The Preparedness Assessment for the Transition Home after Stroke (PATH-s) Instrument

By

MICHELLE ELIZABETH CAMICIA

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Approved

Jill Joseph, MD, PhD, Chair

Katherine Kim, PhD, MBA

Barbara Lutz, PhD, RN, CRRN, PHNA-BC, FAHA, FNAP, FAAN

Christiana Drake, PhD

Theresa Harvath, PhD, RN, FAAN

Committee in Charge

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ABSTRACT

Care transitions for individuals with disabling conditions, such as stroke, are often ineffective and inefficient, resulting in unmet patient and caregiver needs, increased safety risks, readmissions, and increased healthcare costs. An assessment instrument designed to evaluate caregiver's preparation to assume the caregiving role is needed to facilitate the development of tailored care plans and interventions to mitigate the risks of poorly prepared caregivers, and associated health effects on caregiver and stroke survivor. The purpose of this dissertation was to develop and then evaluate selected psychometric properties of the proposed Preparedness Assessment for the Transition Home after Stroke (PATH-s), a 25-item self-administered instrument to assess the commitment and capacity of caregivers based on the *Improving Stroke Caregiver Readiness Model*. We utilized a sequential, multi-method approach, which included item generation from qualitative data, review of items by expert clinicians, and cognitive interviews of caregivers of stroke survivors. This was followed by a cross-sectional study of 183 caregiver-stroke survivor dyads during IRF admission to identify the factor structure, and to evaluate the internal consistency reliability, construct validity, and criterion-related validity of the PATH-s. Data were collected using a self-administered questionnaire to describe participant characteristics, the PATH-s, Preparedness for Caregiving Scale (PCS), PHQ-9, Perceived Stress Scale, and Global Health Survey (GHS). Factor analysis revealed 8 factors aligned with the *Improving Stroke Caregiver Readiness Model*, upon which the PATH-s was developed. The PATH-s demonstrated excellent internal consistency (Cronbach's $\alpha = 0.90$). Criterion related validity of the PATH-s with the PCS was demonstrated (R=0.79; p<0.01). The PATH-s and PCS were negatively correlated with the PHQ-9 (R=-0.26, -

0.27 respectively, $p<0.01$) and positively correlated with the GHS ($R=-0.46$, 0.46 respectively, $p<0.01$), which demonstrated convergent validity. Preliminary psychometric testing of the PATH-s indicated good reliability and validity, although assessment of validity was limited. Further testing of the PATH-s to assess additional psychometric properties is suggested. The PATH-s may support a primary prevention strategy to identify gaps in preparedness for stroke caregivers, with the long-range goal to mitigate the effects of suboptimal preparation. Once gaps are identified, care plans can be tailored to better prepare caregivers for the transition home.

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Introduction

I have been a rehabilitation nurse specialist working in inpatient rehabilitation facilities (IRF) for over 25 years. The IRF setting provides a unique perspective on care transitions and the preparation of family for the caregiving role. The primary goal of the IRF admission is preparation for a discharge from the institutional setting to the home for people with significant disability who are at high risk for consequences of poor transitions due to the high burden of care. I have a passion for quality improvement, with a focus on ensuring patients and their caregivers are prepared for IRF discharge. In my work I have experienced the inadequate or absent assessment of caregivers for the caregiving role. Caregiver preparation to assume the caregiving role is a major component of the IRF to home transition, though prior to this project there was no available assessment instrument that systematically evaluates the caregiver's commitment and capacity for the caregiver role,

My true passion for caregivers emerged when my sister had a spinal cord injury resulting in tetraplegia in 2006. I returned to work after being at her bedside for an extended period with a very deep feeling of compassion for the crisis that the family members were experiencing. This was followed by my entry into a network of leaders involved in the American Heart/Stroke Association (AHA/ASA) whose work is dedicated to improving care for the stroke population and their caregivers. I was subsequently elected as a Fellow of the American Heart Association (FAHA) for my work in stroke care, research, and volunteerism. I am committed to advancing the care for stroke survivors through my work around caregiving and transitions through my work with AHA/ASA, in addition to within the Kaiser Permanente integrated care delivery system and other organizations.

The research undertaken has, and will, continue to contribute to my career goals as a nurse leader and research scientist. This is the foundation of a long-term trajectory that accounts for my areas of interest in measurement, quality, stroke, caregiving, and care transitions. This project has provided me a greater depth of knowledge about the research process and research methods that support my ability to lead a research program, contribute meaningfully on national committees, and to conduct independent research.

Sources of funding

I received a $30,000 grant from the Rehabilitation Nursing Foundation (RNF) to fund participant gifts and a 25% research associate for one year of the study presented here. Additionally, I received funding from the Betty Irene Moore School of Nursing (SON) to pursue this important work.

Problem Statement

The Institute of Medicine (IOM) and National Quality Forum (NQF) identified improving transitions across the continuum of care to home as a national priority (IOM, 2003; National Quality Forum, 2016). Despite this, care transitions for individuals with disabling conditions, such as stroke, are often ineffective and inefficient, resulting in unmet patient and caregiver needs, increased safety risks, high rates of preventable readmissions, and increased health care costs. This is particularly problematic for stroke patients transitioning from an IRF to home (Camicia et al., 2014; Lutz, Young, Cox, Martz, & Creasy, 2011).

Stroke is the leading cause of major disability in the world (Benjamin et al., 2017). Each year almost 800,000 people are hospitalized for a stroke in the U.S. (Mozaffarian et al., 2015). In 2010 there were approximately 6.6 million stroke survivors with a predicted increase in prevalence of more than 20% over the next 20 years (Mozaffarian et al., 2015). Despite medical advances in stroke treatment resulting in reduced mortality, disability following stroke remains a major concern.

Stroke represents a crisis for both the stroke patient and the family. There are two crises associated with stroke; the first crisis is when the serious medical events occur. A second crisis often occurs when the stroke survivor is discharged home from the IRF (Lutz et al., 2011). Shorter lengths of stay in acute care (Steiner C, 2015) and IRF (O'Brien, Xue, Ingersoll, & Kelly, 2013) have resulted in inadequate care coordination across the care continuum and challenging transitions, magnifying this crisis (Lutz et al., 2011). Despite interprofessional programs to train family members in providing stroke survivor care during IRF, caregivers often lack sufficient preparation and support to assume the caregiver role at home (Lutz & Young, 2010; Lutz et al., 2011). The demands and vigilance required to provide safe care are often overwhelming and exhausting, even if family members have previous caregiving experience. Caregivers need training on providing direct care, information and resources on recurrent stroke prevention and recovery, and strategies to manage socio-emotional needs, financial concerns, and family issues (MacIsaac, Harrison, Buchanan, & Hopman, 2011).

There is a paucity of tools to assess caregiver preparedness for the stroke survivor transition from the institutional hospital setting to home. The Preparedness for Caregiving Scale (PCS) (Archbold PG, 1992), is an 8-item self-report scale to assess general caregiver preparedness. The PCS was validated with stroke caregivers at 3 months (Pucciarelli et al., 2014). The scale does not pre-emptively assess the biopsychosocial and ecological factors that must be considered when determining a family member's capacity to assume the caregiving role, nor does it take into consideration the patient's functional limitations and care burden, nor physical environment upon discharge. Caregivers often do not have the requisite knowledge during the IRF stay to determine if they are “prepared” to provide care at home; in short, they “don’t know what they don’t know”. The patient’s physical and cognitive status at discharge as well as caregiver characteristics, such as health concerns and pre-stroke responsibilities; informal, formal, and financial resources; home accessibility; plans for self-care; and relationship with the stroke survivor can influence a caregiver’s capacity and commitment to assume the caregiving role (Young, Lutz, Creasy, Cox, & Martz, 2014). The *Improving Stroke Caregiver Readiness Model* illustrates these important assessment domains related to caregiver capacity and commitment (Lutz et al., 2016). Yet, no assessment instrument has been specifically designed to evaluate a family member’s commitment (strength of the stroke survivor/caregiver relationship, willingness of the caregiver to provide care) and capacity (pre-existing factors, availability and accessibility of resources, and ability to sustain caregiver role over time) to assume the caregiving role before stroke survivor’s discharge from an IRF. Research to develop a well-defined stroke transition preparedness assessment instrument is critically needed to facilitate the development of tailored care plans and interventions to potentially mitigate the risks associated with the “second crisis of stroke” and the associated health effects on the caregiver and stroke survivor (Greenwood, Mackenzie, Cloud, & Wilson, 2008; Lutz et al., 2016; Lutz et al., 2011).

The Development of the Preparedness Assessment for the Transition Home after Stroke (PATH-s) Instrument

Abstract

The purpose of this study was to develop a measure to assess stroke caregivers' commitment and capacity to assume the caregiving role prior to inpatient rehabilitation facility discharge. A sequential, multi-method approach which began with (1) item generation from qualitative data and review of items by expert clinicians, (2) cognitive interviews of caregivers of stroke survivors admitted to an inpatient rehabilitation facility to determine response format (n=22), and item clarity (n=20), and (3) analysis of pilot data collection was utilized. Cognitive interviewing provided information that contributed to the clarity of items. This approach to instrument development resulted in the development of the Preparedness Assessment for the Transition Home after Stroke, a 26-item self-report instrument. The PATH-s represents the domains of the *Model of Caregiver Readiness*, the model from which the instrument was developed. Future research is needed to further validate the psychometric properties of the PATH-s.

Background

Stroke is a leading cause of major disability in the US and globally (Benjamin et al., 2017). Of the estimated 6.6 million stroke survivors living in the US, 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 basic and instrumental activities of daily living (BADL/IADL), usually provided by family members. 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 is a crisis for the family system (Lutz, Young, Cox, Martz, & Creasy, 2011). Stroke occurs abruptly and disability is of sudden onset, thus caregivers are often thrusted into the caregiver role without preparation.

Care transitions for individuals with disabling conditions, such as stroke, are often ineffective and inefficient, resulting in unmet patient and caregiver needs, increased safety risks, high rates of preventable readmissions, and increased health care costs (Camicia, 2014; Lutz, 2011). Stroke survivors and their family caregivers face enormous challenges as they transition through the stroke care continuum from acute care to the inpatient rehabilitation facility (IRF), to living at home post-discharge. Patients experiencing a stroke receive immediate care in the emergency department and acute care hospital, with an average length of stay of 5.7 days in 2014 (Steiner C, 2016). Stroke survivors who have functional impairments that require ongoing hospitalization and rehabilitation are often admitted an IRF for treatment and family caregiver training, as recommended by the American Heart/Stroke Association (Winstein et al., 2016). This setting is where the caregiver, often a family member, assumes the role of caregiver, participating in the patient's nursing care and rehabilitation therapies to learn the skills required upon return to home.

Caregivers often do not have the requisite knowledge during the IRF stay to determine if they are "prepared" to provide care at home; they "don't know what they don't know" (Camicia, Lutz, Markoff, and Catlin, 2018; Lutz, Young, Cox, Martz, & Creasy, 2011). The caregiver's commitment and capacity to assume the caregiving role is influenced by multiple factors (Lutz et al., 2016). These include the patient's physical and cognitive status at discharge, and caregiver characteristics (e.g. the caregiver's health concerns and pre-stroke responsibilities). Additional factors include the availability of informal, formal, and financial resources, the physical accessibility of the home, the caregiver's plans for self-care, and their relationship with the stroke survivor. Lutz et al. (2011) explored the needs of stroke survivors (n=19) and their family caregivers (n=15) as they transitioned from IRF to home in her initial grounded theory study. Participants were interviewed using open-ended questions focused on the stroke experience and how the stroke survivor and caregiver were managing after the acute hospital discharge during the IRF stay and 6 months after IRF discharge. Lutz and colleagues concluded that the stroke survivor and their caregiver faced enormous challenges as they moved through three phases of the post-stroke trajectory: the stroke crisis, expectations for recovery, and the crisis of discharge. Findings from this study suggest that as caregivers move through the phases of the trajectory, they do not have a good understanding of the role to which they are committing, and they are often underprepared to take on even the basic tasks to meet the patients' needs on discharge. In a follow-up study, Lutz et al. (2016) analyzed data from interviews with 40 stroke family caregivers during IRF and within 6 months post-discharge. Caregivers identified critical areas where they felt unprepared to assume the caregiving role after discharge from the IRF. The findings were organized into a theoretical framework, the *Improving Stroke Caregiver Readiness Model* (Lutz et al., 2016), which describes the trajectory of the crisis of stroke based on caregiver perspectives and illustrates these important assessment domains related to caregiver capacity and commitment as they prepare to assume the caregiver role.

There is a need to assess stroke caregivers' commitment to and capacity for the caregiving role before stroke survivor discharge from the IRF (Young, Lutz, Creasy, Cox, & Martz, 2014). Although there is an existing instrument, the Preparedness for Caregiving Scale (Archbold P. G., 1990; Pucciarelli et al., 2014) that addresses the construct of preparation, this instrument does not include other domains that are important to stroke caregiver readiness as they assume the caregiving role. These missing domains include the strength of the caregiver/care recipient relationship; caregiver willingness to provide care, pre-existing health conditions, previous responsibilities, caregiving experience, home and transportation accessibility, available resources, emotional response to the stroke, and ability to sustain the caregiving role (Lutz, 2016; Creasy, 2015). The PATH-s was developed in response to the paucity of existing instruments for assessing these key concepts.

The purpose of this study was to develop an instrument to assess caregivers' commitment and capacity for the caregiving role based on the *Model of Caregiver Readiness*. In this paper we describe the development of the Preparedness Assessment for the Transition Home after Stroke (PATH-s), a 26-item instrument.

Methods

The PATH-s was developed in a three-stage sequential, multi-method approach which is illustrated in Figure 1.

> Stage 1: Item generation for each of the concepts in the *Model of Caregiver Readiness,* and review of items by expert clinicians
>
> Stage 2: Cognitive interviews of stroke caregivers to determine narrative versus Likert response format, to improve item clarity, and to generate new items based on the results
>
> Stage 3: Pilot testing to evaluate respondent burden to complete the PATH-s

This study was approved by the Kaiser Permanente Northern California Institutional Review Board (with a *Reliance Agreement* with the University of California, Davis).

Stage I: Item Generation and Item Review by Experts. The goal of the first stage of instrument development was to generate a set of items that represented the *Model of Caregiver*

Readiness. These included the following caregiver domains: strength of the caregiver/care recipient relationship; caregiver willingness to provide care; caregiver pre-existing health conditions, previous responsibilities, caregiving experience, home and transportation accessibility, available resources, emotional response to the stroke, and anticipated ability to sustain the caregiving role. An item corresponding to the stem in each domain in the *Model of Caregiver Readiness* was created. Responses to the items were formatted using a rank-ordered four-point scale. Items were written at a 6th grade reading level using less than 20 words for each question (Patten, 2011). Time frames for recall were provided when indicated (e.g. "Thinking over the past year, how much conflict have you had in your relationship with the stroke survivor").

Following item generation, the instrument was reviewed by eight expert certified registered rehabilitation nurses who were purposively selected based on their experience of five years or more as a nurse case manager in the IRF setting. Experts evaluated the items for content validity and clarity using a structured procedure described by Lynn (1986). The experts were asked to rate the clarity and relevance of each item for use with stroke caregivers using the index of content validity (CVI), a 4-point ordinal rating scale (4=very relevant and succinct, 3=relevant but needs minor revision, 2=unable to assess or in need of considerable revision, and, 1=not relevant). The CVI for the domain or entire instrument is the proportion of total items judged content valid (Polit & Beck, 2006). All items were scored either very relevant and succinct (scored 4) or relevant but needs minor revision (scored 3). The CVI for the PATH-s as a whole was 1.0, surpassing the threshold established by Lynn (1986). All items were retained as content valid, though wording was revised based on elicited suggestions from the experts to improve item wording and content. The experts identified areas that had been omitted and provided suggestions to enhance the draft instrument as illustrated in Table 1. These responses were analyzed for themes. There were a number of suggestions to provide in lay terms a description of what is involved with personal care. One expert (Expert 3) stated, “People often do not consider the need to provide personal care- they are really more thinking about dressing, cooking/providing meals, assisting with medications, driving to appointments, household tasks and assistance with walking. Toileting is a major issue for caregivers”. Another (4) stated, “It covers a variety of potential red flags… especially the one about caregiver experience. Most people who have not done any think it is supervising someone or running errands and do not get the physical assistance part.” The questions were refined to include “personal care, such as bathing, using the toilet, dressing”.

Further, the experts recommended whether a higher score should represent greater preparation, or if a higher score should represent greater risk. The Likert scale direction was determined by comparing the number of experts who preferred a rating of 4 to indicate “most prepared” to the number who preferred a 4 to indicate “least prepared.” The majority (3 of 4) of experts indicated a preference for having a higher score to indicate greater preparedness. Two experts related this to other scoring systems in which “higher is better”.

Content experts also suggested that some items contained more than one construct. Prior to proceeding with Stage 2 we modified the instrument so that each item was based on a single concept from the *Model of Caregiver Readiness* (Patten, 2011). This resulted in an increase from 14 to 25 items. The instrument was revised according to the experts’ input prior to the next stage.

Stage 2: Cognitive Interviews to Select Format and Refine Items. Cognitive interviews were conducted to a) select the format of the instrument and b) refine the items to improve clarity (refer to Figure 1, Stages 2a and 2b). The participants in both stages of cognitive interviews were caregivers of stroke survivors admitted to a regional IRF within an integrated care delivery system. A caregiver was defined as the person who would provide assistance to the stroke survivor with functional (e.g. bathing, dressing, toileting, mobility) and instrumental (e.g. shopping, cooking) activities of daily living upon discharge. Inclusion criteria for caregiver participants were: caregiver for a stroke survivor whose admission followed a first stroke and had a 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 according to the above criteria and invited to participate following an explanation of the study. Caregivers who indicated an interest in participating were engaged in a discussion of the study and of the consent requirements. As part of this, they were given a consent form and a *Research Participant's Bill of Rights*. Once consent was obtained, the researcher scheduled an appointment to conduct the interview and provided the participant with a copy of the signed consent. Participants were purposefully recruited to include diverse representation of age, gender, race, income level, and relationship to the stroke survivor.

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).The goals of cognitive interview are 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), and to determine how a participant comprehends an item and what the respondent thinks during the formulation of a response to the question (Collins, 2003). This is achieved by gathering information about participants' understanding of the instrument by asking the participant to restate each question in his or her own words. Cognitive interviews allow the researcher to identify the acceptable range of interpretations, provide evidence for item revision, distinguish fixable from fatal flaws, and minimize missing data in the final instrument (Jamcelon, Dixon, & Knafl, 2009). Analysis at the item level provides information regarding reliability. A variety of interpretations of the same item indicate ambiguity and a threat to the instrument's validity and/or reliability. Further, large volumes of narrative data are generated through the cognitive interviews, including information about the participant's thoughts, concerns, or anxieties while responding to the items (Goodwin, 2002). According to Drennan (2003), cognitive interviewing is the most valuable stage in pretesting questions that are complex, where questions are intrusive and personally sensitive, as with the PATH-s.

The original version of the PATH-s had ordinal "narrative" response options (e.g., "I know a lot/some/a little/don't know about what to expect about the stroke survivor's recovery). All response options were stated in the first person, contained the stem of the question, and had a Likert scale embedded in the responses. An alternative version of the PATH-s using the same wording as the original version was formatted into statements with a 4-point Likert scale response option, ordinally ranked to evaluate if this format provided greater clarity. In Stage 2a (refer to Figure 1) the two formats of the draft PATH-s were evaluated to determine the optimal format (Likert versus narrative responses). During this stage the investigator sequentially presented the two versions of the PATH-s for the participant to complete. The sequence of versions provided was randomly determined by a coin toss. The researcher then asked the caregiver to complete the instruments by entering their responses to each of the Likert and narrative versions of the PATH-s in addition to providing basic demographic characteristics including age, gender, race/ethnicity, relationship to stroke survivor, annual household income, and educational level by entering this information directly into Qualtrics (Provo, UT) using an iPad. Qualtrics is an online web-based survey tool that allows for the distribution, collection, and analysis of customized survey items. After completion of both PATH-s versions the participants were asked to answer the question, "In comparing the two surveys overall, which survey was clearer?", and, "Which survey was easier to complete?" The investigator asked the participants what contributed to their responses, and to provide feedback on the instrument. The researcher recorded the participant responses on a note pad.

This was followed by a second phase of cognitive interviews (Stage 2b) to optimize clarity and further refine the items in the PATH-s instrument. Cognitive interviews of an independent convenience sample of 20 caregivers using the same inclusion criteria, recruitment, and consent processes as above were conducted in this stage of the instrument development to refine the PATH-s instrument and ensure clarity of items. The caregiver was provided a private location in the IRF and asked to enter their responses to the PATH-s and demographic items directly into Qualtrics (Provo, UT) using an iPad. This was followed by a semi-structured interview by the first author on an item-by-item basis according to a procedure described by (Knafl et al., 2007) following a script to elicit data on how future respondents are likely to interpret items and to assess clarity of the draft instrument to guide revisions of the instrument. Participants were asked open-ended questions, including what they understood each question of the PATH-s was asking to elicit their understanding of the items, and what they were thinking when they read and answered each question. Verbal probing (to identify poorly worded or ambiguous questions) and paraphrasing were used. Interviews were audio recorded and transcribed verbatim.

In this stage (2b), there were two rounds of interviews (group one n=11, group 2 n=9) with a total sample of n=20 of this iterative process of cognitive interviews to improve item clarity and revise the instrument. The interview data were reviewed after the first round to identify items that lacked clarity or were ambiguous. The instrument was modified to improve clarity prior to recruiting for the next round. Additional language was added in response to new themes that emerged from the interviews in the first round. The second round of interviewing was conducted to test the changes made in the first round and identify if the problems detected in the first round of interviews had been satisfactorily addressed. The responses to the revised PATH-s were assigned a number on a scale from one to four, with one being least prepared and four being most prepared. The sum score of the 26 items provides a possible range of 26 to 104, with a higher value indicating greater preparedness.

Stage 3: Pilot Testing to Evaluate Respondent Burden. Participants (n=20) were asked to complete the PATH-s instrument as part of the cognitive interviews described above. A component of respondent burden is the time required to complete the instrument (Lynn, 2015), especially when interviewing caregivers, many of whom are older and, at times, frail. Additionally, information on the acceptability of the instrument can be evaluated by the level of missing data (Lynn, 2015).

Analysis

Stage 2: Cognitive Interviews to Select Format and Improve Clarity. The number of participants who identified their preference for each of the versions (Likert vs narrative) was summed. Demographic data (age, income, education) was examined using SPSS version 25.0 (IBM, 2017) to identify any correlation with the preferred version (Likert vs narrative). The qualitative data were analyzed to determine any underlying themes related to the preferred format or of the instrument in general.

The interview data from the next cognitive interview phase (Refer to Figure 1, Stage 2b) to improve item clarity and revise the instrument were transcribed verbatim and analyzed by item to modify the instrument as needed to establish the relevance and clarity of the items in the target population. The field notes from the interviews were reviewed by the first and second author for participant reactions to the wording of the questions. Issues identified were grouped into categories as described by Knafl et al. (2007), and included interpretation, applicability, unclear reference, unclear perspective, wording or tone. The notes from each cycle of cognitive interviews were reviewed by the first and second authors who discussed the data and agreed on the identification of dominant trends and patterns across interviews using the groupings listed above. The instrument was revised according to these dominant trends or patterns (e.g. the addition of an item with a trend of respondents indicating the need to address mental preparedness). All revisions to the instrument were discussed with the second author to ensure modifications were consistent with the *Model of Caregiver Readiness* prior to advancing to the next stage of the process. The demographic data were exported from Qualtrics into SPSS version 25.0 (IBM Inc., 2017) and analyzed to identify the sociodemographic characteristics of each group.

Stage 3: Pilot Testing to Evaluate Respondent Burden. The average time required to complete the PATH-s was recorded in Qualtrics. The PATH-s data were exported from Qualtrics into SPSS. Identification of missing responses to items were evaluated. Analysis of the PATH-s results included the mean, median, standard deviation, and minimum and maximum values.

Findings

Stage 2: Cognitive Interviews to Select Format and Refine Items.

The characteristics of the two groups who participated in the cognitive interviews are presented in Table 2. There was representation across age, relationship to stroke survivor, sex, education, annual household income, and race/ethnicity. However, the most represented groups were age 55-74, the spouse of the stroke survivor, female, with some college or college graduate, earning a household income above $100k, and non-Hispanic White-Caucasian.

Most participants (14 of 22) preferred the narrative format, while 6 preferred the Likert version, and 9% (n=2) were indifferent. Participants stated, "The answers fall in line with how I would state it.", "It was easier because it more personally describes the options; and the narrative version "required more thought". The majority (12 out of 15) of items in the Likert and narrative formats were at least moderately correlated ($r \geq 0.3$). There were some changes to the instrument during this stage, for example, two participants commented, "I have volunteer work that I am committed to do. This is important to me."; and, "I am retired but I am an umpire and I didn't know if that counted", thus volunteer work was added to the item related to "other roles and responsibilities". Additionally, we identified that there were some inconsistencies with the examples provided for "personal care". All items were standardized to include, "such as bathing, using the toilet, dressing, and moving around".

The first round concluded after 11 interviews at which time the PATH-s was modified to incorporate information from the first round. This was followed by the next round of 9 interviews. These 9 participants reported that all items in the PATH-s instrument were clear and understandable and did not offer any new information to modify the instrument, thus data collection was determined to be complete.

Items of the PATH-s were refined after the first round (n=11) of cognitive interviews in response to participants' comments to improve clarity as illustrated in Table 3. Most refinements included the addition of examples embedded within the question. For example, pet care and yard work were added to the examples of other roles and responsibilities, and the width of the doorways, stairs, and ramp access were added to the question about home accessibility. The provision of examples improved clarity, as evidenced by a participant (1) who stated, "Originally I was thinking no, then I read the examples and I understood". Examples were added to several items as illustrated in Table 3. Additional refinements were made to reflect the nuances of stroke recovery, for example the item about home accessibility was changed from, "in his/her home" to, "in the home where he/she will be living", as some stroke survivors are discharged to live in the home of another.

Two items were added, and one item was deleted during this stage. The item, "Do you think these other people will be available to help with the stroke survivor's personal care when needed?" was deleted. This was in response to several participants who indicated that people who do not have a close association, such as those identified as family, would not be considered to assist with personal care. A participant (9) stated, "Friends will not do personal care; nor does she (the stroke survivor) want them to do her personal care-not the intimate stuff." This item was modified to ask about other people who will be able to help with, "other responsibilities, for example volunteer work, childcare, pet care, meal preparation, laundry, home maintenance and yard work".

The item, "How concerned are you about your ability to continue providing care for the stroke survivor for the next year?" was added. Many participants expressed concern about their health and the ability to sustain the caregiving role, especially as the support of others diminished. A participant (9) noted, “After three months they forget. Friends were all around right after the stroke and now they have dropped off and don’t visit”.

In response to the question, “How prepared are you to provide the stroke survivor assistance with personal care?” a participant responded, “It made me think of how mentally prepared I am as well.” Another participant (9) responded, “There are two parts to this one. One is how prepared in terms of skills and the other is how prepared in terms of emotions. They are two different things. I think both are very important”. Other participants indicated the importance of “mental” or “emotional” preparedness. The investigator surveyed several caregivers to identify which term was best to elicit the experience, and “mental” was selected as participants indicated that “emotional” had a negative connotation, and that “mental” captured the issue equally well. An item was added, “How mentally prepared are you to be a caregiver?”

Examples of questions include: How willing are you to provide personal care (such as bathing, using the toilet, dressing, and moving around) for the stroke survivor when he/she goes home? The response options include 1) I am not willing to provide any personal care for the stroke survivor, 2) I am willing to provide a little personal care for the stroke survivor, 3) I am willing to provide some care for the stroke survivor, and 4) I am willing to provide a lot of personal care for the stroke survivor. The former 25-item instrument was reduced by one item and increased by two items during this stage of the instrument resulting in a 26-item instrument.

Stage 3: Pilot Testing to Evaluate Respondent Burden. The administration of the PATH-s instrument was feasible in this study. The average response time to complete the 26-items of the PATH-s, in addition to the six demographic questions was fifteen minutes. The analysis of missing data was unremarkable. There was only one missing response for all items and participants. This was question two, “How much do you understand about how the stroke will affect your lives over the next 6 months?" This may have been inadvertently skipped. Results of the responses to the original 24-item version the PATH-s that was administered during the second phase of cognitive interviews are represented in Table 4. There was good distribution across most items, with the majority (n=13) having a minimum rating of one and maximum of four for the response, and six (30%) having a minimum rating of two and a maximum of four. Item nine had a narrow response range, with all participant responses indicating they were willing to provide "some" or "a lot" of personal care. The range of possible sum scores for these 23 items is 24 to 96. The total sum scores ranged from 55 to 95 (SD=12.22), with a mean of 76.

Discussion

Although the cognitive interview study was conducted on a small sample; it was designed using best practices suggested for instrument development, including testing in the target population. Further, the sample size was comparable to published suggestions of 5– 15 participants per cognitive interview round (Patrick et al., 2011a, 2011b). The cognitive interview sample was obtained in a setting where all the stroke survivors for whom the caregivers were associated had healthcare insurance. This likely resulted in a sample that comprised mostly non-Hispanic Caucasians and generally well-educated caregivers with a higher annual household income. We may not have identified the full range of considerations in revising the items due to the limited number of participants representing diverse perspectives. The use of the PATH-s in a more generalized and diverse population is currently under examination as part of the larger field testing study.

The development of a tool that assesses the gaps in caregiver preparedness and can be utilized prior to the transition from the institutional setting to home may enable the identification and evaluation of primary prevention strategies. In turn, this may improve caregiver preparation and expedite adaptation to the new caregiving role and minimize adverse health effects on both the caregiver and stroke survivor (Lutz & Camicia, 2016). The National Academies of Sciences, Engineering, and Medicine (2015) report on Families Caring for an Aging America report the most effective caregiver interventions begin with an assessment of caregivers' risks, needs, strengths, and preferences. The PATH-s instrument was developed based on the *Model of Caregiver Readiness,* a theoretical framework for improving stroke caregiver readiness that is grounded in the experiences of stroke family caregivers (Lutz et al., 2017). The PATH-s was developed and tested with caregivers of stroke survivors during the IRF admission using a sequential multi-method approach to confirm content validity (Lynn, 2015). Developing an instrument from qualitative research supports family and consumer-centered research. Further, this method of instrument development accounts for the complexity of and provides context for human behaviors, reveals qualities of an experience in a way that other forms of research cannot, provides rich data, and helps determine items to measure (Lynn, 2015). The PATH-s is the first instrument designed to assess stroke caregivers' commitment and for the caregiver role prior to discharge from an IRF.

A critically important issue in instrument development is how the target audience interprets and understands the items in a questionnaire. (M.R. Lynn, 1986). The results of the cognitive testing of the initial versions of the PATH-s confirm that these response choices resonate with interview participants and provide evidence to support the content validity of the PATH-s instrument. This preliminary qualitative work can better assure that an instrument adequately captures complex human reactions and behaviors. Utilizing a structured process for content validity contributed to the clarity of the items. The findings from this study indicate that the PATH-s items and instrument as a whole have a high degree of content validity. Maintaining the voice of the participant and using the first person in the response is preferable to a Likert scale in this particular study population. This also supports further research to determine additional properties of reliability and validity of the PATH-s, which is currently underway.

Conclusion

Caregivers play a fundamental role in a patient's ability to return home following a stroke. It is essential that nurses and other providers adequately assess caregivers' needs and incorporate education, preparation, and support for the caregiver role as they transition from the institutional setting to the community. The PATH-s instrument is based on a conceptual model developed from qualitative studies which provides assurance that the instrument adequately captures the complexity of the caregiver role. Furthermore, utilizing a structured process for content validity contributed to the clarity of the items. The PATH-s is a 26-item self-administered novel instrument that may be used to identify gaps in preparedness for stroke survivor-caregiver dyads following the complex transition from IRF to home. Further field testing research is necessary to evaluate the psychometric properties of the PATH-s instrument. If valid and reliable, the PATH-s may be used to identify and address gaps in caregiver preparedness, thus addressing the "Triple Aim" to improve quality of care, improve health, and reduce care delivery system costs by better preparing caregivers for the transition home and their new role as caregiver.

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Figure 1. Stages of Instrument Development

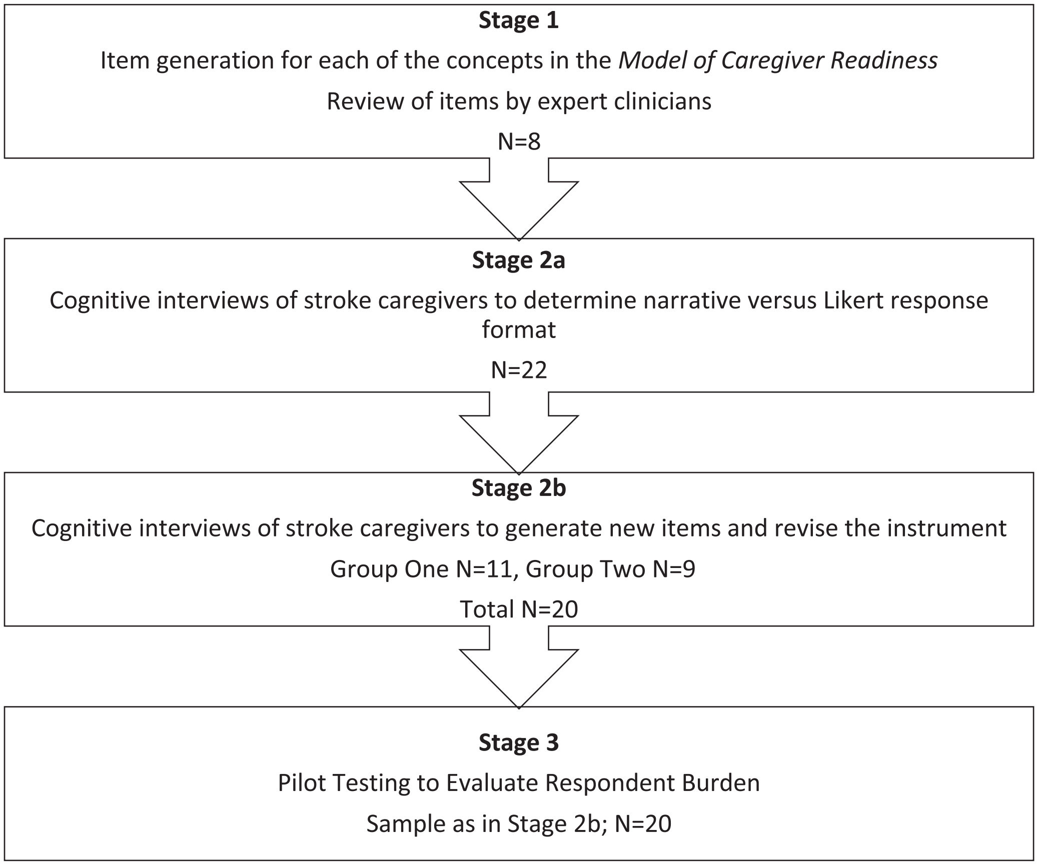

Table 1. Results of Item Review by Experts

Question	Expert Comments (Expert Identification #)
What experience have you had providing care for someone who had a stroke or other disability?	Include more detail in the type of care they may be called upon to provide by adding, "including personal care or hygiene needs" (1)
What other responsibilities do you have that might make caring for the stroke survivor difficult?	Add full time or part time job (5)
	Add a household to manage, children to care for (6)
What friends or family are available to help you with the stroke survivor's care whenever you need it?	Differentiate personal/hygiene needs from non-personal care (1)
	Have you asked them? (2)
	Personal care seems to be the biggest barrier (3)
	Add "capable" (5)
	Define help in real terms, e.g. transport, physical care, showering (6)
	They need to know what they will be doing (8)
Do you have any health problems that may affect your ability to provide care for the stroke survivor (for example, back or joint problems, heart issues, memory, depression, anxiety or other health challenges)?	Add bending, stooping (3)
	Use "health problems" and keep the examples (4)
	Define what care means in real terms, e.g. toileting which is unpredictable (6)
	Define care for the layman in the question-physical assistance (7)
Do you think there will be any problems for the stroke survivor getting around in the house, using the toilet?	Caregiver might not provide a knowledgeable response-they might still be hoping the patient will return to baseline post-rehab (7)

Table 2. Demographics of Cognitive Interview Study Sample

	Format Selection	Item Review
Survey Population (N)	22	20
Age (%)[a]		
25-34	2 (9)	
35-44	3 (14)	2 (10)
45-54	3 (14)	3 (15)
55-64	4 (18)	6 (30)
65-74	7 (32)	7 (35)
75-84	1 (4)	2 (10)
85 years and older	1 (4)	
Relationship to Stroke Survivor		
Child of SS	6 (27)	4 (20)
Friend	1 (4)	
Spouse	9 (41)	12 (60)
Sibling	3 (14)	3 (15)
Parent of SS		1 (5)
Sex (%)		
Female	10 (45)	16 (80)
Male	12 (54)	4 (20)
Education (%)		
Some High School (1-3 years)	1 (4)	2 (10)
High School Graduate (4 years)	3 (14)	2 (10)
Some college (1-3 years)	5 (23)	5 (25)
College graduate (4 or more years)	12 (54)	12 (60)
Household Annual Income (%)		
$20 to <$35k	2 (9)	
$20 to <$35k	3 (14)	1 (5)
$35k to <$50K	2 (9)	2 (10)
$50k to <$75K	5 (23)	2 (10)
$75k to <$100K	4 (18)	10 (50)
Above $100k	4 (18)	5 (25)
Race/Ethnicity (%)		
Non-Hispanic Asian	3 (14)	5 (25)
Non-Hispanic Black/African American	2 (9)	1 (5)
Non-Hispanic White/Caucasian	10 (45)	11(55)
Hispanic (may be any race)	4 (18)	2 (10)
Other	2 (9)	

a Totals may not add up to 100% due to missing responses

Table 3. Item Revisions Based on Cognitive Interviews

Item	Original Question	Suggestion (Participant ID)	Modification	Revised Question
4	How much do you understand about what assistance the stroke survivor will need with personal care (such as bathing, using the toilet, and dressing) when he/she goes home?	"It's also moving around"(20)	Added "moving around"	How much do you understand about what assistance the stroke survivor will need with personal care (such as bathing, using the toilet, dressing, and moving around) when he/she goes home?
13	Do you have other roles and responsibilities other than providing care for the stroke survivor (for example: work, childcare)?	"Add volunteer work"(9); "I did include my cat thinking that is someone to help. Doesn't ask if I can pay for things like my laundry or yard."(17); "Add pets"(18)	Added "volunteer work, pet care, meal preparation, laundry, home maintenance and yard work"	Do you have other roles and responsibilities other than providing care for the stroke survivor (for example: work, volunteer work, childcare, pet care, meal preparation, laundry, home maintenance and yard work)?
15	Do you have other people (not including the family and friends you thought of above) who will be able to help you with the stroke survivor's personal care when needed (for example co-workers, your church, a club or social group)?	"Friends will not do personal care. She (SS) does not want her to do her personal care, not the intimate stuff. I would separate these. With family there is more of an expectation that they should be able to do it."(9)	Changed from helping with personal care to helping with other responsibilities. Added "(for example: work, volunteer work, childcare, pet care, meal preparation, laundry, home maintenance and yard work)"	Do you have other people (for example co-workers, your church, a club or social group) who will be able to help you with your other responsibilities (for example: volunteer work, childcare, pet care, meal preparation, laundry, home maintenance and yard work)?
	Do you think these other people will be available to help with the stroke survivor's personal care when needed?	Not applicable due to modification as above	Item deleted	
16	How much experience do you have helping someone else with daily activities like shopping, errands, taking to appointments, medications, etc.?	"expand to include banking"(18)	Added, "banking"	How much experience do you have helping someone else with daily activities like shopping, errands, taking to appointments, medications, banking, etc.?

Table 3. Item Revisions Based on Cognitive Interviews

Item	Original Question	Suggestion (Participant ID)	Modification	Revised Question
17	How willing are you to help the stroke survivor with daily activities such as shopping, errands, taking to appointments, medications, etc.?	As above	Added, "banking"	How willing are you to help the stroke survivor with daily activities such as shopping, errands, taking to appointments, medications, banking, etc.?
18		"3 months…then they forget; Friends were all around right after the stroke and now they have dropped off and don't visit."(9)	New item	How concerned are you about your ability to continue providing care for the stroke survivor for the next year?
19	Do you have enough money available to pay for things not paid for by insurance, Social Security income, Workers compensation, In Home Support Services, or other benefits (for example medications, someone to help with personal care, medical equipment, shower chair, co-pays)?	"Is it her financial situation or my financial situation? I am not working or bringing any money."(3)	"Do you have enough" changed to "Is there enough"	Is there enough money available to pay for things not paid for by insurance, Social Security income, Workers compensation, In Home Support Services, or other benefits (for example medications, someone to help with personal care, medical equipment, shower chair, co-pays)?
20	Will there be any accessibility problems for the stroke survivor getting around in the house or using the toilet or shower (for example, the width of doorways, stairs, ramp access) in his/her home?	"I needed to read this a couple of times. I was thinking about my home then this talked about her home. She is going to my home."(4)	"in his/her home" changed to "in the home where he/she will be living"	Will there be any accessibility problems for the stroke survivor getting around in the house or using the toilet or shower (for example, the width of doorways, stairs, ramp access) in the home where he/she will be living?
21	Will you need to make any changes to the home to make it accessible?	"I'm thinking ramps, shower chair. It might be good to give some examples". (1)	Added "(e.g. ramp, widen doors)"	Will you need to make any changes to the home (e.g. ramp, widen doors) to make it accessible?
22	Do you have enough money available to pay for the necessary changes to the home to make it accessible?	As above for item 20	Do you have enough" changed to "Is there enough"	Is there enough money available to pay for the necessary changes to the home to make it accessible?

Table 3. Item Revisions Based on Cognitive Interviews				
Item	**Original Question**	**Suggestion (Participant ID)**	**Modification**	**Revised Question**
23	Will the stroke survivor have accessible transportation that he/she can use to go places (e.g. the doctor, grocery store)?	"What about a driver if they can't drive?"(18)	Added "(e.g. car that he/she can get in and out of, someone to drive, Paratransit, etc.)"	Will the stroke survivor have accessible transportation (e.g. car that he/she can get in and out of, someone to drive, Paratransit, etc.) that he/she can use to go places (e.g. the doctor, grocery store)?
26		In response to Item 6, "There are two parts to this one... How prepared in terms of skills and how prepared in terms of emotions. They are two different things. I think both are very important."(9); In response to Item 11 "You should add physically and mentally capable" (12)	New item	How mentally prepared are you to be a caregiver?

Table 4. PATH-s Results

PATH-s Item	N	Min,Max	Mean	SD
Understand stroke survivor's expected recovery over the next 6 months	20	1,4	3.00	0.86
Understand how the stroke will affect lives over the next 6 months	19	1,4	3.32	0.95
Understand what to do to get things ready before the stroke survivor goes home	20	2,4	3.30	0.80
Understand what assistance the stroke survivor will need with personal care when he/she goes home	20	2,4	3.25	0.72
Experience providing physical help with personal care for someone who has a stroke or other disability	20	1,4	2.30	1.13
How prepared to provide the stroke survivor assistance with personal care when he/she goes home	20	1,4	3.10	1.12
How willing to provide personal care for the stroke survivor when he/she goes home	20	3,4	3.80	0.41
How much time to provide personal care for the stroke survivor when he/she goes home	20	2,4	3.65	0.59
Physical or mental health problems	20	2,4	3.40	0.75
Physical or mental health problems will affect ability to provide care	20	1,4	3.55	0.89
Do you have family and/or friends who are capable of providing help with the stroke survivor’s personal care	20	1,4	2.65	0.93
Family and/or friends available to help with the stroke survivor’s personal care when needed	20	1,4	3.15	0.99
Other roles and responsibilities other than providing care for the stroke survivor	20	1,4	2.70	1.13
How other roles and responsibilities impact availability to provide care	20	1,4	2.90	1.02
Other people who will be able to help you with other responsibilities	20	1,4	2.15	1.04
Experience helping someone else with daily activities	20	1,4	3.00	1.30
Willing to help the stroke survivor with daily activities	20	2,4	3.65	0.75
Enough money available to pay for things not paid for by insurance or other benefits	20	1,4	3.20	1.11
Accessibility problems for the stroke survivor getting around in the house or using the toilet or shower in the home	20	1,4	2.95	0.94
Need to make changes to the home to make it accessible	20	1,4	2.95	0.89
Enough money available to pay for necessary changes to the home to make it accessible	20	1,4	3.50	1.00
Accessible transportation that stroke survivor can use to go places	20	1,4	3.65	0.88
Regularly engage in activities to take care of own health	20	1,4	3.50	0.76
Conflict in relationship with the stroke survivor	20	2,4	3.40	0.82
Total Items Sum Score	20	55,95	76.00	12.22

The Psychometric Properties of the Proposed Preparedness Assessment for the Transition Home after Stroke (PATH-s) Instrument

Abstract

The purpose of this study was to evaluate selected psychometric properties of the proposed Preparedness Assessment for the Transition Home after Stroke (PATH-s) instrument. A cross-sectional study was performed with a convenience sample of caregiver-stroke survivor dyads (n=183) during inpatient rehabilitation facility admission. Data were collected using a self-administered questionnaire to describe participant characteristics, the PATH-s, Preparedness for Caregiving Scale (PCS), PHQ-9, Perceived Stress Scale, and Global Health Survey (GHS). Factor analysis revealed 8 factors aligned with the *Improving Stroke Caregiver Readiness*, upon which the PATH-s was developed. The PATH-s demonstrates excellent internal consistency (Cronbach's $\alpha = 0.90$). Criterion related validity of the PATH-s with the PCS was demonstrated (R=0.79; p<0.01). Both the PATH-s and PCS were negatively correlated with the PHQ-9 (R=-0.26, -0.27 respectively, p<0.01) and positively correlated with the GHS (R=-0.46, 0.46 respectively, p<0.01), which demonstrated convergent validity. Preliminary psychometric testing of the PATH-s indicated good reliability and validity, although assessment of validity was limited. Further testing of the PATH-s to assess additional psychometric properties, including predictive validity is suggested.

Background

Stroke is a leading cause of major disability in the US and globally Benjamin et al. (2017). Of the estimated 6.6 million stroke survivors living in the US, more than 4.5 million have some level of disability following stroke (Mozaffarian et al., 2016). Stroke is also a crisis for the family system (Lutz et al., 2011). When stroke survivors return home they frequently require assistance with basic and instrumental activities of daily living (BADL/IADL), usually provided by family members. There are approximately 4 million family members in the United States who provide care for stroke survivors at home (National Alliance for Caregiving, 2015).

Care transitions for individuals with disabling conditions, such as stroke, are often ineffective and inefficient, resulting in unmet patient and caregiver needs, increased safety risks, high rates of preventable readmissions, and increased health care costs (Camicia et al., 2014; B. J. Lutz et al., 2011). Patients experiencing a stroke receive immediate care in the emergency department and acute care hospital, with an average length of stay of 5.7 days in 2014 (Steiner C, 2016). Stroke survivors 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). This setting is where the caregiver, often a family member, assumes the role of caregiver, participating in the patient's nursing care and rehabilitation therapies to learn the skills required upon return to home.

Stroke survivors and their family caregivers face enormous challenges during the transition from the IRF to living at home post-discharge (Lutz et al., 2011; Lutz et al., 2017; Young et al., 2014). In a review of 33 qualitative studies, Luker et al. (2017) found that stroke caregivers felt emotionally overwhelmed and had difficulty managing the transition home. Caregivers indicate their needs for preparation for discharge and reassurance regarding their abilities to care for the stroke survivor at home are often not met during the IRF stay (Camicia, Lutz, Markoff, & Catlin, 2018). Poorly prepared caregivers are more likely to experience negative physical, mental, and emotional health outcomes during the transition from inpatient care to home (Haley et al., 2009); effects which are sustained over time (Cameron, Naglie, Silver, & Gignac, 2013; Greenwood et al., 2008). The adverse effects of caregiving for stroke survivors and need for interventions to address this issue are well document in the literature (Lutz & Camicia, 2016).

Caregivers often do not have the requisite knowledge during the IRF stay to determine if they are "prepared" to provide care at home; they "don't know what they don't know". The patient's physical and cognitive status at discharge as well as pre-existing caregiver factors, such as the caregiver's health concerns and pre-stroke responsibilities; informal, formal, and financial resources; home accessibility; plans for self-care; and relationship with the stroke survivor can influence a caregiver's capacity and commitment to assume the caregiving role (Lutz et al., 2016). Findings from the Lutz et al (2016) study suggest that as caregivers move through the phases of the trajectory from IRF to home, they do not have a good understanding of the role to which they are committing, and they are often underprepared to take on even the basic tasks to meet the patients' needs on discharge. In a follow-up study, Lutz et al. (2016) analyzed data from interviews with 40 stroke family caregivers during an IRF admission and within 6 months post-discharge. Caregivers identified critical areas where they felt unprepared to assume the caregiving role after discharge from the IRF. The findings of the dimensional and comparative analysis in this grounded theory study were organized into a conceptual framework, *Improving Stroke Caregiver Readiness Model,* which is illustrated in Figure 1 (Lutz et al., 2016); this model illustrates the trajectory of the crisis of stroke based on caregiver perspectives, and identifies the important assessment domains related to caregiver capacity and commitment.

Although there is a need to assess the caregiver's commitment to and capacity for the caregiver role (Young et al., 2014), there is a paucity of instruments available for measuring a caregiver's preparedness to assume the role of caregiver for a stroke survivor. The most widely used instrument is the Preparedness for Caregiving Scale (PCS) (Archbold PG, 1992), The PCS was developed to assess caregivers who provide care to frail older people (Archbold P. G., 1990), and is not stroke-specific. The PCS is an 8-item self-report scale to measure caregiver sources and methods of learning, perceived preparation to care for the emotional and physical needs of another, and preparation to arrange services needed. The 5-point Likert scale ranges from 0 (not at all prepared) to 4 (very well prepared). The overall score is computed by summing the responses and dividing them by the number of items answered; thus, the total scores range from 0 to 4, with higher scores indicating better preparedness. The Cronbach's alpha for the PCS in an Italian study of 156 stroke caregivers 3 months after stroke survivor IRF discharge in one stroke caregiver population was 0.90 (Puciarelli et al, 2014).

There are several limitations to the PCS. First, as mentioned above, it is not specifically designed for assessment of caregiving for stroke survivors. Second, it has generally been used for research rather than addressing clinical needs, whereas the PATH-s was designed for clinical and research use. Third, in the stroke caregiver research it has most commonly been used after the caregiver had already assumed the caregiver role, rather than to pre-emptively assess caregiver readiness prior to leaving an institutional setting. Finally, since the development of the PCS, the understanding of other important factors that impact preparedness for caregivers of stroke survivors have emerged (Bakas et al., 2014; Lutz & Young, 2010; Lutz et al., 2011; Young et al., 2014). These include the capacity and commitment of the caregiver, and biopsychosocial and ecological factors that must be considered to holistically view preparedness.

The PATH-s was developed based on this recent evidence and is inclusive of these factors. It is also designed specifically for use in clinical assessment with caregivers of stroke survivors prior to their discharge from an IRF. No other comparable assessment instrument is currently available. Thus, it was designed to address a perceived gap in available clinically relevant assessment methods.

The items in the PATH-s were generated from the *Improving Stroke Caregiver Readiness Model* (Lutz et al., 2016). Items are rated on a 4-point ordinal scale from 1 to 4 with 4 being highest. The overall score is computed by summing the responses and dividing them by the number of items answered; thus, the total scores range from 1 to 4. For example, the response options to the question "How willing are you to provide personal care (such as bathing, using the toilet, dressing, and moving around) for the stroke survivor when he/she goes home?" include: I am not willing to provide any personal care for the stroke survivor (scored 1), I am willing to provide a little personal care for the stroke survivor (scored 2), I am willing to provide some care for the stroke survivor (scored 3), and I am willing to provide a lot of personal care for the stroke survivor (scored 4). The development of the PATH-s is described by Camicia et al. (under review). We expected that the PATH-s would have comparable outcomes to the PCS in relation to the variables under study. Multiple activities were undertaken to assess the validity and reliability of the PATH-s instrument. The purpose of this study was to explore the psychometric properties of this proposed instrument.

Methods

Research Design

A cross-sectional study was conducted to establish the psychometric properties of the PATH-s draft instrument. The constructs of interest to validate the PATH-s for use in clinical care and research included internal consistency reliability, the factor structure, construct validity, and concurrent validity. Analyses were guided by principles of instrument development. We describe the characteristics of caregiver responses on the PATH-s draft instrument during IRF.

Sample and Procedures

The participants in this study were informal caregiver-stroke survivor dyads admitted to a regional IRF within an integrated care delivery system. The caregiver was identified as the person who would provide assistance to the stroke survivor with functional (e.g. bathing, dressing, toileting, mobility) and instrumental (e.g. shopping, cooking) activities of daily living upon discharge. The associated stroke survivors were enrolled in the study to obtain characteristics of the stroke survivor for whom the caregiver was providing care. Participants needed to meet the following criteria: caregiver/stroke survivor with moderate-severe functional impairments, admission following first stroke, stroke survivor planned discharge to home with designated caregiver, the ability to speak and read English, and 18 years of age or older.

Following approval by the institution's Institutional Review Board, potential participants were identified through review of the facility census. The IRF in this study had an average daily census of 46 and discharged approximately 700 stroke survivors in 2017. Caregivers of stroke survivors who were present at the facility within 7 days of stroke survivor IRF anticipated discharge were screened by a member of the research team using the above criteria. Concurrently, the electronic health record (EHR) of the stroke survivor was reviewed for potential eligibility. Those stroke survivor-caregiver dyads who met the inclusion criteria were approached by a member of the research team and invited to participate following an explanation of the study. Enrollment in the study required the consent of both the stroke survivor and caregiver. Once consent was obtained, the researcher scheduled an appointment to conduct the data collection and provided the participants with a copy of the signed consent. The caregiver participants received a small incentive (value ~$10) for study participation. Tinsley and Tinsley (1987) recommend a ratio of 5-10 subjects per item up to 300 subjects. Based on this heuristic, we established a target sample size of 125 to 250 subjects for this 25-item instrument. A sample of 183 participants was ultimately recruited, achieving an adequate sample for analysis.

Instruments

Measures under study included the PATH-s and the PCS (described above), the Patient Health Questionnaire (PHQ-9), the Perceived Stress Scale (PSS), and the PROMIS Global Health Survey (GHS). Basic caregiver demographic information, including age, sex, race/ethnicity, relationship to the stroke survivor, educational attainment, and annual household income, was collected.

Depressive symptoms were measured by the Patient Health Questionnaire (PHQ-9) scale, a 9-item instrument in which the respondents indicated how often in the past 2 weeks they experienced symptoms associated with depression on a 4-point Likert scale (Kroenke, 2001). Individual item scores range from 0 to 3, with the sum score indicating the severity of depression. A score of 0-4 indicates minimal or no depressive symptoms, 5-9 mild depressive symptoms, 10-14 moderate depressive symptoms, 15-19 moderately severe depressive symptoms, and a score of 20-27 indicating severe depressive symptoms. The PHQ-9 has been used in numerous caregiver studies and has demonstrated good reliability (α=.89) and validity (sensitivity 68-95%; specificity 95-84%)(Kroenke, Spitzer, & Williams, 2001; Lowe, Kroenke, Herzog, & Grafe, 2004). The PHQ-9 has been validated with stroke caregivers (Bakas & Burgener, 2002; Bakas et al., 2009; Williams et al., 2005). It was hypothesized that the PHQ would be negatively associated with the PATH-s.

The Perceived Stress Scale (PSS) is a 10-item instrument used to rate the extent to which caregivers felt their life to be stressful during the past month. Item scores are rated on a 5-point scale (0 =never to 4 =very often) range from 0 to 40, with higher scores suggesting higher levels of stress. The PSS has demonstrated good internal consistency in the general population (α=.78) (Cohen, Kamarck, & Mermelstein, 1983) and with stroke caregivers (α=.85)(Ostwald, Bernal, Cron, & Godwin, 2009). It was hypothesized that the PSS would be negatively associated with the PATH-s.

The PROMIS Global Health Score (GHS) consists of 10 items that assess general domains of health and functioning, including overall physical health, mental health, social health, pain, fatigue, and overall perceived quality of life (Hayes, 2009). Item scores are rated on a 5-point scale (1 = poor to 5 = excellent) range from 0 to 50, with higher scores suggesting higher levels of health. The GHS has been used extensively in the general public and demonstrated internal consistency (α=.81) in a study of family caregivers of elders (Weierbach & Cao, 2016). It was hypothesized that the GHS would be positively associated with the PATH-s.

The data were collected by a self-administered questionnaire. Participants were provided instructions to complete the questionnaire on an iPad in a private location on the IRF where the stroke survivors were admitted. Participants responses to the PATH-s, PCS, PSS, PHQ-9, GHS, and demographic data were directly deposited from the questionnaire into the secure Qualtrics (Provo, UT) database.

Stroke Survivor data included age, sex, race/ethnicity, days from stroke event to admission to the IRF, the IRF length of hospital stay, and the discharge Functional Independence Measure (FIM™) score. The FIM™ is an 18-item instrument used to assess the level of independence in motor and cognitive function (Granger, Cotter, Hamilton, & Fiedler, 1993; Keith, Granger, Hamilton, & Sherwin, 1987). The FIM™ has been used extensively in rehabilitation and post-discharge (Camicia, Wang, DiVita, Mix, & Niewczyk, 2015; Epstein-Lubow, Beevers, Bishop, & Miller, 2009), and has demonstrated reliability (α=.95) and validity

(Ottenbacher, Hsu, Granger, & Fiedler, 1996). The FIM™ instrument is completed in the electronic health record during the IRF stay by direct care providers as part of usual care. It was hypothesized that the FIM would be positively associated with the PATH-s.

Data Analysis

Data were cleaned by double checking for inconsistencies or errors. SPSS version 25 (IBM Inc. 2017) was used for all analyses, with a significance level set at 0.05. Descriptive statistics were used to examine for extreme skewness and kurtosis. We analyzed the data both including and excluding outliers.

Exploratory factor analysis of the 26 items was conducted to identify and interpret the number of important latent factors in the PATH-s instrument. Principal axis factoring with a Varimax Rotation with Kaiser Normalization was used to yield more interpretable factor loadings (Netemeyer, Bearden, & Sharma, 2003). The Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy was calculated. Bartlett's test of Sphericity was used to test the items inter-correlation. Loadings of at least 0.4 on one factor and less than 0.3 on all other factors and eigenvalues greater than 1.0 were set as the acceptable threshold (Welsh, 2016).

Internal consistency reliability was assessed using Cronbach's alpha (α). Item analysis of medians, standard deviations, percentage ceiling and floor effects, inter quartile range, corrected item-to-total correlations, average inter-item correlations, and Cronbach's alpha coefficients were calculated based on a covariance matrix for the instrument as a whole (DeVellis, 2017). Cronbach's alpha coefficient was set at the acceptable level of 0.7 (Lynn, 2015).

Pearson's product-moment correlation coefficient was used to assess the strength and direction of the relationships to determine the extent to which the PATH-s performed as predicted with regard to the other measures (PCS, PHQ-9, PSS, GHS). Construct validity was evaluated by examining the relationship of the PATH-s scale and the PCS. Convergent validity was evaluated by examining the relationship between the PATH-s and each of the PHQ-9, PSS, and GHS. As described above, it was hypothesized that the PATH-s and PCS would be negatively correlated with the PHQ-9 and PSS, and positively correlated with the GHS, indicating a higher PATH-s would be associated with lower depressive symptoms, lower stress symptoms, and better health respectively.

The socio-demographic variables were collapsed to reduce the number of variables in the regression model. Caregiver age categories 18-24, 25-34, 35-44 were combined into “younger than 45”; age categories 45-54 and 55-64 were combined into “45 to 64”; and age categories 65-74, 75-84, and 85 and older were combined into 65 and older. For caregiver education, elementary, some high school, and high school graduate were combined into “high school or less”; leaving the original categories of some college and college graduate. The stroke survivor relationship to the caregiver categories child, parent, and sibling were combined into “family”, friend, partner, and spouse remained. The household income variables under $10,000, $10,000 to less than $20,000, $20,000 to less than $35,000, $35,000 to less than $50,000, and $50,000 to less than $75,000 were combined into a variable “below $75k/year”, and income of $75,000 to less than $100,000 and $100,000 or more were combined into a variable “income $75k and greater”. This was consistent with the California median family income of $79,003 per year in 2017 (deptofnumbers.com). The race/ethnicity of the stroke survivor was analyzed to determine the level of agreement.

We created a linear regression model to identify if there were any caregiver characteristics that were highly correlated with the PATH-s. We adjusted for stroke survivor confounders, including days from stroke to IRF admission, IRF length of stay, and the FIM™

score at IRF discharge. We checked for normality of residuals. The reduced model was selected based on best fit. Variables were evaluated for low correlation and multicollinearity and removed accordingly.

Findings

Caregiver and stroke survivor participant characteristics are presented in Tables 1 and 2 respectively. There were 366 participants in the study (n= 183 stroke survivor- caregiver dyads). The PATH-s score range was 1.68 to 4.00 with a mean of 3.11 (SD±0.48).

The Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy was 0.85 ($p<0.001$), indicating the sampling was meritorious according to Kaiser (1974). Rotation converged in seven iterations. The items loaded on eight factors which revealed alignment with domains of the *Improving Stroke Caregiver Readiness Model*, upon which the PATH-s was developed. Four items loaded on the long-term implications of stroke (prognosis and insight), 5 items loaded on caregiver commitment (willingness), 3 items loaded on formal and informal resources, financial resources, and 2 on each of capacity (pre-stroke caregiver experience), and capacity (pre-existing caregiver health problems). Although 2 items loaded on accessibility, the accessible transportation item was added to this factor as it aligned with the *Improving Stroke Caregiver Readiness Model*. The remaining 4 items factored onto a construct referencing social context, which includes the strength of relationship, pre-stroke caregiving roles and responsibilities, and the ability to sustain. The item, “Do you regularly engage in activities to take care of your own health” (μ=3.30, SD=0.83) was eliminated as it did not meet the threshold of .03. This reduced the instrument to 25 items. The 25-item instrument was used for all subsequent analyses. The factor loadings, item means, standard deviation, and item-total correlations are presented in Table 3.

Cronbach' s alpha reliability coefficient was employed as an estimate of internal consistency for the PATH-s. The PATH-s instrument as a whole demonstrated excellent internal consistency reliability (α=0.90) (Nunnally, 1994). Examining the scores at the item level revealed a corrected item-total correlation of the items range from 0.30 to 0.76, with an average inter-item correlation of 0.28.

The correlations between the PATH-s and other measures are presented in Table 4. The scale score is included in the analysis if all items in the scale were completed, thus accounting for different sample sizes represented in the results. The PATH-s scale and the PCS had a strong and positive correlation (r=0.80, p<0.01, n=160), which demonstrated criterion related validity of the PATH-s with the PCS (the best currently available instrument). The PATH-s performed similarly to the PCS with the PHQ-9, PSS, and GHS. There was a weak negative relationship between the PHQ-9 and both the PATH-s (r=-0.26, p<0.01, n=160) and PCS (r=-0.27, p<0.01, n=160). There was a moderate positive correlation between the GHS and the PATH-s (r=0.46, p<0.01, n=160) and PCS (r=0.46, p<0.01, n=160). There was a weak correlation between the PSS and both the PATH-s (r=-0.12, p>0.05, n=160) and PCS (r=-0.15, p>0.05, n=160), though this relationship was not significant. The above findings support the convergent validity of the PATH-s and the PCS in this population. The stroke survivor’s total FIM™ score at discharge had a slight but significant correlation to the PATH-s (r=0.15, p<0.01, n=178) and PCS (r=0.11, p<0.01, n=177).

Multiple regression analysis was used to test if the caregiver demographic characteristics (age, relationship, sex, education, annual household income, and race/ethnicity) were significant predictors of the PATH-s score. The results of the regression indicated three predictors explained 27% of the variance (β = 1.56, p<.001). Friend (β = -0.35, p<.05) and Asian (β = -0.19, p<.05), were negatively associated with preparedness, while health status was positively associated ($\beta = 0.04$, $p<.01$).

Discussion

This study evaluated the psychometric properties of the proposed PATH-s instrument. The PATH-s demonstrated internal consistency reliability, and the factor structure aligned with the *Improving Stroke Caregiver Readiness Model*. The PATH-s and PCS were highly correlated, indicating criterion validity. The PATH-s correlation with other measures results were as anticipated (see Table 4), and demonstrated convergent validity of the PATH-s. It was expected that each of the PATH-s and PCS would have a negative correlation with each of the PHQ-9 and PSS; that a higher preparedness would be associated with lesser symptoms of depression and stress. Similarly, we expected the positive correlation between each of the PATH-s and PCS and the GHS, indicating greater preparedness is associated with better global health. Our findings indicated that the PATH-s and PCS perform similarly. Given that the PATH-s assesses several constructs that are not included in the PCS, and is specific to caregivers of stroke survivors, it fills an identified gap in assessing stroke caregivers.

Although the item, “Do you regularly engage in activities to take care of your own health” was eliminated as it did not meet the threshold in the factor analysis, clinicians may choose to include this item in the assessment of caregivers. A recent update on the State of the Evidence (Bakas, 2017) identified the majority of stroke family caregiver and dyad interventions reviewed emphasized how to care for the stroke survivor, rather than how to take care of oneself as a family caregiver. It was recommended that more emphasis be directed towards interventions that are targeted towards the health and well- being of the family caregiver and that more tailored approaches are provided to meet the assessed needs of caregivers.

We also identified caregiver characteristics such as Asian and friend that are highly correlated with the PATH-s. We recognize Asian is a heterogeneous category which was not fully defined, and the ethnicity of the Asian participants was not further explored in this study, thus we cannot explain this association. However, Qiu (2018) conducted a qualitative study of stroke caregivers and identified Chinese cultural influences on stroke caregiving. These include the culturally prescribed obligation and expression of reciprocal love, and associated acceptance of family caregiving as an expected part of life, and Chinese caregiver's avoidance of using formal caregiving services regardless of the hardships and neglect of their own health. The influences of Chinese culture on stroke caregiving are attributed to Confucianism and the associated filial piety. In contrast to this, a friend caregiver, regardless of culture, may not experience the obligation that a family relation may experience. Further, a friend may be fulfilling the role of caregiver due to the absence of a willing and available family caregiver. These caregiver characteristics may be used in future research to explore which subgroups of caregivers are at greater risk of low preparedness. Further exploration to understand how sociodemographic factors influence caregiver preparedness is warranted.

The PATH-s can be used to pre-emptively assess the biopsychosocial and ecological constructs not present in the PCS that are important to caregivers of stroke survivors as they prepare for the transition from IRF to home. Ongoing assessments to determine caregivers' commitment and capacity to assume the caregiver role should be conducted so that evidenced-based care management interventions can be tailored to their changing needs over time. The stroke care trajectory can be non-linear and repeated clinical assessment of caregivers is needed across the stroke caregiving trajectory, allowing the implementation of interventions tailored to the caregiver and family system as needed (Graf, 2017). This may result in improved health and quality of life for the caregiver. Pucciarelli et al. (2017) identified that decreases in caregiver burden were significantly associated with improvement in caregiver physical, psychological, and environmental quality of life. 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 reviewed on a regular basis. It is essential that nurses and other providers adequately assess caregivers' needs and incorporate education, preparation, and support for the caregiving role. Further longitudinal investigation to determine if the PATH-s is adequately responsive to change over time would be beneficial, although the similarity of its performance to the PCS suggests this is likely to be the case.

Limitations

The current study was exploratory in nature and due to the specificity of participant selection methods, may be generalizable beyond the caregivers of stroke patients admitted to the IRF under study with limitations. Secondly, although there was representation across sociodemographic groups, there was underrepresentation in several racial/ethnic groups (e.g. Native American). The setting for this study has a robust caregiver training program and demonstrates industry-leading clinical outcomes, which may have underestimated the PATH-s scores in the general stroke caregiver population. Additionally, all the stroke survivors in this study had health insurance coverage. Divergent validity, an important component of instrument testing, was not included in this study, however future studies will evaluate this. Further, studies are underway to evaluate the predictive validity of the PATH-s.

Implications/Conclusion

Caregivers play a fundamental role in a patient's ability to return home following a stroke. This study provides evidence for the elements of reliability and validity tested here for the

PATH-s, an instrument proposed to assess caregivers' commitment and capacity for the caregiving role. The factor analysis revealed alignment with the *Improving Stroke Caregiver Readiness Model*, upon which the PATH-s was developed. Preliminary psychometric testing of the PATH-s illustrates excellent internal consistency, in addition to criterion and convergent validity. Further testing of the PATH-s to assess additional psychometric properties, including predictive validity is suggested. An instrument such as the PATH-s, once further validated, may be used by healthcare providers to assess the risk/needs of caregivers as their needs change over time. Further, the PATH-s may identify which families/caregivers are at risk for poorer outcomes in order to target interventions that can be offered at the right time across the caregiving trajectory.

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Figure 1. Improving Stroke Caregiver Readiness

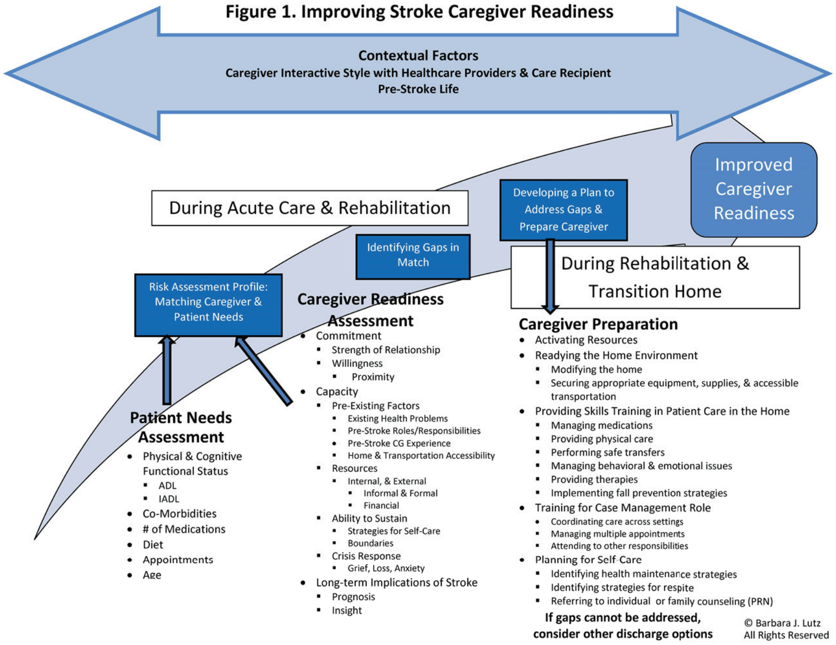

Table 1. Characteristics of Caregiver Study Sample

Survey Population (n=183)	N (%)[a]
Age (%)	
18-44	35 (19)
45-64	94 (51)
65 and older	53 (29)
Sex (%)	
Female	128 (70)
Male	50 (27)
Race/Ethnicity (%)	
Hispanic (may be any race)	35 (19)
Non-Hispanic Asian	12 (6)
Non-Hispanic Black/African American	95 (52)
Non-Hispanic White/Caucasian	29 (16)
Non-Hispanic Native American	2 (1)
Other	9 (5)
Relationship to Stroke Survivor	
Family (child, parent, sibling)	67 (36)
Spouse	102 (55)
Partner	8 (4)
Friend	5 (3)
Education (%)	
High School or less	41 (22)
Some college (1-3 years)	65 (35)
College graduate (4 or more years)	75 (41)
Household Annual Income (%)	
<$75K	89 (49)
≥ $75k	83 (45)

[a] Totals

may not add up to 100% due to missing responses

Table 2. Characteristics of Stroke Survivor Study Sample

Survey Population (n=183)	**Mean (±SD) or N (%)a**
Age	66.9 (±13.03)
Sex (%)	
Female	72 (39)
Male	111 (61)
Race/Ethnicity	
Hispanic (may be any race)	19 (10.4)
Non-Hispanic Asian	34 (18.6)
Non-Hispanic Black/African American	18 (9.8)
Non-Hispanic White	108 (59.0)
Non-Hispanic Pacific Islander	4 (2.2)
Discharge FIM™ Score	79.10 (±15.82)
Onset Days	10.95 (±15.44)
IRF Length of Stay	14.81 (±5.77)

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

Table 3. PATH-s factor analysis results				
	PATH-s		Factor	Item-total
Construct/Items	mean	SD	Loadings	Correlation
Total PATH-s	3.16	±0.45		
Long-term Implications of Stroke: Prognosis & Insight				
Understand expected recovery	3.11	±0.73	0.620	0.56
Understand stroke effect on lives	3.15	±0.81	0.616	0.54
Understand things to get ready	3.40	±0.71	0.758	0.48
Understand assistance needed	3.52	±0.75	0.728	0.44
Commitment: Willingness				
Prepared to assist with personal care	3.16	±0.82	0.459	0.70
Willing to provide personal care	3.71	±0.64	0.840	0.60
Time to provide personal care	3.54	±0.63	0.573	0.51
Willing to help w/ daily activities	3.65	±0.71	0.671	0.54
Mentally prepared	3.30	±0.82	0.484	0.76
Capacity: Formal & Informal Resources				
Family/friends capable to help w/ care	2.66	±0.98	0.821	0.42
Family/friends available to help w/ care	3.25	±0.94	0.390	0.52
Other people to help w/ responsibilities	2.37	±1.10	0.638	0.57
Capacity: Pre-stroke Caregiver experience				
Experience helping w/ personal care	2.28	±1.19	0.603	0.42
Experience helping w/ daily activities	2.91	±1.21	0.815	0.35
Capacity: Financial Resources				
Money for items not covered	2.73	±0.96	0.867	0.33
Money for home modification	3.08	±0.96	0.692	0.47
Capacity: Pre-Existing Health Problems				
Physical or mental health problems	3.41	±0.77	0.872	0.30
Health problems interfere w/ caregiver role	3.62	±0.71	0.713	0.38
Capacity: Home & Transportation Accessibility				
Accessibility problems in home	3.10	±0.89	0.618	0.55
Need to make changes to home	2.97	±0.88	0.777	0.47
Accessible transportation available [a]	3.42	±0.91	0.288[a]	0.54
Social Context: Commitment (Strength of Relationship) & Capacity (Pre-stroke Roles/Responsibilities; Ability to Sustain)				
Other roles & responsibilities	2.17	±1.00	0.544	0.33
Other roles impact availability	2.76	±1.00	0.714	0.62
Concern w/ ability to continue caregiver role	2.98	±1.07	0.402	0.73
Conflict in relationship	3.54	±0.71	0.465	0.33

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[a] Item loaded at .364 on Social Context factor but aligned in the *Improving Stroke Caregiver Readiness Model* with the Capacity: Accessibility factor

Table 4. PATH-s Correlations with PCS and Other Measures

		PCS	PHQ-9	PSS	GHS	FIM™
PATH-s	*R*	0.80**	-0.26**	-0.12	0.46**	0.15**
PCS	*R*	1	-0.27**	-0.15	0.46**	0.11**
Hypothesized relationship		positive	negative	negative	positive	positive

** Correlation is significant at the 0.01 level (2-tailed)

Implications for Nursing Science and Healthcare Leadership

The use of the PATH-s in clinical care, research, and policy has the potential for shifting the current care delivery paradigms by addressing a significant gap in the transition of patients with stroke and their caregivers from IRF and other settings (e.g. acute care, skilled nursing facilities, long term care hospitals) to the community, and across the caregiving trajectory. Prior to the development of the proposed PATH-s instrument there was no instrument specifically designed to assess the commitment and capacity of stroke survivors and their caregivers as they prepare for the transition home following IRF. Additionally, exploration of the use of the PATH-s in different populations where disability is of sudden onset (e.g. brain injury and spinal cord injury) is indicated.

This dissertation study resulted in an instrument for health care providers to use to identify the gaps in preparedness of caregivers as they transition from IRF (and other settings with further testing) to home. The goal was to identify suboptimal preparation and potentially mitigate the resulting adverse events associated with this transition on the health of caregivers and stroke survivors. The PATH-s may guide healthcare care providers in the development of individually tailored care plans to address identified gaps and better prepare caregivers for the role, thus improve outcomes for caregivers and care recipients, as recommended by the Family Caregiver Alliance (2012). A tool kit of interventions and associated resources could be developed to address areas where caregivers score low on the PATH-s items. Examples include: assisting with planning caregiving and other responsibilities, providing resources for how to manage home modifications in a rental situation, and engaging in activities to improve mutuality in a relationship where conflict exists. Strength-based approaches that focus on sustaining areas where an individual rates high on the PATH-s may also be considered. For example, reinforcement for maintaining a schedule that includes engaging the caregiver in other meaningful activities, and strategies for sustaining a relationship post-stroke that has been identified as low conflict. These interventions and resources might be integrated into a plan of care across the caregiving trajectory. Implementation research must be conducted to evaluate such programs.

An essential future step following the additional testing in the IRF is the development and testing of modified versions of the PATH-s in different settings (acute care, skilled nursing facilities, long term care hospitals) and across the trajectory of caregiving. The PATH-s version used in this study could be tested with caregivers in the skilled nursing facility and long-term care hospital settings for similar use, as used here in the IRF. A shorter version might be developed for use in acute care to for two purposes. First, the PATH-s could be used to screen caregivers who will assist the stroke survivor upon the transition directly to home. Second, a short-version might be used for caregivers of patients being evaluated for an IRF admission when it is anticipated that the patient's functional status at IRF discharge will require assistance with caregiving. A probable discharge to the community is a criterion for IRF admission, and the identification of a caregiver in many situations is necessary to illustrate how this requirement is met pre-admission to the IRF. Providers have expressed great interest in both acute care applications. The development of a version for conducting intermittent assessments in the community setting is also necessary to address the changing needs of caregivers over time.

A version of the PATH-s adapted for caregivers who have already assumed the caregiving role may be a vehicle to address the National Academies of Sciences (2016) recommendation to, "Develop, test, and implement effective mechanisms …to ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and long-term services and supports." Stroke caregiving differs greatly from caregiving for adults with dementia (and other progressive conditions), for which most caregiving research has been conducted. The necessity of a caregiver to assume the caregiving role for a stroke survivor is sudden, triggered by the acute medical crisis. Further, the trajectory of stroke caregiving is not always linear with increasing burden over time. Many stroke patients continue to have functional recovery and/or learn adaptive techniques that result in a decrease in caregiver burden. This requires intermittent assessments to modify the plan of care for the family unit as needs change. Further, using the PATH-s for research may help us better understand the stroke caregiving trajectory to identify how changing caregiver needs can be better anticipated and addressed. This includes the identification of the triggers and timepoints when assessments should be conducted. The PATH-s might also be studied in other populations where the caregiver role is assumed suddenly, e.g. with caregivers of patients with traumatic brain and spinal cord injuries, or other conditions resulting in sudden onset of disability.

Improving care transitions from acute care facilities to other care settings and home was established as a national priority by the Institute of Medicine (IOM, 2003). Since this time the focus in the healthcare industry has been on improving care transitions with the goal of preventing acute care hospital readmissions. Great effort has been directed at the patient's medical risk factors, such as the use of predictive analytics to identify patients at medium and high risk for readmissions based on their medical condition and physiologic events (Hu, Chan, Zubizarreta, & Escobar, 2018). Care management programs based on readmission risk scores have been developed to address patients at risk for hospital readmission. Recently, there has been an interest in the patients' social determinants associated with readmissions. However, there has not been attention to the assessment of the caregiver and family unit to address readmission risk.

A subset of the PATH-s might be integrated into electronic health record algorithms for stroke survivors to enhance readmission risk predictive analytics (as noted above) in this population.

The Centers for Medicare and Medicaid Services (2015) recognize that the discharge planning process should ensure that patients and their caregiver are properly prepared to be active partners and advocates for their health care and community support needs upon discharge. Additionally, the National Academies of Sciences (2016) recommends that, “The nation’s health care and long-term services and supports (LTSS) systems and workplaces to effectively and respectfully engage family caregivers and to support their health, values, and social and economic well-being”. The administration of the PATH-s instrument may provide a mechanism for enlisting caregivers as partners in care and supporting their health, values, and social and economic well-being. To this end, the PATH-s could be integrated into technology-enabled solutions that promote shared decision-making.

The findings from this study may inform health policy and the evolution of the inclusion of measures of caregiver preparedness in the Continuity Assessment and Record Evaluation (CARE) Item Set, which was developed as a part of the Medicare Post-Acute Care Payment Reform Demonstration (PAC-PRD) (Centers for Medicare and Medicaid, 2015). The CARE Item Set is a standardized patient assessment tool that was developed for use at acute hospital discharge and at post-acute care admission and discharge and is being considered for use within the Bundled Payments for Care Improvement (BPCI). Currently, there are no items in the CARE Item Set that assess a caregiver’s commitment and capacity for the caregiving role.

The long-term goal of this program of research is to complete the psychometric testing, including test re-test reliability and the assessment of predictive validity of the PATH-s to stratify risk for those stroke survivor-caregiver family units who are at greatest risk for poorer outcomes prior to the transition from IRF to home. This study is currently underway and includes collection of caregiver and stroke survivor data up to 3 months after discharge. If these study data illuminate a relationship between caregiver preparedness and caregiver and stroke survivor health outcomes, findings from caregiver research using the PATH-s may be used to advocate for funding for programs and services, and for policies to provide more paid time for caregiver preparation leading up to and following the transition home. Additionally, this may support funding of programs to provide greater social and care management support.

The reciprocity of caregiver and stroke survivor health is well documented, particularly when the stroke survivor has moderate to severe impairments (B. Lutz & Camicia, 2016; Ostwald et al., 2009). Given that the majority of caregivers are spouses of the stroke survivor, as in this study, and likely share the same health plan, health plans in accountable care organizations would benefit from assessing the stroke survivor and caregiver as a unit of care. By addressing the needs of caregivers, these interventions might improve the health of both health plan “covered lives”, avoiding the healthcare costs incurred by the stroke survivor and caregiver that may otherwise result from the adverse health effects of caregiving.

The PATH-s has the potential for shifting the current care delivery paradigms by addressing a significant gap in the transition of patients with stroke and their caregivers from IRF and other settings (e.g. acute care, skilled nursing facilities, long term care hospitals) to the community and across the caregiving trajectory. Prior to the development of the proposed PATH-s instrument there was no instrument specifically designed to assess the commitment and capacity of stroke survivors and their caregivers as they prepare for the transition home following IRF (nor any other care setting transition). The use of the PATH-s with in clinical care across the care continuum, in health services research, and to inform policy change responds to the call of the Institute for Healthcare Improvement “Triple Aim” to improve quality of care, improve health, and reduce costs for the care delivery system.

Appendix A: Literature Review

The Adverse Health Effects of Caregiving for a Stroke Survivor

Multiple studies have shown that being a family caregiver can negatively affect health and psychological wellbeing, and Family caregivers are at a greater risk for depression and other physical illness (Han & Haley, 1999). The demands and vigilance required for adequate care at home are often overwhelming and exhausting, even if the caregiver has had previous experience caring for individuals with disabilities. Caregivers often describe feeling isolated, abandoned, and alone (Brereton & Nolan, 2000; van Exel, Koopmanschap, van den Berg, Brouwer, & van den Bos, 2005). What frequently follows in the caregiver is a predictable trajectory of depression and a downward spiral of deteriorating physical health (Chumbler, Rittman, Van Puymbroeck, Vogel, & Qin, 2004; Greenwood et al., 2008; Perrin, Heesacker, Hinojosa, Uthe, & Rittman, 2009).

A systematic review of the adverse health effects of stroke caregivers during the first year following stroke identified the most commonly reported negative health outcomes in caregivers of stroke survivors as depression and anxiety. Klinedinst et al. (2009) mailed the Centers for Epidemiological Studies Depression Scale (CESD) and the Health-Related Quality of Life (HRQOL) survey to 132 caregiver-stroke survivor dyads during the acute phase and 4 and 12 months following the stroke. A high level of depressive symptoms was assessed in 20% of caregivers.

There is mixed evidence on the relationship between the physical burden associated with the severity of stroke and caregiver depression and anxiety. Caregiver burden as measured by the Oberst Caregiving Burden Scale (OCBS) was associated with greater caregiver anxiety and depression in a self-report of 153 caregivers of stroke survivors with spasticity greater than six months following a stroke (Denno et al., 2013). Every 1-point increase in the OCBS increased the odds of anxiety by 2.57 times ($P<0.001$) and depression by 1.88 times ($P<0.007$). Using the Beck Depression Inventory, Berg, Palomaki, Lonnqvist, Lehtihalmes, and Kaste (2005) conducted in-person interviews during acute care and 6 and 18 months following the stroke. Depression was identified in 30-33% of the participants. Stroke severity was correlated with caregiver depression. Caregivers of male stroke survivors had a higher prevalence of depression. Additionally, exhaustion was reported in 38% of spousal caregivers at 6 months with a decrease to 29% at 18 months ($p<0.05$).

Caregivers experience stress and strain as a result of caring for stroke survivor (Haley et al., 2009; King, Ainsworth, Ronen, & Hartke, 2010). King et al. (2010) found the interpersonal disruption theme was the most stressful problem theme followed by sustaining the self and family, and stroke survivor functioning in a mixed methods study of 58 caregivers. Haley et al. (2009) conducted telephone interviews of 75 stroke caregivers 8-12 months following a stroke using a self-developed instrument. The participants were asked to rate their experience of stress or strain with a list of caregiver duties and stroke survivor problems using a Likert scale. No strain was reported by 44% of respondents, 41.33% reported some strain, and 14.67% reported a lot of strain. The most stressful problems were when the stroke survivor appeared sad or depressed, demonstrated loneliness, did not have bowel control, expressed feeling worthless, exhibited anxiety, asked repeated questions, and when the stroke survivor had trouble remembering recent events. However, caregivers identified positive aspects of caregiving with 90% of caregivers reporting that the caregiving role had increased their appreciation for life.

Cameron et al. (2014) conducted telephone interviews using the CESD and found caregivers reported more emotional distress when caring for stroke survivors exhibiting more depressive symptoms and in those with greater cognitive impairment. In contrast to the above studies, in this study the stroke survivors' physical disability, stroke severity, and comorbidity were not significantly associated with caregiver depression. The set of significant predictors (excluding cognitive impairment) remained consistent after two years.

The mental health of the stroke survivor is related to anxiety and depression in the caregiver. In a large prospective study of caregivers (N=162) by Atteih et al. (2015) six months after a stroke identified that caregiver anxiety was predicted by stroke survivor anxiety (OR = 3·47, 95% CI 1·35–8·93), depression (OR = 5·17, 95% CI 1·83–14·58), and stroke survivor cognitive impairment (OR 2·35, 95% CI 1·00–5·31). Caregiver depression was predicted by stroke survivor anxiety (OR = 4·41, 95% CI 1·53–12·72) and stroke survivor depression. Depressive symptoms in both the stroke survivor and the caregiver are also associated with personal characteristics. A secondary analysis of an in-person survey of 112 spousal caregivers within 2 months of the stroke by Chung, Bakas, Plue, and Williams (2015) identified that stroke survivors' and spousal caregivers' self-esteem, optimism, and perceived control were significantly associated with their own depressive symptoms as measured by the PHQ-9 in a predictive regression model. Additionally, stroke caregivers with moderate to severe depressive symptoms have greater difficulty with caregiving tasks and worse life changes than those without depressive symptoms (Bakas et al. (2014)).

Although these studies illustrate caregivers experience anxiety and depression as a result of caregiving, these changes may subside over time. Godwin, Ostwald, Cron, and Wasserman (2013) conducted in person interviews of 30 stroke caregivers greater than 2 years after the stroke. Caregiver depression measured by the Geriatric Depression Scale decreased from 3.3 at baseline to 2.2 and 2.5 at 2 years($p<0.05$), though this may not be clinically significant.

Caregiver characteristics are associated with the negative effects of caregiving for stroke survivors (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011; Jessup, Bakas, McLennon, & Weaver, 2014; Klinedinst et al., 2009; McCullagh, Brigstocke, Donaldson, & Kalra, 2005). Cameron et al. (2014) conducted telephone interviews using the CESD and, found caregiver characteristics including younger age, female, in poorer physical health, perceived more lifestyle interference, and those who reported less mastery were also associated with more emotional duress. The set of significant predictors remained consistent after two years. Additionally, Klinedinst et al. (2009) reported that in a study of 132 caregivers, male gender caregivers was negatively associated with stroke survivor health related quality of life (HRQoL) in communication and mood domains items (as assessed by the Stroke Impact Scale (Duncan et al., 1999)) at 12 months in a study of 132 caregivers. Jessup et al. (2014) studied 243caregivers within 8 weeks after discharge from the hospital and found females and non-African Americans experienced more negative life changes after assuming the caregiver role. Additionally, female caregivers were found to be 4.45-times more likely than males to report having difficulty with finding care for the stroke survivor while they were away ($p<.001$). In summary, there is conflicting evidence related to the effects of gender on the mental health effects of caregiving.

Adverse Stroke Survivor Health Outcomes Following Stroke

A focus on the needs of family members, in addition to the patient, during hospitalization and post-acute care (PAC) has illustrated the crucial role that support and involvement of the family members play in the patient's rehabilitation process, the patient's psychosocial functioning, and other patient outcomes following a stroke (Clark & Smith, 1999). Caregiver preparedness may have an impact on stroke survivor outcomes such as acute hospital readmissions and falls.

Readmissions: Hospital readmissions (also referred to as re-hospitalization), defined as an admission to a hospital within 30 days of a discharge to the community from the same or another hospital, are closely monitored as a measurement of the effectiveness of stroke survivor care transitions. Readmissions may indicate unresolved problems, discharge to an inappropriate level of care, the quality of immediate post-hospital care, or a combination of these factors (Lichtman et al., 2010). Readmission rates 30 days following discharge from an IRF have been reported as 9.0% to 16.7%, varying with stroke case mix group (CMG) (Ottenbacher et al., 2014). CMGs serve as a proxy for patient severity on the basis of impairment, age, and comorbidities, as determined by the Centers for Medicare and Medicaid Services (CMS) (MEDPAC, 2014). The majority of unexpected hospital admissions the first year after stroke events were stroke-related, either directly (e.g. recurrent stroke, seizures) or secondary to disability related to the stroke (e.g. 9.4% experienced one or more falls) (Ostwald, Godwin, Ye, & Cron, 2013).

Factors associated with readmission in patients with stroke as reported in the literature include function, living situation, demographics, and socioeconomic status. Socioeconomic status was shown to be associated with disability following acute ischemic stroke in a study by Bettger et al. (2014). In this prospective cohort study of 1965 ischemic stroke survivors who were unemployed or homemakers, disabled and not-working, retired, less educated, or reported inadequate income prior to their stroke had a significantly higher odds of post-stroke disability.

Thirty-day readmissions have been evaluated from several perspectives. The most common diagnoses for readmission regardless of the initial post –acute discharge site included infections and pneumonitis (Kind, Smith, Pandhi, Frytak, & Finch, 2007). Several studies illustrate the relationship between function and readmission. Hoyer et al. (2013) found a significant association (p< .001) between lower motor functional independence measure (FIM) scores (walking, transfers) and thirty-day readmission. In a subsequent retrospective cohort study of patients admitted to an IRF from an acute care hospital, lower FIM scores near the time of discharge from acute care hospital were associated with acute care readmission (Hoyer et al., 2014). Given that disability is associated with re-hospitalization in other studies these findings are relevant. Improving caregiver preparation for their role and the transition to home will likely reduce readmissions. Readmission rate is a priority for the CMS (CMS, 2013) and an indicator for the Hospital Inpatient Quality Reporting Program for payment determination as of 2016 (CMS, 2013).

Appendix B: Additional Methods

Appendix B. Methods			
Process	Definition	Variable	Statistical test/Analysis
Aim 1: Further develop the PATH-s draft instrument with modifications based on cognitive appraisal interviews			
Stage 1. Cognitive interviews	Elicit data on how future respondents will interpret items. Verbal probing, think aloud, and paraphrasing. Identify the acceptable range of interpretations, provides evidence for item revision, distinguishes fixable from fatal flaws, and minimizes missing data in the final instrument (Knafl, 2007)	PATH-s questions & CA Interview Script & Record	The Knafl Method of interpretation (Knafl et al., 2007) using the Analysis of Cognitive Appraisal Interview Data • Identify themes within and across participants that represent participants thinking behind each response (validity). • Determine rate of agreement among participants (reliability) • Determine any untoward effects of completing the instrument.
Aim 2: Evaluate the PATH-s' psychometric properties in caregivers of stroke patients with moderate to severe impairments			
Stage 2. Construct validity	The degree to which it measures the theoretical construct that it was designed to measure (Allen & Yen, 1979)	PATH-s	Exploratory factor analysis using principal axis factoring & hierarchical multiple regression (Netemeyer et al., 2003).
Stage 3. Internal consistency reliability	The degree to which all the items measure a common characteristic of the person and are free from measurement error (acceptable Cronbach's alpha coeffecient.7)	PATH-s	Item analysis of medians, standard deviations, percentage ceiling and floor effects, intra quartile range, item-to-total correlations, Cronbach's alpha coefficients.
Stage 4. Criterion related reliability	To what extent the text performance is related to other valid measure (criteria) (Linn & Gronlund, 1995)	PATH-s PCS	Pearson r correlation assessing the strength and direction of the relationship.

Stage 4. Multi-trait, validity (a form of construct validity): Convergent validity	High correlations on scores on tests measuring the same thing (Allen & Yen, 1979). The tests converge on the trait.	PATH-s with each of PCS, PHQ-9, GHS	Pearson r correlation assessing the strength and direction of the relationship.
1) Examine distributions and skewedness of the results of the PATH-s completed by caregiver of stroke survivors with moderate to severe impairment following stroke			
Descriptive statistics	stroke survivor characteristics: Functional status, age, length of stay, onset days, race/ethnicity	PATH-s stroke survivor and caregiver characteristics (demographics & other variables under study)	PATH-s median, mode, frequency, percentages, and Pearson's correlation coefficient stroke survivor and caregiver characteristics

A multiple linear regression was calculated to predict PATH-s scores based on caregiver characteristics, including age, relationship, sex, education, annual household income, and race/ethnicity. All caregiver characteristics were entered into the model. Stroke survivor characteristics that were expected to confound the relationship between the predictors and the PATH-s score were included in all models. These include the FIM™ score at discharge, the days from onset from stroke to admission to inpatient rehabilitation, and the IRF length of stay. Because of the high correlation of the PATH-s and PCS, the PCS was eliminated from all models.

We evaluated demographic data to identify if there were any variables that were highly correlated with the PATH-s. The findings from these analyses can be used in future studies to 1) identify those caregiver characteristics that can be used to identify caregivers who are not prepared if an instrument, such as the PATH-s, is not available, and 2) these demographic data elements may be included in further analysis of the PATH-s predictive validity to identify which demographic data elements, if added to the instrument, would improve the predictive validity of the PATH-s.

The model summary below illustrates that the best-fitted model identifies a reasonable amount of variation, though the model leaves components that are not explained by the model. The results of this regression may be used to develop a predictive model that looks at preparedness measuring the factors that the PATH-s represents and other characteristics such as socioeconomic status, age, income to predict certain outcomes.

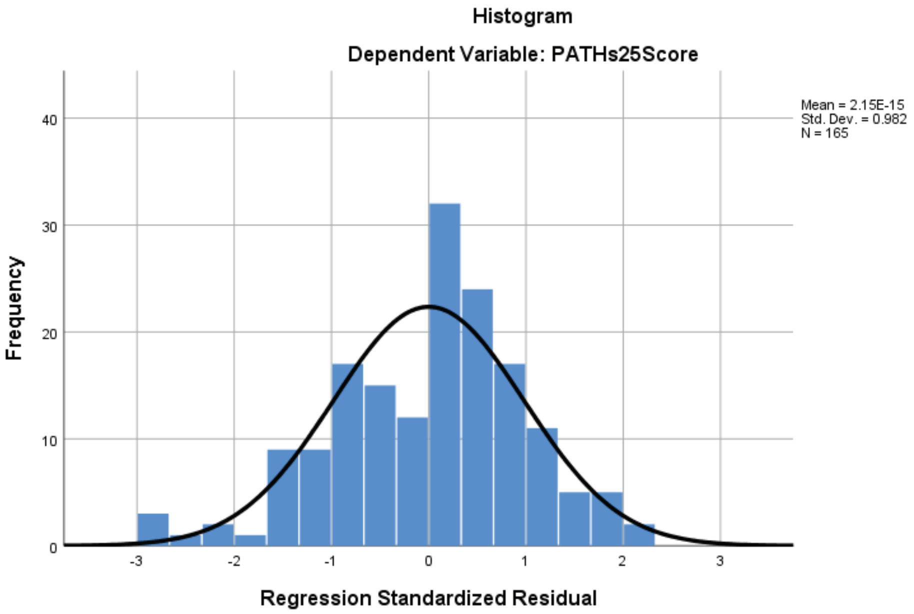
Model Summary[b]

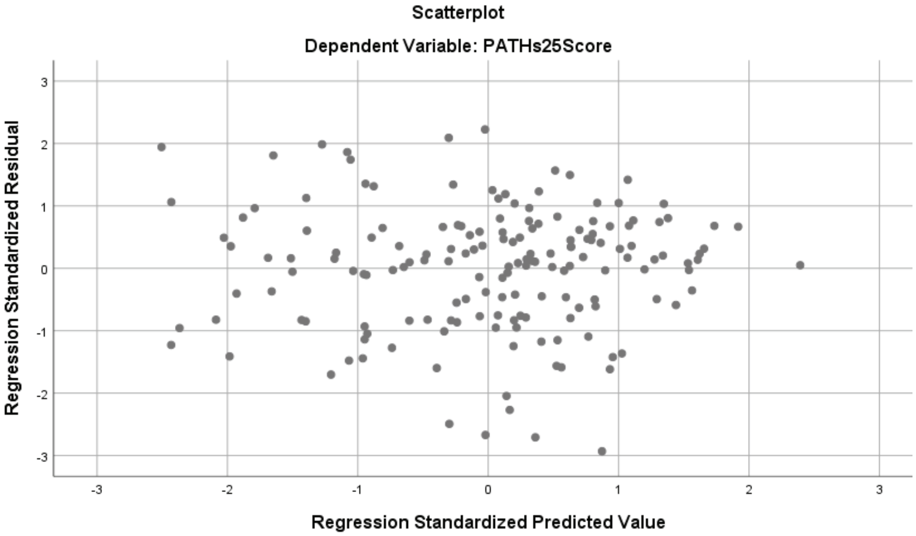
R	R Square	Adjusted R Square	Standard Error of the Estimate	*P*
.547[a]	.299	.273	.38415	.000[b]

a. Predictors: (Constant), GHS3, SS Onset Days, CG Asian, Actual LOS, Discharge Total FIM(R) Score

b. Dependent Variable: PATHs25Score

	Coefficients			
	B	Standard Error	*P*	Partial Correlations
(Constant)	1.560	.272	.000	
Days from Stroke to IRF Admission	-.001	.002	.679	-.033
IRF Length of Stay	-.002	.005	.759	-.024
Discharge FIM(R) Score	.004	.002	.037	.165
Friend Relationship	-.349	.176	.049	-.156
Caregiver non-Hispanic Asian	-.193	.078	.014	-.193
Global Health Summary	.036	.005	.000	.479


Histogram
Dependent Variable: PATHs25Score
Mean = 2.15E-15
Std. Dev. = 0.982
N = 165
Frequency
40
30
20
10
0
-3
-2
-1
0
1
2
3
Regression Standardized Residual


Scatterplot
Dependent Variable: PATHs25Score
Regression Standardized Residual
3
2
1
0
-1
-2
-3
-3
-2
-1
0
1
2
3
Regression Standardized Predicted Value

Appendix C: Data Collection Instruments

PATH-s Instrument

Q2 How much do you understand about the stroke survivor's expected recovery over the next 6 months?

- ○ I have no understanding about the stroke survivor's expected recovery over the next 6 months. (1)

- ○ I have little understanding about the stroke survivor's expected recovery over the next 6 months. (2)

- ○ I have some understanding about the stroke survivor's expected recovery over the next 6 months. (3)

- ○ I have a lot of understanding about the stroke survivor's expected recovery over the next 6 months. (4)

Q3 How much do you understand about how the stroke will affect your lives over the next 6 months?

- ○ I do not understand how the stroke will affect our lives over the next 6 months. (1)

- ○ I understand a little about how the stroke will affect our lives over the next 6 months. (2)

- ○ I understand some about how the stroke will affect our lives over the next 6 months. (3)

- ○ I understand a lot about how the stroke will affect our lives over the next 6 months. (4)

Q4 How much do you understand about what you need to do to get things ready before the stroke survivor goes home?

○ I do not understand what I need to do to get ready before the stroke survivor goes home. (1)

○ I understand a little about what I need to do to get ready before the stroke survivor goes home. (2)

○ I understand some about what I need to do to get ready before the stroke survivor goes home. (3)

○ I understand a lot about what I need to do to get ready before the stroke survivor goes home. (4)

Q5 How much do you understand about what assistance the stroke survivor will need with personal care (such as bathing, using the toilet, dressing, and moving around) when he/she goes home?

○ I do not understand what assistance the stroke survivor will need with personal care when he/she goes home. (1)

○ I understand a little about what assistance the stroke survivor will need with personal care when he/she goes home. (2)

○ I understand some about what assistance the stroke survivor will need with personal care when he/she goes home. (3)

○ I understand a lot about what assistance the stroke survivor will need with personal care when he/she goes home. (4)

Q13 How much experience have you had providing physical help with personal care (such as bathing, using the toilet, dressing and moving around) for someone who has a stroke or other disability?

○ I do not have any experience providing physical help with personal care for someone who has a stroke or other disability. (1)

○ I have less than one-month experience providing physical help with personal care for someone who has a stroke or other disability. (2)

○ I have at least one month but less than a year experience providing physical help with personal care for someone who has a stroke or other disability. (3)

○ I have a year or more of experience providing physical help with personal care for someone who has a stroke or other disability. (4)

Q6 How prepared are you to provide the stroke survivor assistance with personal care (such as bathing, using the toilet, dressing and moving around) when he/she goes home?

○ I am not prepared to provide the stroke survivor assistance with personal care when he/she goes home. (1)

○ I am a little prepared to provide the stroke survivor assistance with personal care when he/she goes home. (2)

○ I am somewhat prepared to provide the stroke survivor assistance with personal care when he/she goes home. (3)

○ I am very prepared to provide the stroke survivor assistance with personal care when he/she goes home. (4)

Q9 How willing are you to provide personal care (such as bathing, using the toilet, dressing, and moving around) for the stroke survivor when he/she goes home?

○ I am not willing to provide any personal care for the stroke survivor. (1)

○ I am willing to provide a little personal care for the stroke survivor. (2)

○ I am willing to provide some personal care for the stroke survivor. (3)

○ I am willing to provide a lot of personal care for the stroke survivor. (4)

Q10 How much time will you have to provide personal care for the stroke survivor when he/she goes home?

○ I will not have any time to provide personal care for the stroke survivor. (1)

○ I will have a little time to provide personal care for the stroke survivor. (2)

○ I will have some time to provide personal care for the stroke survivor. (3)

○ I will have a lot of time to provide personal care for the stroke survivor. (4)

Q7 Do you have any physical or mental health problems (for example difficulty bending or stooping, back or joint problems, heart issues, memory, depression, anxiety or other health challenges)?

○ I have many physical or mental health problems. (1)

○ I have some physical or mental health problems. (2)

○ I have a few physical or mental health problems. (3)

○ I do not have any physical or mental health problems. (4)

Q8 Do you think your physical or mental health problems will affect your ability to provide care for the stroke survivor?

○ Not applicable: I do not have any physical or mental health problems. (4)

○ I think my physical or mental health problems will greatly affect my ability to provide care. (1)

○ I think my physical or mental health problems will somewhat affect my ability to provide care. (2)

○ I think my physical or mental health problems will slightly affect my ability to provide care. (3)

○ I do not think my physical or mental health problems will affect my ability to provide care. (4)

Q14 Do you have family and/or friends who are capable of providing help with the stroke survivor’s personal care (such as bathing, using the toilet, dressing, and getting in and out of bed)?

- ○ I do not have any family and/or friends who are capable of providing help with the stroke survivor’s personal care. (1)
- ○ I have a few family and/or friends who are capable of providing help with the stroke survivor's personal care. (2)
- ○ I have some family and/or friends who are capable of providing help with the stroke survivor's personal care. (3)
- ○ I have many friends and/or family who are capable of providing help with the stroke survivor's personal care. (4)

Q17 Do you think these family and/or friends will be available to help with the stroke survivor’s personal care when needed?

- ○ Not applicable-I do not have any family and/or friends who will be available to help with the stroke survivor’s personal care. (4)
- ○ I do not think these family and/or friends will be available to help when needed. (1)
- ○ I think these family and/or friends will seldom be available to help when needed. (2)
- ○ I think these family and/or friends will sometimes be available to help when needed. (3)
- ○ I think these family and/or friends will be available to help when needed. (4)

Q11 Do you have other roles and responsibilities other than providing care for the stroke survivor (for example: work, volunteer work, childcare, pet care, meal preparation, laundry, home maintenance and yard work)?

- ○ I have many other roles and responsibilities other than providing care for the stroke survivor. (1)
- ○ I have some other roles and responsibilities other than providing care for the stroke survivor. (2)
- ○ I have few other roles and responsibilities other than providing care for the stroke survivor. (3)

○ I do not have any other roles and responsibilities other than providing care for the stroke survivor. (4)

Q12 How will your other roles and responsibilities impact your availability to provide care for the stroke survivor?

○ Not applicable-I do not have any other roles and responsibilities other than providing care for the stroke survivor. (4)

○ My other roles and responsibilities will greatly impact my availability to provide care for the stroke survivor. (1)

○ My other roles and responsibilities will have some impact on my availability to provide care for the stroke survivor. (2)

○ My other roles and responsibilities will have little impact on my availability to provide care for the stroke survivor. (3)

○ My other roles and responsibilities will not impact my availability to provide care for the stroke survivor. (4)

Q16 Do you have other people (for example co-workers, your church, a club or social group) who will be able to help you with your other responsibilities (for example: work, volunteer work, childcare, pet care, meal preparation, laundry, home maintenance and yard work)?

○ I do not have any other people who will be able to help with my other responsibilities. (1)

○ I have a few other people who will be able to help with my other responsibilities. (2)

○ I have some other people who will be able to help with my other responsibilities. (3)

○ I have a lot of other people who will be able to help with my other responsibilities. (4)

Q18 How much experience do you have helping someone else with daily activities like shopping, errands, taking to appointments, medications, banking, etc.?

○ I do not have any experience helping someone else with daily activities. (1)

○ I have less than one-month experience helping someone else with daily activities. (2)

○ I have at least one month but less than a year experience helping someone else with daily activities. (3)

○ I have a year or more experience helping someone else with daily activities. (4)

Q19 How willing are you to help the stroke survivor with daily activities such as shopping, errands, taking to appointments, medications, banking, etc.?

○ I am not willing to help the stroke survivor with daily activities such as shopping, errands, taking to appointments, medications, etc. (1)

○ I am willing to help the stroke survivor with a few daily activities such as shopping, errands, taking to appointments, medications, etc. (2)

○ I am willing to help the stroke survivor with some daily activities such as shopping, errands, taking to appointments, medications, etc. (3)

○ I am willing to help the stroke survivor with a lot of daily activities such as shopping, errands, taking to appointments, medications, etc. (4)

Q35 How concerned are you about your ability to continue providing care for the stroke survivor for the next year?

○ I am very concerned about my ability to continue providing care for the stroke survivor for the next year. (1)

○ I am somewhat concerned about my ability to continue providing care for the stroke survivor for the next year. (2)

○ I am a little concerned about my ability to continue providing care for the stroke survivor for the next year. (3)

○ I am not concerned about my ability to continue providing care for the stroke survivor for the next year. (4)

Q20 Is there enough money available to pay for things not paid for by insurance, Social Security income, Workers compensation, In Home Support Services, or other benefits (for example medications, someone to help with personal care, medical equipment, shower chair, co-pays)?

○ We do not have money to pay for things not covered by insurance or other benefits. (1)

○ We have a little money to pay for things not covered by insurance or other benefits. (2)

○ We have some money to pay for things not covered by insurance or other benefits. (3)

○ We have enough money to pay for things not covered by insurance or other benefits. (4)

Q21 Will there be any accessibility problems for the stroke survivor getting around in the house or using the toilet or shower (for example, the width of doorways, stairs, ramp access) in the home where he/she will be living?

○ There will be a lot of accessibility problems for the stroke survivor in the home. (1)

○ There will be some accessibility problems for the stroke survivor in the home. (2)

○ There will be a few accessibility problems for the stroke survivor in the home. (3)

○ There will not be any accessibility problems for the stroke survivor in the home. (4)

Q22 Will you need to make any changes to the home (e.g. ramp, widen doors) to make it accessible?

○ A lot of changes need to be made to the home to make it accessible. (1)

○ Some changes need to be made to the home to make it accessible. (2)

○ A few changes need to be made to the home to make it accessible. (3)

○ No changes need to be made to make the home accessible. (4)

Q23 Is there enough money available to pay for the necessary changes to the home to make it accessible?

○ Not applicable-There are no changes necessary to make the home accessible. (4)

○ We do not have money to pay for the necessary changes to the home to make it accessible. (1)

○ We have a little money to pay for the necessary changes to the home to make it accessible. (2)

○ We have some money to pay for the necessary changes to the home to make it accessible. (3)

○ We have enough money to pay for the necessary changes to the home to make it accessible. (4)

Q24 Will the stroke survivor have accessible transportation (e.g. car that he/she can get in and out of, someone to drive, Paratransit, etc.) that he/she can use to go places (e.g. the doctor, grocery store)?

○ I am not certain if the stroke survivor will have accessible transportation that he/she can use to go places. (1)

○ I am a little certain that the stroke survivor will have accessible transportation that he/she can use to go places. (2)

○ I am somewhat certain that the stroke survivor will have accessible transportation that he/she can use to go places. (3)

○ I am very certain that the stroke survivor will have accessible transportation that he/she can use to go places. (4)

Q25 Do you regularly engage in activities to take care of your own health (for example exercise, doing things you enjoy, managing your stress and eating well)?

○ I don’t engage in activities to take care of my own health. (1)

○ I rarely engage in activities to take care of my own health. (2)

○ I sometimes engage in activities to take care of my own health. (3)

○ I regularly engage in activities to take care of my own health. (4)

Q26 Thinking over the past year, how much conflict have you had in your relationship with the stroke survivor?

○ We have substantial conflict between us. (1)

○ We have some conflict between us. (2)

○ We have a little conflict between us. (3)

○ We do not have conflict between us. (4)

Q33 How mentally prepared are you to be a caregiver?

○ I am not mentally prepared to be a caregiver. (1)

○ I am a little mentally prepared to be a caregiver. (2)

○ I am somewhat mentally prepared to be a caregiver. (3)

○ I am very mentally prepared to be a caregiver. (4)

Q29 What is the approximate yearly (annual) for everyone in your household before taxes?

○ Under $10,000 (1)

○ $10,000 to less than $20,000 (2)

○ $20,000 to less than $35,000 (3)

○ $35,000 to less than $50,000 (4)

○ $50,000 to less than $75,000 (5)

○ $75,000 to less than $100,000 (6)

○ $100,000 or more (7)

Q88 What is your sex?

○ Male (1)

○ Female (2)

Q31 What is your age?

- ○ 18-24 (1)
- ○ 25-34 (2)
- ○ 35-44 (3)
- ○ 45-54 (4)
- ○ 55-64 (5)
- ○ 65-74 (6)
- ○ 75-84 (7)
- ○ 85 or older (8)

Q33 Which of the following best describes your racial or ethnic background? Please check one.

○ Asian (1)

○ Black/African American (2)

○ White/Caucasian (3)

○ Hispanic (may be any race) (4)

○ Native American (5)

○ Other (6)

Q35 What is your relationship to the stroke survivor?

○ I am his/her Child (1)

○ I am his/her Friend (2)

○ I am his/her Spouse (3)

○ I am his/her Partner (4)

○ I am his/her Sibling (5)

○ I am his/her Parent (6)

Q37 What is your highest level of education completed?

○ Elementary (0 to 8 years) (1)

○ Some high school (1 to 3 years) (2)

○ High school graduate (4 years) (3)

○ Some college (1 to 3 years) (4)

○ College graduate (4 or more years) (5)

Preparedness for Caregiving Scale

Q37 How well prepared do you think you are to take care of his/her physical needs? Would you say you are?

○ Not at all prepared (1)

○ Not too well prepared (2)

○ Pretty well prepared (3)

○ Very well prepared (4)

Q39 How well prepared do you think you are to take care of his/her emotional needs? Would you say you are?

○ Not at all prepared (1)

○ Not too well prepared (2)

○ Pretty well prepared (3)

○ Very well prepared (4)

Q41 How well prepared do you think you are to find out about and set up services for him/her? Would you say you are?

○ Not at all prepared (1)

○ Not too well prepared (2)

○ Pretty well prepared (3)

○ Very well prepared (4)

Q43 How well prepared do you think you are for the stress of caregiving? Would you say you are:

○ Not at all prepared (1)

○ Not too well prepared (2)

○ Pretty well prepared (3)

○ Very well prepared (4)

Q45 How well prepared do you think you are to make caregiving activities pleasant for both you and your family member? Would you say you are:

○ Not at all prepared (1)

○ Not too well prepared (2)

○ Pretty well prepared (3)

○ Very well prepared (4)

Q47 How well prepared do you think you are to respond to and handle emergencies that involve him or her? Would you say you are?

○ Not at all prepared (1)

○ Not too well prepared (2)

○ Pretty well prepared (3)

○ Very well prepared (4)

Q49 How well prepared do you think you are to get the help and information you need from the health care system? Would you say you are:

○ Not at all prepared (1)

○ Not too well prepared (2)

○ Pretty well prepared (3)

○ Very well prepared (4)

Q51 Overall, how well prepared do you think you are to care for him/her? Would you say you are:

- ○ Not at all prepared (1)
- ○ Not too well prepared (2)
- ○ Pretty well prepared (3)
- ○ Very well prepared (4)

Perceived Stress Scale

Q53 In the last month, how often have you been upset

- ○ Never (1)
- ○ Almost never (2)
- ○ Sometimes (3)
- ○ Fairly often (4)
- ○ Very often (5)

Q55 in the last month, how often have you felt that you were unable to control the important things in your life?

- ○ Never (1)
- ○ Almost never (2)
- ○ Sometimes (3)
- ○ Fairly often (4)
- ○ Very often (5)

Q57 in the last month, how often have you felt nervous and “stressed”?

○ Never (1)

○ Almost never (2)

○ Sometimes (3)

○ Fairly often (4)

○ Very often (5)

Q59 In the last month, how often have you felt confident about your ability to handle your personal problems?

○ Never (1)

○ Almost never (2)

○ Sometimes (3)

○ Fairly often (4)

○ Very often (5)

Q61 In the last month, how often have you felt that things were going your way?

○ Never (1)

○ Almost never (2)

○ Sometimes (3)

○ Fairly often (4)

○ Very often (5)

Q63 In the last month, how often have you found that you could not cope with all the things that you had to do?

- ○ Never (1)
- ○ Almost never (2)
- ○ Sometimes (3)
- ○ Fairly often (4)
- ○ Very often (5)

Q65 in the last month, how often have you been able to control irritations in your life?

- ○ Never (1)
- ○ Almost never (2)
- ○ Sometimes (3)
- ○ Fairly often (4)
- ○ Very often (5)

Q67 In the last month, how often have you felt that you were on top of things?

- ○ Never (1)
- ○ Almost never (2)
- ○ Sometimes (3)
- ○ Fairly often (4)
- ○ Very often (5)

Q69 In the last month, how often have you been angered because of things that were outside of your control?

○ Never (1)

○ Almost never (2)

○ Sometimes (3)

○ Fairly often (4)

○ Very often (5)

Q71 In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

○ Never (1)

○ Almost never (2)

○ Sometimes (3)

○ Fairly often (4)

○ Very often (5)

PHQ-9

Q73 Over the last 2 weeks, how often have you had little interest or pleasure in doing things

○ Not at all (1)

○ Several days (2)

○ More than half the days (3)

○ Nearly every day (4)

Q75 Over the last 2 weeks, how often have you felt down, depressed or hopeless?

- ○ Not at all (1)
- ○ Several days (2)
- ○ More than half the days (3)
- ○ Nearly every day (4)

Q77 Over the last 2 weeks, how often have you had trouble falling or staying asleep, or sleeping too much?

- ○ Not at all (1)
- ○ Several days (2)
- ○ More than half the days (3)
- ○ Nearly every day (4)

Q79 Over the last 2 weeks, how often have you felt tired or had little energy?

- ○ Not at all (1)
- ○ Several days (2)
- ○ More than half the days (3)
- ○ Nearly every day (4)

Q81 Over the last 2 weeks, how often have you had a poor appetite or overate?

- ○ Not at all (1)
- ○ Several days (2)
- ○ More than half the days (3)
- ○ Nearly every day (4)

Q83 Over the last 2 weeks, how often have you felt bad about yourself- or that you are a failure or have let yourself or your family down?

○ Not at all (1)

○ Several days (2)

○ More than half the days (3)

○ Nearly every day (4)

Q85 Over the last 2 weeks, how often have you had trouble concentrating on things, such as reading the newspaper or watching television?

○ Not at all (1)

○ Several days (2)

○ More than half the days (3)

○ Nearly every day (4)

Q87 Over the last 2 weeks, how often have you moved or spoke so slowly that other people could have noticed. Or the opposite- been so fidgety or restless that you have been moving around a lot more than usual?

○ Not at all (1)

○ Several days (2)

○ More than half the days (3)

○ Nearly every day (4)

Q89 Over the last 2 weeks, how often have you had thoughts that you would be better off dead, or thought of hurting yourself?

- ○ Not at all (1)
- ○ Several days (2)
- ○ More than half the days (3)
- ○ Nearly every day (4)

Q91 Over the last 2 weeks, how difficult have problems made it for you to do your work, take care of things at home, or get along with other people?

- ○ Not at all difficult (1)
- ○ Somewhat difficult (2)
- ○ Very difficult (3)
- ○ Extremely difficult (4)

PROMIS Global Health

Q79 In general would you say your health is

- ○ Excellent (5)
- ○ Very good (4)
- ○ Good (3)
- ○ Fair (2)
- ○ Poor (1)

Q80 In general, would you say your quality of life is

- ○ Excellent (5)
- ○ Very good (4)
- ○ Good (3)
- ○ Fair (2)
- ○ Poor (1)

Q81 In general, how would you rate your physical health?

- ○ Excellent (5)
- ○ Very good (4)
- ○ Good (3)
- ○ Fair (2)
- ○ Poor (1)

Q82 In general, how would you rate your mental health, including your mood and your ability to think?

- ○ Excellent (5)
- ○ Very good (4)
- ○ Good (3)
- ○ Fair (2)
- ○ Poor (1)

Q83 In general, how would you rate your satisfaction with your social activities and relationships?

○ Excellent (5)

○ Very good (4)

○ Good (3)

○ Fair (2)

○ Poor (1)

Q84 In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)

○ Excellent (5)

○ Very good (4)

○ Good (3)

○ Fair (2)

○ Poor (1)

Q89 In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)

○ Excellent (5)

○ Very good (4)

○ Good (3)

○ Fair (2)

○ Poor (1)

Q85 In the past 7 days how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

○ Never (5)

○ Rarely (4)

○ Sometimes (3)

○ Often (2)

○ Always (1)

Q86 How would you rate your fatigue on average?

○ None (5)

○ Mild (4)

○ Moderate (3)

○ Severe (2)

○ Very severe (1)

Q87 How would you rate your pain on average?

○ 0 No pain (5)

○ 1 (4)

○ 2 (4)

○ 3 (4)

○ 4 (3)

○ 5 (3)

○ 6 (3)

○ 7 (2)

○ 8 (2)

○ 9 (12)

○ 10 Worst imaginable pain (1)

FIM™ Instrument

DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTER FOR MEDICARE & MEDICAID SERVICES

OMB No. 0938-0842

Function Modifiers*

Complete the following specific functional items prior to scoring the FIM™ Instrument:

	Admission	Discharge
29. Bladder Level of Assistance (Score using FIM Levels 1 - 7)	☐	☐
30. Bladder Frequency of Accidents (Score as below)	☐	☐

7 - No accidents
6 - No accidents; uses device such as a catheter
5 - One accident in the past 7 days
4 - Two accidents in the past 7 days
3 - Three accidents in the past 7 days
2 - Four accidents in the past 7 days
1 - Five or more accidents in the past 7 days

Enter in Item 39G (Bladder) the lower *(more dependent) score from Items 29 and 30 above*

	Admission	Discharge
31. Bowel Level of Assistance (Score using FIM Levels 1 - 7)	☐	☐
32. Bowel Frequency of Accidents (Score as below)	☐	☐

7 - No accidents
6 - No accidents; uses device such as a ostomy
5 - One accident in the past 7 days
4 - Two accidents in the past 7 days
3 - Three accidents in the past 7 days
2 - Four accidents in the past 7 days
1 - Five or more accidents in the past 7 days

Enter in Item 39H (Bowel) the lower (more dependent) score of Items 31and 32 above.

	Admission	Discharge
33. Tub Transfer	☐	☐
34. Shower Transfer	☐	☐

(Score Items 33 and 34 using FIM Levels 1 - 7; use 0 if activity does not occur) *See training manual for scoring of Item 39K (Tub/Shower Transfer)*

	Admission	Discharge
35. Distance Walked	☐	☐
36. Distance Traveled in Wheelchair	☐	☐

(Code items 35 and 36 using: 3 - 150 feet; 2 - 50 to 149 feet; 1 - Less than 50 feet; 0 – activity does not occur)

	Admission	Discharge
37. Walk	☐	☐
38. Wheelchair	☐	☐

(Score Items 37 and 38 using FIM Levels 1 - 7; 0 if activity does not occur) See training manual for scoring of Item 39L (Walk/Wheelchair)

39. FIM™ Instrument*

	Admission	Discharge	Goal
SELF-CARE			
A. Eating	☐	☐	☐
B. Grooming	☐	☐	☐
C. Bathing	☐	☐	☐
D. Dressing - Upper	☐	☐	☐
E. Dressing - Lower	☐	☐	☐
F. Toileting	☐	☐	☐
SPHINCTER CONTROL			
G. Bladder	☐	☐	☐
H. Bowel	☐	☐	☐
TRANSFERS			
I. Bed, Chair, Wheelchair	☐	☐	☐
J. Toilet	☐	☐	☐
K. Tub, Shower	☐	☐	☐
	W - Walk C - Wheelchair B - Both		
LOCOMOTION			
L. Walk/Wheelchair	☐ ☐	☐ ☐	☐
M. Stairs	☐	☐	☐
	A - Auditory V - Visual B - Both		
COMMUNICATION			
N. Comprehension	☐ ☐	☐ ☐	☐
O. Expression	☐ ☐	☐ ☐	☐
	V - Vocal N - Nonvocal B - Both		
SOCIAL COGNITION			
P. Social Interaction	☐	☐	☐
Q. Problem Solving	☐	☐	☐
R. Memory	☐	☐	☐

FIM LEVELS

No Helper
7 Complete Independence (Timely, Safely)
6 Modified Independence (Device)
Helper - Modified Dependence
5 Supervision (Subject = 100%)
4 Minimal Assistance (Subject = 75% or more)
3 Moderate Assistance (Subject = 50% or more)
Helper - Complete Dependence
2 Maximal Assistance (Subject = 25% or more)
1 Total Assistance (Subject less than 25%)

0 Activity does not occur; Use this code only at admission

- The FIM data set, measurement scale and impairment codes incorporated or referenced herein are the property of U B Foundation Activities, Inc. ©1993, 2001 U B Foundation Activities, Inc. The FIM mark is owned by UBFA, Inc.

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