers' responses to the questions. An audit trail of research team discussions was maintained. The researchers came to consensus about key

themes and related concepts. Relevant participant quotations were identified, and coding was agreed upon for each core concept. The demographic data were entered into SPSS Version 25 (IBM Corp.) for descriptive analysis.

Findings

Participant characteristics are presented in Table 2. The participants' narratives provided insight into their thought processes as they completed the items on the PATH-s tool. The analysis of these rich data revealed two core concepts, uncertainty and anticipation, and completing the PATH-s cued the caregivers to take actions. The think-aloud and probing techniques used during the CIs focusing on the caregivers' thoughts as they completed each item, revealed that caregivers were often uncertain about the stroke survivors' prognosis and their capacity to assume the caregiving role. The items also cued caregivers to consider strategies they had not thought of previously, for example, making a schedule, obtaining outside help, and accessing support services. In the following examples, these two caregivers contemplated

additional assistance that they might need: "At some point I may decide to pay for [help] rather than do it myself" (Participant 10) and "If she cannot walk and uses a wheelchair do I need paratransit?" (Participant 3).

Participants described their uncertainty and anticipation as they approached the caregiver role and how the PATH-s provided cues to action as they prepared for this new role and anticipated the transition to home. For example, several caregivers indicated that completing the instrument made them aware of issues and concerns that they had not considered prior to completing the tool as described by this caregiver,

It made me think of my own health and the capabilities I may need to work on, like building upper body strength to help with what she may need. It made me think about mentally how prepared I am as well. (Participant 3)

As caregivers read and responded to the PATH-s questions, they described how they were cued to contemplate the stroke in the context of their lives in a different way. The focus shifted from the present moment and associated functional impairments to that of the future and framed what recovery may mean for their lives as caregivers. The core concepts and dimensions, PATH-s items that elicited the responses, participant quotations, and the associated domain of the *Improving Stroke Caregiver Readiness Model* are further outlined in Table 3. For example, the concept of "uncertainty" is related to several model domains, including strength of relationship, preexisting factors, and ability to sustain. The concept of "anticipating" is related to model domains of willingness, ability to sustain, and resources.

Dimensions of Uncertainty

Participants described multiple dimensions of uncertainty, including clinical questions related to prognosis/recovery and the long-term implications of stroke, resource needs, and the physical ability to sustain the caregiver role. Interviewees were concerned about living in uncertainty and the effect of caregiving on themselves and the relationship. Finally, they expressed uncertainty about their ability to fulfill other roles and responsibilities.

Uncertainty About Prognosis and Hope for Recovery

The PATH-s triggered caregivers to think about recovery and the ambiguity of the prognosis in the context of the long-term recovery process. In the presence of ambiguity, caregivers reported that they questioned providers in search of definitive information. They perceived that providers gave them vague responses to their questions, contributing to even greater uncertainty. Several participants referenced the temporal nature of recovery, noting their understanding that recovery lasts from 3 months up to a year. A

Table 2 Demographics of Study Sample

Survey Population	<i>n</i> = 20
Age in years, <i>n</i> (%)	
35–44	2 (10)
45–54	3 (15)
55–64	6 (30)
65–74	7 (35)
75–84	2 (10)
Relationship to stroke survivor, <i>n</i> (%)	
Child of stroke survivor	4 (20)
Spouse	12 (60)
Sibling	3 (15)
Parent of stroke survivor	1 (5)
Gender, <i>n</i> (%)	
Female	16 (80)
Male	4 (20)
Education, <i>n</i> (%)	
Some high school (1–3 years)	2 (10)
High school graduate (4 years)	2 (10)
Some college (1–3 years)	5 (25)
College graduate (≥4 years)	11 (55)
Household annual income, <i>n</i> (%)	
\$20,000 to <\$35,000	1 (5)
\$35,000 to <\$50,000	2 (10)
\$50,000 to <\$75,000	2 (10)
\$75,000 to <\$100,000	10 (50)
Above \$100,000	5 (25)
Race/ethnicity, <i>n</i> (%) ^a	
Asian	5 (25)
Black/African American	1 (5)
White/Caucasian	11 (55)
Hispanic (may be any race)	2 (10)

^aTotals may not add up to 100% due to missing responses.

Table 3 Core Concepts and Dimensions and Associated Domain of the Model

Core Concept: Uncertainty			
Dimension	Question	Participant Response	Model Domain
Living in uncertainty and effect on the relationship	Do you think your physical or mental health problems will affect your ability to provide care for the stroke survivor?	"What if she needs a lot of help and we are providing it? How long is your patience? How can I do it every day? ... I can do it, but it will make both of our lives worthless. Maybe I need to get help to sustain other things to preserve our relationship." (10)	Commitment: strength of relationship
Uncertainty about physical ability to sustain CG role	Do you have any physical or mental health problems?	"I would have a problem lifting. Using that transfer board and all of that—I do not have the strength. He is a big man." (20)	Capacity: preexisting factors (health problems)
	Do you think your physical or mental health problems will affect your ability to provide care for the stroke survivor?	"I use mind over matter. If it is painful I do what I have to do. I push through." (15)	
Uncertainty about ability to fulfill other roles and responsibilities	How much time will you have to provide personal care for the stroke survivor when they come home?	"I am retired. I still have other responsibilities for which I commit for which I am not paid... I make commitments and need to balance them." (10)	Capacity: preexisting factors (other roles and responsibilities)
Uncertainty about resource needs	How much do you understand about what you need to do to get ready before the stroke survivor goes home?	"A lot is wait and see to see how far he goes. Is it going to take one person or two people? Now we do not even know about the ramps." (20)	Capacity: resources (internal/external, informal/formal, financial)
	Will the stroke survivor have accessible transportation that he/she can use to go places?	If she cannot walk and uses a wheelchair do I need paratransit? Can I put the wheelchair in the car?" (3)	
Uncertainty about the long-term implications of stroke	How much do you understand about what assistance the stroke survivor will need with personal care?	"Physically and emotionally it is hard... I have to be strong. I worry later I will not be able to keep doing this." (11)	Capacity: ability to sustain Capacity: crisis response
	How much do you understand about what you need to do to get ready before the stroke survivor goes home?	"I do not know how ready I am, so I just pray." (11)	
Uncertainty about prognosis/recovery	How much do you understand about the stroke survivor's expected recovery over the next 6 months?	"The doctor talked to us about how the next 6 months is the big time of what recovery will be. He told us what he is like now has no bearing on 6 months, but 6 months is where it is not the big jumps as much." (1) "I was told in the first 3 months she will make some gains. After a year what you see is what you get." (6) "Sometimes I ask but the answers I get are not definitive. 'It depends,' that is what everyone says." (11)	Long-term implications of stroke: prognosis Long-term implications of stroke: insight
	How much do you understand about how the stroke will affect your lives over the next 6 months?	"I know she's going to need a lot of care. Until I start going through it I will not fully understand." (6) "I know it is going to be all consuming, but I do not know how." (12)	

(continues)

Table 3 Core Concepts and Dimensions and Associated Domain of the Model, Continued

Core Concept: Anticipation			
Dimension	Question	Participant Response	Model Domain
Anticipating management strategies	How much do you understand about how the stroke will affect your lives over the next 6 months?	"It makes me think about my personal life, home life, her life, everybody's family life. The different challenges we will have and the changes we need to make; things to adjust." (3)	Capacity: resources and ability to sustain
Anticipating choices that will need to be made	How much time will you have to provide personal care for the stroke survivor?	"I thought of my responsibilities and how much extra time it will take and what I need to move around." (4) "They will take the back seat, so the care can take the front seat. But if it takes the back seat too long I will not be able to do them. My initial response is that this is going to be an issue." (9)	Commitment: willingness
Anticipating need for self-care	Do you have any physical or mental health problems?	"I have been meaning to do things like getting more exercise, eating better, making sure I am centered mentally, this is very important." (3)	Capacity: ability to sustain
	Do you think your physical or mental health problems will affect your ability to provide care?	"I am very positive and upbeat, and I know how important it is to keep the patience to care for her. I also need to take care of me, so I can take care of her." (3)	

participant indicated that, "after 1 year what you see is what you get" (Participant 6), indicating there would not be any more gains in function, based on beliefs about the recovery timeline from information received from providers. Caregivers often referenced arbitrary recovery timelines presented by providers as a way to mitigate the uncertainty of stroke recovery.

Caregivers also searched for information within the rehabilitation program to help reduce their uncertainty about the prognosis and to obtain hope. For example, one participant referenced a film (Shapiro, 2009) that is shown to caregivers as part of usual care in the study setting. The caregiver reflected, "I did not know he could regain the ability to walk, I was hoping, but I did not dream of that.... It gave him hope. I referred him to that movie and then he took a couple of steps..." (Participant 20). Caregivers compared the stroke survivor to other stroke survivors in an attempt to find definitive answers and deal with the uncertainty of the prognosis. The ambiguity about the timing and extent of recovery appeared to be the greatest source of uncertainty for caregivers in this study, as this led to uncertainty in all other dimensions.

Uncertainty About Resource Needs

Participants associated uncertainty about the prognosis with uncertainty about resources necessary to address the needs of the stroke survivor. This included transportation, help from others for personal care and other tasks, as well as financial

resources. For example, there were financial concerns about sufficient resources to hire necessary help and pay for home modifications, for medical equipment and supplies, and for the cost of living when there was an economic impact due to loss of stroke survivor or caregiver income. Participant 20 stated, "A lot is wait and see to see how far he goes. Is it going to take one person or two people? Now we do not even know about the ramps." Resources also included emotional support from friends and family. The prognosis determined the resources necessary to provide care; an uncertain prognosis led to uncertainty about resources needed and further uncertainty whether those resources would be available.

Living in Uncertainty and the Effect on the Relationship

The strength of the relationship between the caregiver and the stroke survivor influenced how the caregiver expected to manage their responsibilities. Participants reflected on their current and past relationship with the stroke survivors and how the stroke might change the relationship in the future. This included the loss of the former relationship due to hospitalization, stroke survivor personality changes, and concern over the future relationship being different and of lesser quality in the future. In some cases, the caregivers found that the stroke brought them closer because of the stroke survivor's dependence on the caregiver. Participants expressed concerns about preserving the future relationship

amidst increased caregiving burden. This concern and uncertainty provoked anticipation about the need to obtain help to sustain the relationship. A participant stated,

What if she needs a lot of help and we are providing it? How long is your patience? How can I do it every day? ...I can do it, but it will make both of our lives worthless. Maybe I need to get help to sustain other things to preserve our relationship. (Participant 10)

Uncertainty About Physical Ability to Sustain Caregiver Role

The PATH-s cued caregivers to contemplate their health and revealed uncertainty about fulfilling the physical demands of caregiving. Participants shared concerns regarding their own preexisting health conditions, though many expressed their dedication as a caregiver despite their health challenges. They also tended to minimize their health issues, “pushing through” even when providing the stroke survivor physical assistance caused them pain. The PATH-s cued the caregiver to think about their health issues, which revealed concerns about the physical demands of caregiving and the long-term ability to sustain the role.

Uncertainty About Ability to Fulfill Other Roles and Responsibilities

The PATH-s highlighted the uncertainty of what the caregiver role might involve and created questions regarding the impact on their ability to manage their other life roles. Participants shared their lists of existing responsibilities and expressed the need to maintain preexisting roles. Administration of the PATH-s illuminated the breadth of responsibility associated with caregiving, for example, the time anticipated for direct care in addition to assuming duties that the stroke survivor formerly performed. Many caregivers noted that preexisting roles (e.g., volunteering in the community) helped sustain them mentally, though were uncertain they would have time for them once in the caregiver role.

Uncertainty About the Long-Term Implications of Stroke

The PATH-s illuminated that assuming the caregiver role was a change that caregivers may have to deal with for the long term and an awareness that the long-term is dependent on the stroke survivor’s functional recovery. The participants shared the uncertainty of their ability to sustain in the caregiver role physically, mentally, and financially, though identified that this was all dependent on the recovery and associated stroke survivor future needs. They also expressed uncertainty about the future assistance that would be available from others. For example, a participant stated, “Others are going to be more available in the first 3 months than they will be in the next 3 months because people forget” (Participant 9).

Dimensions of Anticipation and Cues to Action

Completion of the PATH-s prompted participants to think about the stroke in the context of recovery, initiating an anticipatory process that enabled them to begin to plan for the future. The PATH-s stimulated the caregivers to anticipate what issues and questions they needed to consider and what resources they might need in order to provide care. Several participants indicated the PATH-s illuminated what is involved with being a caregiver. For example, a participant stated, “It’s a scary questionnaire, but it is a good thing. It lets me know what I did not know” (Participant 16).

Anticipating Management Strategies

Administration of the PATH-s prompted caregivers to anticipate the impact of stroke on their lives and how they needed to respond to sustain in the caregiver role. For example, in response to the item about time to fulfill the caregiver role, a participant stated,

It made me think if I am going to need outside help when I am at work, and how I need to also make sure I have time for me in all of this. I have to do this somewhere in all of that. (Participant 3)

This was followed by, “Maybe I need to do a schedule like she has here,” in response to the question about other roles and responsibilities. The caregivers anticipated and sought out internal strengths and coping strategies to draw upon when faced with the uncertainty about the stroke survivor’s recovery and future needs. Multiple participants discussed drawing on spirituality and a positive attitude to manage through the crisis, as illustrated here, “My faith is all I have left. I need to trust that God will provide” (Participant 11).

Caregivers described the challenge of identifying strategies that might be necessary when the extent of the stroke survivor’s recovery was not clear. Without clear prognostic information, they perceived that they could not plan for the future. However, the caregivers tried to identify a plan and resources they might need (e.g., assistance with ADLs, home modifications, a different car), despite uncertainty about the prognosis. This is illustrated by a participant who stated, *The doctor told me this is the beginning of recovery. It will take 2–3 months to get back to where he was...It led me into what I will be doing with my life...I do not want to lose patience with him...I need to take care of myself; I need to use the people who will take care of him. (Participant 8)*

Anticipating Choices That Will Need to Be Made

Completing the PATH-s triggered the caregiver to contemplate the stroke survivor’s recovery and how recovery might impact future choices. Participants reflected on the additional time the caregiver role would require and what was

necessary to manage their lives given these new responsibilities. They identified where they needed to obtain help from others and what activities they may not be able to continue.

Anticipating the Need for Self-Care

The PATH-s also cued the caregivers to think about how their own health affected their ability to sustain the caregiver role. A participant stated, "I need to take care of me, so I can take care of him" (Participant 8). Several referenced a prior intention to engage in behaviors (e.g., exercise, diet), to improve their mental and emotional health. The PATH-s cued them to revisit these plans. Participants noted they needed to keep a positive attitude, stay centered mentally, and allow time for activities they enjoy to bring their lives meaning.

Participants indicated feeling emotionally overwhelmed and greatly affected by the crisis of stroke, as has been previously described (Camicia et al., 2018; Luker et al., 2017; Lutz et al., 2017). Many were tearful at some point during the interviews. Two participants (Participants 11 and 19) became so distraught while completing the PATH-s that it necessitated the researcher to stop the interview and provide support. However, participants expressed deep appreciation for the inquiry into their experiences and the attention to their concerns and interest in understanding the contextual factors as they approached the caregiver role. They verified that the instrument described their experiences, as one participant stated, "I hope I am asked about this (the overall survey) because it is going to be a problem. I can envision those problems" (Participant 9). This illustrates the caregiver's desire to have the support of a provider to help them sort out the issues that are illuminated through an assessment using an instrument such as the PATH-s.

Discussion

An assessment tool, such as the PATH-s, may serve as an intervention to facilitate caregiver preparation. Completing the PATH-s highlighted for caregivers the uncertainty inherent in stroke recovery and the rehabilitation process and provided a trigger for the stages of change, from precontemplation to contemplation, preparation, and, in some cases, action (Mishel, 1998). There was recognition that the uncertainty may be resolved or it may be enduring.

Uncertainty is the inability to determine the meaning of illness-related events and occurs in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking (Mishel, 1998). It contributes to feelings of being overwhelmed and out of control and may lead to caregiver strain and burden (Mishel, 1990). Uncertainty about being prepared can trigger apprehension and anxiety about the patient's transition from the IRF to home.

Findings from this study support other literature identifying stroke caregiver uncertainty during rehabilitation and post-discharge (Lou, Carstensen, Jorgensen, & Nielsen, 2017).

This study also provides examples of how prognostic uncertainty can burden caregivers as they prepare for the caregiving role. Caregivers perceive that providers give arbitrary timelines, noting the variation in stroke recovery is based on individual characteristics ("everyone is different"). Participants in this study were given recovery timelines ranging from 3 months to a year or more. There is an opportunity for rehabilitation nurses to assess caregivers' understanding of stroke recovery and provide evidence-based education on the trajectory of recovery, including evidence that, although most functional gains occur in 3–6 months, functional gains up to 3 years poststroke and beyond can be achieved (Bunketorp-Kall, Lundgren-Nilsson, Nilsson, & Blomstrand, 2018). Models to predict functional recovery after stroke are being explored (van der Vliet et al., 2020); however, further research is necessary to produce meaningful prognostic tools. Providers must balance the need for prognostic information and the caregiver's desire for certainty with the need for hope and the possibility of greater functional recovery. Lou et al. (2017) identified the importance of hope as a personal characteristic and/or intentional strategy that is a potentially beneficial coping strategy that motivates and engages both stroke survivors and caregivers, allowing positivity and optimism.

The PATH-s provides an opportunity for caregivers to identify elements of uncertainty and think about components of the caregiver role relevant to their lives that they may not have otherwise considered. Rehabilitation nurses and case managers may use this information to provide anticipatory guidance to help caregivers process current and future implications of fulfilling the caregiver role, potentially minimizing uncertainty.

It is essential that rehabilitation nurses and other providers conduct ongoing assessments to determine caregiver readiness so that evidence-based care management interventions can be tailored to their changing needs over time (Cameron et al., 2016; Family Caregiver Alliance, 2012; Lutz et al., 2017). For example, the *Canadian Best Practice Recommendations for Stroke Care* (Cameron et al., 2016) provides Level A evidence, including the recommendation that caregivers should have their individual psychosocial and support needs evaluated on a regular basis. The American Heart Association's guidelines for adult stroke rehabilitation and recovery (Winstein et al., 2016) recommend supporting caregivers through education, training, counseling, and development of a support structure and including caregivers in treatment planning and decision-making (Level of Evidence: IA). The PATH-s provides a means for addressing these recommendations.

Key Practice Points

- Anticipating and recognizing the needs and concerns of stroke caregivers are an important competency of rehabilitation nurses. Using validated tools to assess caregivers' understanding of stroke recovery and the caregiving role and addressing gaps in understanding through evidence-based education and training are a critical component of rehabilitation nursing care.
- The PATH-s may be used to assess the needs of family caregivers to address uncertainty, providing anticipatory guidance and assisting with planning to prepare caregivers for the transition to home.
- The PATH-s may illuminate the need to develop education programs to address the uncertainty caregivers face and identify strategies to assist with anticipating the transition to home.

Limitations

The current study was exploratory in nature, and because of the specificity of participant selection methods and sample size, the findings may not be transferable to caregivers at other IRFs. Further research in other settings and with an expanded sample could help establish replicability and applicability of these findings beyond the caregivers of stroke patients admitted to the IRF under study.

Conclusion

Caregivers play a fundamental role in a patient's ability to return home following a stroke. The administration of the PATH-s instrument provoked the identification and discussion of specific sources of uncertainty and anticipation of key items to inform the plan of care for the transition from IRF to home for stroke survivors and their caregivers. The contemplation initiated by the PATH-s enabled the caregivers to begin to break down the uncertainty into concrete components assisting with preparation for the caregiver role, cueing them to action to develop a plan for the transition to home. An instrument such as the PATH-s may be used by rehabilitation nurses to identify gaps in stroke caregiver preparation, thus enabling provision of anticipatory guidance as caregivers approach the complex transition from IRF to home. This expanded knowledge of uncertainties and discharge anticipations can assist with the education and planning for both caregivers and stroke survivors toward optimizing recovery and for rehabilitation and improving quality of life.

Conflict of Interest

The authors declare no conflicts of interest.

Funding

This study was supported by the Rehabilitation Nursing Foundation and the Gordon and Betty Moore Foundation.

References

- Benjamin, E. J., Muntner, P., Alonso, A., Bittencourt, M. S., Callaway, C. W., Carson, A. P., ... Virani, S. (2019). Heart disease and stroke statistics—2019 update: A report from the American Heart Association. *Circulation*, *139*(10), e56–e528. doi:10.1161/CIR.0000000000000659.
- Bunketorp-Kall, L., Lundgren-Nilsson, A., Nilsson, M., & Blomstrand, C. (2018). Multimodal rehabilitation in the late phase after stroke enhances the life situation of informal caregivers. *Topics in Stroke Rehabilitation*, *25*(3), 161–167. doi:10.1080/10749357.2017.1413761.
- Cameron, J. I., O'Connell, C., Foley, N., Salter, K., Booth, R., Boyle, R., ... Lindsay, P. (2016). Canadian stroke best practice recommendations: Managing transitions of care following stroke, guidelines update 2016. *International Journal of Stroke*, *11*(7), 807–822. doi:10.1177/17474930166660102.
- Camicia, M., Black, T., Ferrell, J., Waites, K., Wirt, S., Lutz, B., & Association of Rehabilitation Nurses Task Force (2014). The essential role of the rehabilitation nurse in facilitating care transitions: A white paper by the Association of Rehabilitation Nurses. *Rehabilitation Nursing*, *39*(1), 3–15. doi:10.1002/rnj.135.
- Camicia, M., Lutz, B., Drake, C., Kim, K. K., Harvath, T., & Joseph, J. G. (2018). Assessing caregiver commitment and capacity: Development of the Preparedness Assessment for the Transition Home After Stroke (PATH-s). *Stroke*, *49*(Suppl. 1), WMP111. doi:10.1161/str.49.suppl.1.WMP111.
- Camicia, M., Lutz, B. J., Harvath, T., Kim, K. K., Drake, C., & Joseph, J. G. (2019). The development of the Preparedness Assessment for the Transition Home After Stroke instrument. *Rehabilitation Nursing*. Advanced online publication. doi:10.1097/rnj.0000000000000204.
- Camicia, M., Lutz, B. J., Markoff, N., & Catlin, A. (2019). Determining the needs of family caregivers of stroke patients during inpatient rehabilitation using interview, art, and survey. *Rehabilitation Nursing*, *44*(6), 328–337. doi:10.1097/RNJ.0000000000000129.
- Collins, D. (2003). Pretesting survey instruments: An overview of cognitive methods. *Quality of Life Research*, *12*(3), 229–238. doi:10.1023/A:1023254226592.
- Family Caregiver Alliance. (2012). Selected caregiver assessment measures: A resources inventory for practitioners (2nd ed.). Retrieved from https://www.caregiver.org/sites/caregiver.org/files/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf
- Goodwin, L. D. (2002). Changing conceptions of measurement validity: An update on the new standards. *The Journal of Nursing Education*, *41*(3), 100–106. doi:10.3928/0148-4834-20020301-04.
- Guest, G., MacQueen, K., & Namey, E. (2012). *Applied thematic analysis*. Thousand Oaks, CA: Sage. doi:10.4135/9781483384436.
- Knafl, K., Deatrick, J., Gallo, A., Holcombe, G., Bakitas, M., Dixon, J., & Grey, M. (2007). The analysis and interpretation of cognitive interviews for instrument development. *Research in Nursing & Health*, *30*(2), 224–234. doi:10.1002/nur.20195.
- Lou, S., Carstensen, K., Jorgensen, C. R., & Nielsen, C. P. (2017). Stroke patients' and informal carers' experiences with life after stroke: An overview of qualitative systematic reviews. *Disability and Rehabilitation*, *39*(3), 301–313. doi:10.3109/09638288.2016.1140836.
- Luker, J., Murray, C., Lynch, E., Bernhardsson, S., Shannon, M., & Bernhardt, J. (2017). Carers' experiences, needs, and preferences during inpatient stroke rehabilitation: A systematic review of qualitative studies. *Archives of Physical Medicine and Rehabilitation*, *98*(9), 1852–1862. e1813. doi:10.1016/j.apmr.2017.02.024.
- Lutz, B. J., & Camicia, M. (2016). Supporting the needs of stroke caregivers across the care continuum. *Journal of Clinical Outcomes Management*, *23*(12), 1–10.

- Lutz, B. J., Young, M. E., Cox, K. J., Martz, C., & Creasy, K. R. (2011). The crisis of stroke: Experiences of patients and their family caregivers. *Topics in Stroke Rehabilitation, 18*(6), 786–797. doi:10.1310/tsr1806-786.
- Lutz, B. J., Young, M. E., Creasy, K. R., Martz, C., Eisenbrandt, L., Brunny, J. N., & Cook, C. (2017). Improving stroke caregiver readiness for transition from inpatient rehabilitation to home. *The Gerontologist, 57*(5), 880–889. doi:10.1093/geront/gnw135.
- Mishel, M. H. (1998). Methodological studies: Instrument development. In Brink, P. J., & Wood, M. J. (Eds.), *Advanced design in nursing research* (2nd ed., pp. 235–282). Thousand Oaks, CA: Sage. doi:10.4135/9781452204840.
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image—The Journal of Nursing Scholarship, 22*(4), 256–262.
- Mozaffarian, D., Benjamin, E. J., Go, A. S., Arnett, D. K., Blaha, M. J., Cushman, M., ... Turner, M. B. (2016). Heart disease and stroke statistics—2016 update: A report from the American Heart Association. *Circulation, 133*(4), e38–e360. doi:10.1161/cir.0000000000000350.
- National Alliance for Caregiving. (2015). *Caregiving in the US 2015*. Retrieved from <http://www.caregiving.org/research/>
- Nettina, S. (2019). *Lippincott manual of nursing practice* (11th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Ryan, G., & Bernard, H. (2003). Techniques to identify themes. *Field Methods, 15*(1), 85–109. doi:10.1177/1525822X02239569.
- Shapiro, A. (2009). *What now? Sharing brain recovery lessons*. Retrieved from <http://healingintopossibility.com/media/>
- Steiner, C. B. M., & Weiss, A. (2016). *CUP projections: Acute myocardial infarction (AMI) and acute stroke 2005 to 2016* (HCUP Projections Report #2016-01). Retrieved from https://www.hcup-us.ahrq.gov/reports/projections/projections_rpts.jsp
- van der Vliet, R., Selles, R. W., Andrinopoulou, E. R., Nijland, R., Ribbers, G. M., Frens, M. A., ... Kwakkel, G. (2020). Predicting upper limb motor impairment recovery after stroke: A mixture model. *Annals of Neurology, 87*, 383–393. doi:10.1002/ana.25679.
- Willis, G. B. (1999). *Cognitive interviewing: A "how to" guide*. Paper presented at the 1999 Meeting of the American Statistical Association, Research Triangle Park, NC.
- Willis, G. B., & Artino, A. R., Jr. (2013). What do our respondents think we're asking? Using cognitive interviewing to improve medical education surveys. *Journal of Graduate Medical Education, 5*(3), 353–356. doi:10.4300/JGME-D-13-00154.1.
- Winstein, C. J., Stein, J., Arena, R., Bates, B., Cherney, L. R., Cramer, S. C., ... Zorowitz, R. D. (2016). Guidelines for adult stroke rehabilitation and recovery: A guideline for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke, 47*(6), e98–e169. doi:10.1161/str.0000000000000098.
- Zhang, J., & Lee, D. T. (2017). Meaning in stroke family caregiving: A literature review. *Geriatric Nursing, 38*(1), 48–56. doi:10.1016/j.gerinurse.2016.07.005.

For more than 43 additional continuing professional development articles related to the topic of Caregivers, go to www.NursingCenter.com/ce.

Lippincott®
NursingCenter®

NCPD Nursing Continuing
Professional Development

TEST INSTRUCTIONS

- Read the article. The test for this nursing continuing professional development (NCPD) activity is to be taken online at www.nursingcenter.com/CE/RNJ. Tests can no longer be mailed or faxed.
- You'll need to create an account (it's free!) and log in to access My Planner before taking online tests. Your planner will keep track of all your Lippincott Professional Development online NCPD activities for you.
- There's only one correct answer for each question. A passing score for this test is 7 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost.
- For questions, contact Lippincott Professional Development: 1-800-787-8985.
- Registration deadline is December 2, 2022

PROVIDER ACCREDITATION

Lippincott Professional Development will award 3.0 contact hours for this nursing continuing professional development activity. Lippincott Professional Development is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation. This activity is also provider approved by the California Board of Registered Nursing, Provider Number CEP 11749 for 3.0 contact hours.

Lippincott Professional Development is also an approved provider of continuing nursing education by the District of Columbia, Georgia, and Florida, CE Broker #50-1223. Your certificate is valid in all states.

Payment: The registration fee for this test is \$10.00 for members and \$12.50 for nonmembers.

1. ARN members can access the discount by logging into the secure "Members Only" area of <http://www.rehabnurse.org>.
2. Select the Education tab on the navigation menu.
3. Select Continuing Education.
4. Select the Rehabilitation Nursing Journal article of your choice.
5. You will appear at nursing.CEConnection.com.
6. Log in using your Association of Rehabilitation Nursing username and password. The first time you log in, you will have to complete your user profile.
7. Confirm the title of the CE activity you would like to purchase.
8. Click start to view the article or select take test (if you have previously read the article.)
9. After passing the posttest, select + Cart to add the CE activity to your cart.
10. Select check out and pay for your CE activity. A copy of the receipt will be emailed.