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Donna Pawlowski  
[donna.pawlowski@bemidjistate.edu](mailto:donna.pawlowski@bemidjistate.edu)

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# Communicating the Significance of Home: Stroke Survivors and Caregivers Share their Stories

**Donna Pawlowski**

Professor of Communication Studies

Bemidji State University

[donna.pawlowski@bemidjistate.edu](mailto:donna.pawlowski@bemidjistate.edu)

## Abstract

*The goal of this qualitative study was to examine how stroke survivors and caregivers communicated the significance of home in the short-term transition from hospital discharge to home care. Narratives from 12 stroke survivors and their caregivers produced five themes: marker events as motivation, comfort of home and family, emotional privacy of home, excited anticipation of going home, and nervous preparation for home. While much of the communication focused on the positive and hopeful recovery of stroke survivors upon going home, caregiver preparedness and the modifications to home impacted physical and emotional recovery. Results have implications for the transactive model of person-environment relationships, narrative theory, gendered care, health care practitioners, and the continued need for stroke research.*

**Keywords:** *Health Communication, Meaning of Home, Stroke Survivor, Stroke Caregiver, Short-term Stroke Rehabilitation, Narrative Theory*

Regardless of one's health, one thing is evident; strokes randomly choose their "targets." Stroke is the fifth leading cause of death behind diseases of the heart, cancer, accidents, and chronic lower respiratory diseases (American Stroke Association, 2018; Center for Disease Control, 2018), as well as the primary source of disability in the home (Klinke, Hafsteinsdottir, Thorsteinsson, & Jonsdottir, 2013; Stineman et al., 2014). According to new statistics from the

American Stroke Association (2018), someone in America suffers a stroke every 40 seconds, and approximately 800,000 suffer a new or recurrent stroke annually.

Up to 80-85% of stroke survivors return to the home post-discharge (Anderson & Whitfield, 2012; Stineman et al., 2014), and rely on family members for home rehabilitation (Cecil, Thompson, Parahoo, & McCaughan, 2012; Egbert, Koch, Coeling, & Ayers, 2006; Ghazzawi, Zuziemsky, & O'Sullivan, 2016; Kitzman, Hudson, Feltner, & Lovins, 2017). Caregivers and practitioners realize the goal is to send stroke survivors home to rehabilitate and regain functioning. This recovery process is difficult as stroke families experience unfamiliar territory (Brunborg & Ytrehus, 2013; Lopez-Espuela et al., 2018; O'Sullivan, Ghazzawi Hon, Stanek Hon, & Lemyre, 2012; Kitzman et al., 2017). Research has examined the various aspects of transition from the rehabilitation facility to home regarding the process of, or quality of life after discharge (Brunborg & Ytrehus, 2013; Ellis-Hill et al., 2009; Moeller & Carpenter, 2013; Rachpukdee, Howteerakul, Suwannapong, & Tang-aroonin, 2013; Stineman et al., 2014), and the role of caregiving (Brann, Himes, Dillow, & Weber, 2010; Cecil et al., 2012; Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014; Tsai et al., 2018). The focus of this particular research is to examine the personal significance of going home through the narratives of both stroke survivors and caregivers.

Understanding how stroke survivors and caregivers communicate their experiences during this acute shift in life can help health practitioners prepare stroke families for the transition from rehabilitation centers to home, and act on the patient's behalf in providing necessary resources for this transition. Going home is one of the first steps for stroke survivors, where uncertainty abounds concerning physical place, emotional and physical well-being, and potential changes in relationships. This transition is successful if patients feel like they are being

heard and their needs are being met. If not, patients may lack the social support necessary, affecting their overall emotional and physical recovery. As noted by Harter (2009), “humans reach for storytelling when trying to make sense of expectations gone awry” (p. 141). Listening to and learning from survivors’ and caregivers’ stories can help individuals process and make sense of this new meaning of home in this life-altering transition and help practitioners provide appropriate survivor-centered care.

Given the pervasiveness of strokes and the prevalence of home caregiving, the goal of this project is to gain a better understanding of how survivors and caregivers communicate the significance of “home” during this life transition. Research has investigated the importance of home for stroke survivors; however, those methods specifically asked about such transitions to home (Marcheschi, Von Koch, Pessah-Rasmussen, & Elf, 2018; Olofsson, Andersson, & Carlberg, 2005). The uniqueness of this project is that home emerged as a theme from a larger data set, rather than a priori, and thus, warranted special attention. Also, this data reflects both the survivors’ and their caregivers’ meaning of home. In examining this phenomenon, this literature review will provide an examination of the transition to home for survivors and caregivers, explain the transactive model of person-environment relationships, offer the narrative theory as conceptual grounding, and identify the research question that guides this project.

### **Literature Review**

As a stroke occurs instantly, individuals are put into a position of uncertainty. Survivors literally are trying to survive, and caregiving happens without warning or preparation. The uncertainty of stroke damage necessitates the importance of productive communication among the family members and health care partners to give the best quality of health care for the stroke survivor. Primarily, survivors and caregivers are concerned with physical activities of

daily living and cognitive issues of the survivor during medical interviews (Cecil et al., 2012; Nussbaum, Pecchioni, Grant, & Folwell, 2000) while still in a hospital or rehabilitation center. Health care providers try to provide the best preparation possible for the transition to home, but often the readiness of the survivor overshadows the preparedness of the caregiver.

### **Transitioning to Home**

Once survivors are assured enough stability, early supported discharge to home is a preferred method of rehabilitation rather than long-term conventional care in rehabilitation centers (Taule, Inger Strand, Sture Skouen, & Raheim, 2015). Research reporting short-term transition typically ranges from discharge up to six months, though some research (Ellis-Hill et al., 2009; Ogunlana et al., 2014; Rachpukdee et al., 2013; Silva-Smith, 2007) extends to two years from the time of stroke onset.

While survivors prefer home care, this transition to home is stressful. According to Palmer, Glass, Palmer, Loo, and Wegener (2004), stroke survivors and their families face a *double crisis*: the physical and emotional aspects of the stroke itself, and the need to create an effective health care system that requires rapid adaptation. In the initial discharge phase, communication between health providers, survivors, and caregivers is critical to provide a smooth transition. Taule et al. (2015) examined stroke families concerning early discharge and discovered that better communication and appropriate emotional support for recovery need to occur with all stakeholders to prepare patients to adapt to home rehabilitation. Based on their results, they call for more open-ended communication with patients and more focus on individual needs during this transition from hospital to home.

As noted, this transition from hospital to home “is associated with substantial emotional, social and health-related challenges” (Reeves et al., 2017, p. 2), and has been recognized as a

period of great significance and uncertainty (Chen, Chair, & Chau, 2014; Brauer, Schmidt, & Pearson, 2001; Ellis-Hill et al., 2009; Lopez-Espuela et al., 2018; Snape & Burton, 2002). These uncertainties affect both survivors and caregivers. For the survivor, “returning home after a stroke is a challenging experience for patients who struggle to adapt to their new life conditions because of physical disabilities, stress, depression, cognitive impairment and reduced quality of life” (Simeone, Savin, Cohen, Alvaro, & Vellone, 2014, pp. 1-2). These conditions create questions for survivors of going back to work, participating in regular activities, and engaging in regular social network opportunities (Lutz et al., 2017; Reid, 2004). Taule and Raheim (2014) indicate that “change and disruption of life becomes more obvious for patients once they return home” (p. 2108). It is then that survivors realize the loss of independence, increased fatigue, and restrictions in their social activities. Also, several changes take place regarding the structure of time. As survivors’ daily activities fluctuate, activities take longer to complete (Rittman et al., 2004; Simeone et al., 2014), which impacts what and how much one can accomplish concerning necessity activities versus time for pleasure. In the short-term, the overall abilities of the survivor are tested, socially challenged, and time-intensive.

While the survivor faces challenges, caregivers also experience physical, emotional, and psychological health issues (Lutz et al., 2017; Wittenberg-Lyles, Washington, Demiris, Oliver, & Shaunfield, 2014). Becoming a caregiver for a stroke survivor is a sudden role compared to caregiving for other progressive illnesses, and individuals feel ill-prepared for providing quality care to the survivor (Baumann, Le Bihan, Chau, & Chau, 2014; Cameron & Gignac, 2008; Lutz et al., 2017). The primary caregiver is typically a family member, and often the spouse (Lopez-Espuela et al., 2018; Olivier, Phillips, & Roy, 2018). In many instances, performing the necessary physical activities to care for the survivor is difficult. For example, caregivers may

need to help survivors with daily living and rehabilitation needs (e.g., transfers, feeding, grooming, helping with physical therapy exercises for the patient) (Alpert & Womble, 2015; Lutz et al., 2017). Household responsibilities, supervision, driving, and shopping often also become caregivers' sole responsibility (Alpert & Womble, 2015; Hellgeth, 2002; Palmer & Glass, 2003). In many instances, with traditional married couples, role reversal responsibilities of outside yard work or domestic tasks of cooking and cleaning also create new skill sets for the caregivers (Pawlowski, 2006). This new role becomes more difficult as the couple enters elderly stages of life and physical ailments of the caregivers may interfere with the stamina and ability for daily routines.

Like survivors, caregivers may have to give up or limit employment to take care of the survivors' needs (Braithwaite & McGown, 1993; Menon & Pradesh, 2017). As such, neither the survivors nor caregivers can contribute to additional income at a time when financial contributions are needed to pay for rehabilitation therapy and medical bills. Due to these additional responsibilities and anxieties, caregivers report a decrease in physical and emotional well-being (Wittenberg-Lyles et al., 2014).

Despite the challenges, a successful transition to home is critical for positive rehabilitation. Olofsson et al. (2005) interviewed stroke survivors about their experiences of the hospital, coming home, and follow-up appointments. They discovered that "the yearning to come home overshadowed everything else, and the patients saw it as an important factor for their recovery" (p. 437). According to Marcheschi et al. (2018), the home setting facilitates an attachment with place, and when individuals feel connections to home, it positively impacts their quality of life. Regardless of the physical or psychological restrictions of one's life during short-

term transitioning, the home provides a “safe harbor” (Marcheschi et al., 2018) of familiar and comfortable surroundings.

Pringle, Hendry, and McLafferty (2008) reviewed 28 studies related to the transition of stroke survivors to their homes. They discovered that studies focused primarily on the “rehabilitation and adjustment process”; however, “none had a specific focus of examining the impact that arriving home had on the participants” (p. 2394). They concluded that additional research concerning survivors' and caregivers' perspectives on how individuals feel about returning to their homes and community is needed.

### **Transactive Model of Person-Environment Relationships**

Home seems to be essential for stroke families, but what is it about home that has such a connection for stroke survivors and caregivers, and how do individuals communicate this importance? One model that may help examine this connection is the transactional framework of understanding person-environment relationships (Oswald & Wahl, 2005; Tanner, Tilse, & de Jonge, 2008). The theoretical grounding for this model has primarily been in environmental psychology and environmental gerontology about understanding older adult housing needs and home modifications (Oswald & Wahl, 2005). Scholars have identified three dimensions that reflect elders' meaning of home: physical, social, and personal (Bigonnesse, Beaulieu, & Garon, 2014; Meijering, Nanninga, & Lettinga, 2016; Oswald & Wahl, 2005; Tanner et al., 2008). While elder care and housing needs have been the focus of much of this research, scholars have used variations of this model (Law et al., 1996; Meijering et al., 2016; Wong & Leland, 2018) in health care contexts with dementia care patients and stroke survivors.

Overall, within these dimensions, home is an experience that happens within a temporal framework. As Tanner et al. (2008) state, “people’s relationships with their homes have histories,



futures, recurrences, and rhythms that affect their current experience and meaning” (p. 199). Rather than seeing these dimensions as isolated instances in individuals’ lives, people’s behaviors are interdependently influenced by context, time, and physical and psychological characteristics (Law et al., 1996). Within occupational therapy, Law et al. (1996) state that a transactional approach is valuable because it considers “that a person’s contexts are continually shifting and as contexts change, the behaviour necessary to accomplish a goal also changes” (p. 10). As a communication phenomenon, this transactional model could be useful when examining health communication among physicians and patients, in particular for stroke families where their life’s contexts are continuously changing.

The first dimension is the physical dimension, which consists of the physical aspects of the home, the brick and mortar so to speak, with the layout of the home and its history for those who dwell in it (Tanner et al., 2008). This physical dimension also provides the functionality for individuals and allows for the comfort and safety of being in the home to perform routine activities and rituals (Tanner et al., 2008). How people are able to maneuver within their space impacts their independence and overall relationship with the physical place to carry out such daily activities.

Stroke survivors function differently in clinical settings than in their own homes. Clinical and rehabilitation facilities are built to accommodate survivors’ movements with larger physical spaces and everything being all one level, whereas survivors discover physical limits upon being back home (Meijering et al., 2016). Thus, while home allows stroke survivors to get back to routines and rituals (e.g., bathing, eating, getting dressed) (Meijering et al., 2016), it also can create restraints in one’s mobility (e.g., wheelchair accessibility, hand railings, bathtubs, stairs). When the body is physically altered and no longer able to act as it once did, alterations to the

home are usually necessary to accommodate a survivor's mobility for accessibility and safety (Bigonnessee et al., 2014). If modifications are appropriate, the physical home creates a comfort level for positive recovery for survivors who need to feel safe and have a sense of independence in their own homes.

Second, the social dimension reflects one's sense of connection with, as well as the privacy that one feels in the home (Bigonnessee et al., 2014). This connection can come from relationships and others in the surrounding community who provide social and emotional support and informal care when needed (Meijering et al., 2016). For the stroke survivor, this support comes primarily from the caregiver. Bigonnessee et al. (2014) indicate that this social dimension includes the roles (e.g., parent, grandparent, husband) one plays in the home, as home is the place where people "gather and experience continuity in their social roles" (p. 370). We connect with others based on who we are in the family unit and the space we use to carry out those roles in the home.

Third, the personal dimension refers to how the home becomes a place of self-expression and sense of identity, which can include behavioral, cognitive, and emotional aspects one attaches to home (Bigonnessee et al., 2014; Tanner et al., 2008). How people perceive themselves with physical routines, activities of daily life, personal security, and familiarity of self to home are part of this personal dimension. Bigonnessee et al. (2014) state that for older adults, there is a sense of pride and joy in taking care of one's home.

In the case of a stroke, "survivors abruptly face huge changes in their identity, and struggle to accommodate their changed selves in an unchanged house, which does not feel like home anymore" (Meijering et al., 2016, p. 36). For example, caregivers may need to help survivors with daily living needs, which may alter the survivors' sense of independence within

one's own home. Survivors experience a "potential gap between their desired and actual roles, which require them to learn how to live in a changed state and with a new sense of identity" (Marcheschi et al., 2018, p. 2). Within the first three months, survivors experience overwhelming emotions "due to unaccustomed restrictions, loss of freedom and abilities, and difficulty in relating to others" (Taule & Raheim, 2014, p. 2108). Such changes in identity impact one's personal life as well as their communicative and personal relationship with others. If survivors do not feel like themselves in their own home, others are inherently affected by their changed behaviors.

While this personal dimension impacts the stroke survivor, changes also occur in the caregiver's identity. As noted above, performing additional daily physical activities is not typical for caregivers. In addition to helping survivors with their physical needs in the home, other household domestic responsibilities such as driving or shopping may become the primary responsibilities of the caregiver (Hellgeth, 2002; Palmer & Gass, 2003). For example, with an older traditional couple, the survivor husband may have been primarily responsible for the outside yard work, something in which the wife may not have much experience but may now be expected to perform. Similarly, if the survivor wife is the one to take care of domestic tasks of cooking and cleaning typically, the husband may need to learn new skills in addition to general physical caregiving (Pawlowski, 2006). This newly identified role alters the familiarity and control of the physical environment.

It is important to understand how people are affected by their homes when their lives have been altered. Research often focuses on the physical modifications sought by professionals to make the home safe, but the home has significant meaning for stroke families. Also, research has focused primarily on the stroke survivor, with a specific goal of asking about the meaning of

home. This research project taps into an undeveloped area of research, to obtain emergent narratives from both the survivor and the caregiver in how they communicate the importance of home.

### **Narrative Theory as Conceptual and Methodological Foundation**

One of the best ways to understand the experiences of stroke families is through the narratives of those who live it. Communication scholars (Brann et al., 2010; Brunborg & Ytrehus, 2013; Egbert et al., 2006; Harter, 2013; Kirkevold, Martinsen, Bronken, & Kvigne, 2014; Martinsen, Kiekevold, & Svern, 2012) use narratives to reveal the storytellers' emotional and cognitive journeys through their recovery process, as it provides the richness of lived experiences of participants. Faircloth, Boylstein, Rittman, and Gubrium (2005) explain narrative as looking at strokes "through the act of telling a story and the varied ways in which the event is communicated" (p. 929). Throughout her overview of patients' needs, Thompson (2000) argues that to understand patients, asking open-ended and reflective questions will allow patients to communicate emotional and content-level concerns. Also, Harter and Bochner (2009) emphasize the importance of narrative theory and methodologies: "As assumptions of scientific methods prove limiting in understanding the human condition, scholars across disciplines have turned to narrative as an organizing framework for studying and showing how meaning is performed and negotiated" (p. 113). Narrative-based research allows participants to extend beyond the biomedical to communicate the psychosocial aspects of their lives through storytelling (Brunborg & Yrehus, 2013; Griggs, 2010; Miller & Crabtree, 1992).

The narrative approach also is being recognized by health care professionals (Charon, 2001). Harter and Bochner (2009) argue that healthcare providers realize the advantages of exploring the narratives of patients to help with treatment, and to understand patients' suffering.

Typical training for physicians is in the biomedical aspect of patients, but taking a holistic approach to a patient through patients' narratives is a necessity for physicians to "gain a deep and essential understanding of the whole-life meanings and impacts of illness in their lives" (Wheeler Cardillo, 2010, p. 527). Harter (2009) further argues that health care is not possible without understanding the lived experience of others through narrative. She states that narrative theory and methods are important "for the way we study, talk about, organize around, and otherwise perform health and health care" (p. 141).

Narrative medicine, as developed by Charon (2001), states that physicians need to perform narrative tasks of understanding patients through communication, genuine dialogue, and listening, otherwise the patient "might not tell the whole story, might not ask the most frightening questions, and might not feel heard" (2001, p. 1899). The result of this could be a misdiagnosis, more expense, noncompliance, seeking other opinions, and unproductive relationships with health care providers. This whole story needs to include more than what is happening in the present time with patients. Patients need to attach meaning to their lives by temporally organizing and understanding disparate events in their lives (Harter, 2009). Burke (1954/1984) states that we use narratives to examine circumstances and try to make sense of our lives, and our moments of struggle. Thus, patients need to share their story by connecting moments in their lives from what they know, to their current state of being, to their hopes with what could be in the future.

Critical to storytelling as sensemaking is the distance in time between actions and the "telling" of the story (Thompson, 2000). Asking individuals to reflect upon their illnesses in retrospect helps them to interpret events and actions, and to make links that they could not have done in real-time. For stroke survivors, real-time during the crisis mode itself focuses on

immediate issues (Pawlowski, 2006). Thus, retrospective accounts are valid data because they represent what the event has come to mean to the storyteller.

Given this review of the literature, the following research question was employed to investigate the importance of home for stroke survivors and their caregivers who experienced the short-term recovery process:

RQ1: How do stroke survivors and caregivers communicate the significance of home during short-term recovery?

## **Methodology**

### **Participants**

Twenty-four individuals consisting of 12 survivors (2 women and 10 men) and their spousal caregivers (2 men and 10 women) participated in the study. I sought out participants through a volunteer network sampling method, a method used when respondents are difficult to obtain, information-rich cases are needed, or both (Baxter & Babbie, 2004). Volunteers for this study were survivors and caregivers from the community and obtained for information-rich data. The first few participants were referrals from pilot participants, who in turn were asked to provide additional names of others who experienced strokes. Thus, I used a purposeful sampling method to obtain participants (Lindlof & Taylor, 2002). In some instances, participants contacted the referral families first to make a personal connection before I contacted them as additional participants.

To qualify for the study, participants had to meet three specific criteria. First, caregivers had to be the sole caregiver for a stroke survivor since the time of the stroke. Second, stroke survivors had to have undergone hospitalization and rehabilitation (e.g., speech, occupational,

and physical) therapy. Third, the onset of the first stroke had to be at least two years prior to the interview, which allowed participants to communicate retrospectively.

Regarding demographics, individuals ranged from 54 to 79 with a mean of 63 years of age. The time frame from the stroke onset was 3 to 20 years, with over half being post ten years. All participants were married (first-time marriages for all couples) 22 to 59 years. Stroke survivor occupations before the health conditions varied and included homemakers, mechanics, factory workers, construction workers, bankers, farmers, health care workers, business/salespersons, and railroad engineers. While a few individuals were technically “retired” from their professions, all remained active on the farm, in their communities, or were still involved in the business at some level. Post-stroke, all survivors had to give up their occupations, or significantly reduce the capacity in which they carried out their professions. Caregiver occupations included homemakers, librarians, farmers, secretaries, social workers, real estate agents, and school teachers. Those who labeled themselves as “homemakers” also had additional temporary or part-time jobs throughout their lives. All caregivers were full-time spousal caregivers, and many had to alter employment to become a caregiver. None of the families had other family members living with them at the time of the research.

Ten of the 12 pairs came from rural farming communities where the health care facilities were over 60 miles from the survivor’s residence. Participants resided in their own homes, but many homes needed to be adapted or remodeled for increased physical mobility and accessibility. All survivors had some permanent paralysis, as a result of the stroke. Also, while some had slight speech problems (i.e., slurring, repeating, stuttering), all individuals had the cognitive ability to understand and respond clearly to the questions.

## **Methods and Procedures**

After institutional review board approval, I contacted individuals via telephone or in person and asked them to participate in the study. I met in the homes of the participants, a meeting time and place of convenience chosen by the interviewee. Survivors and caregivers were interviewed independently and asked a series of open-ended questions. All interviews were audiotaped. A guided interview protocol enabled me to understand participants' experiences and perceptions of stroke recovery (Creswell, 2012; Strauss & Corbin, 1998). Questions guided the participants through topics that included the initial onset of the acute incident, hospitalization and rehabilitation, temporary and permanent physical conditions, emotional issues, caregiving issues, communication with family members, changes in the family functioning, and difficulties and successes of their conditions.

The interview protocol was pilot-tested with three individuals to ensure accuracy and understandability of questions. Individuals in the pilot study also experienced strokes, thus were similar in the project criteria. I solicited participants for the project after making minor changes in the protocol. The actual data analysis did not include pilot-tested individuals.

## **Data Analysis**

Participants were assigned an identification number and pseudonym to protect their privacy. Audiotaped interviews were transcribed verbatim, checked for accuracy, and edited. Interviews ranged from 45 minutes to three hours in length, ranging from 35 to 97 pages in length with an average of 60 single-spaced pages of transcribed data resulting in a total of 1474 pages of transcriptions. Using steps in constant comparative thematic analysis (Braun & Clarke, 2006; Schreier, 2012; Strauss & Corbin, 1998; Thomas, 2006), I first read transcripts while listening to the tape recordings to gather a more familiar and holistic view of the participants'



experiences. As Braun and Clarke (2006) state, “it is ideal to read through the entire data set at least once before you begin your coding ... identification of possible patterns will be shaped as you read through” (p. 16). As previously noted, upon this initial analysis, the notion of home became prevalent enough to warrant individual analysis, and was the focus for further analysis.

Second, I began a close re-reading of the transcripts, creating initial codes for analysis, which consisted of identifying features of the data that seem interesting or meaningful. As such, excerpts of transcripts (or narratives) were bracketed out and labeled with the essence of the statement. Often items get coded and re-coded as potential patterns emerge, which is employing the method of constant comparison. Coding can be with the entire data set, or particular features of the data (Braun & Clarke, 2006). For this particular project, coding continued by identifying the patterns from participants related to the notion of home. The result of this coding was a list of different codes that had “patterns, and relationships between them” (p. 19), and helped to organize data into meaningful and emerging groups or categories.

Third, I finalized the categories. This step involves sorting and combining coded excerpts from the narratives into potential categories, which became themes to capture the meaning of home for the participants. As such, I collated and checked relevant excerpts for each theme against each other for coherency, consistency, and distinctiveness (Braun & Clarke, 2006; Strauss & Corbin, 1998). Overall, sorting the codes illuminated five separate themes.

Finally, I created names for each theme, capturing the essence of what each represented in the narrative. The overall goal was to create a thematic story about communicating the importance of home for the participants. To ensure accurate perceptions of data and achieve methodological rigor (Baxter & Babbie, 2004; Creswell, 2012), member checks were conducted

independently with three survivors and three caregivers, who confirmed the accuracy of the interpreted themes.

## **Results**

The research question examined how stroke survivors and caregivers communicate the short-term significance of home. Data coding uncovered five substantive themes of what home meant for survivors and caregivers: marker events as motivation, comfort of home and family, emotional privacy of home, excited anticipation of going home, and nervous preparation for home. It is interesting to note that while overall themes emerged, communicating the notion of home was an essential piece of participants' narratives. Brief references using "home" almost reflected a sense of peace and comfort for participants. Over 60 phrases such as "he's home," "I'm going home," "to be home again," "stay home," "I'm finally home," "it's good to be home," "she'd be at home," "be home," "at home," among others, appeared throughout the narratives. Though the interviews were retrospective in nature, many participants spoke in the present tense, re-living the moments of their lives in their stories.

### **Marker Events as Motivation**

Survivors and caregivers referenced important events related to family or daily functioning as the impetus of discharge for the survivor. Such events seemed to motivate the survivors to be home. One man communicated his need to be home for the holidays stating, "I just want to make it home for Christmas – I don't want the family to have to celebrate with ham at the rehab." Another female survivor stated, "My grandson graduates in two weeks – I want to be home for his graduation." One caregiver offered the following as the emergent need for the survivor to be home. She said,

I know our granddaughter was getting married in a few months, and I know he'd want nothing more than to be home to watch her walk down the aisle – that's what was driving him to work so hard to get home.

These marker points reflected individuals playing out the roles within the family unit, reflecting the social dimension. As Bigonnesse et al. (2014) noted, the place of home is where people gather and carry out roles. For participants, roles of being a grandparent for events in the home were important for survivors and caregivers. Attending weddings, graduations, and being visited by grandchildren were more meaningful when the survivor could be home or able to participate in such events.

Marker points also showed the necessity for accomplishing specific goals within one's life. As one survivor indicated, “And I, uh, I told them gals down there, I said, ‘You know,’ I says, ‘I really like this therapy.’ ‘Well, why’s that?’ ‘Well,’ I says, ‘When I’m done, I can drive home.’” For these participants, survivors soon discovered that during this short-term recovery, what was once an automatic routine became an exercise of re-learning how to complete daily rituals. These rituals, such as driving, marked the point at which the survivor could leave the rehabilitation center. Throughout the responses, there was some motivation for attending a particular event, or accomplishing a personal goal to make it home—it kept hope alive and gave survivors something to strive for in their recovery process.

### **Comfort of Home and Family**

Many survivors and caregivers mentioned the comfort of being home surrounded by family as support throughout the recovery process. According to one survivor, “My kids were too busy to come every day at the rehab, but they farm at home, so it's easier for them to just stop

by the house – I'm glad I'm back home." Another survivor noted, "There is nothing like being home with family to make you feel better."

For caregivers, one caregiver indicated, "It's nice to have him home; I feel safer when he is home even if he can't do everything he used to, it's just nice to have him home." Another caregiver wife stated, "Everyone is excited that he is home. The grandchildren were scared to go to the rehab but excited to be at home to see Grandpa. That's where they know Grandpa – home in his favorite rocking chair." A third caregiver noted, "I know family is the most important for him – just having the kids and grandkids around to visit with him will boost his spirits and give him the encouragement he needs to get better."

As most individuals were from rural areas, survivors and caregivers indicated their overall contentment of being home where family members are there for support and recovery. Home became the gathering place for family and loved ones to be together. As one survivor summed it up, "There is nothing like the comforts of home to boost your recovery."

Overwhelmingly, participants mentioned that just having the person home or being home would allow more time to be with family and promote a positive recovery. These results have implications for family social support, which is essential for coping and tending to physical and emotional needs of patients (Egbert et al., 2006; Pecchioni, Thompson, & Anderson, 2006; Taule & Raheim, 2014). Egbert et al. (2006) discovered that "what seemed to bridge the gap for the more well-adjusted SSs [stroke survivors] was the quality of their internal resources, developed as a function of communication from caregivers, friends, and family members" (p. 52). Support mentioned by participants focused on the caregiving and family relationships but did not include outside social networks during this short-term transition. It is possible that in the short-term

transition, the focus is on the immediate transition to home where the family is likely the front-line of communication.

### **Emotional Privacy of Home**

Some survivors wanted to be home to do things they were uncomfortable doing in the rehabilitation center. Some disclosed activities they felt were awkward or were not able to do in rehab because they perhaps found it embarrassing. One man stated,

I just want to rehab at home where I can bathe/shower in my own home where I know where things are and have my privacy. I know I need to be here, and they respect my privacy as much as possible, but I feel like I'm showering in the hallway for everyone to see.

For men, in particular, modesty was important. One male survivor felt embarrassed about getting emotional, where someone may see him expressing his feelings. He stated,

So then if I got a card, I'd just kind of look at it, read who it was from, and put it back in the envelope, I was too emotional to read it, so I done that to all the cards I got. I know strokes make you more emotional, but I thought I'd still wait until I got home, I was not used to showing my emotions so I waited until I was home to read my cards where no one would see me get emotional.

Caregivers also expressed their understanding of the need for privacy for their surviving family members. One caregiver explained, "I know it kills him to be in the rehab – he is such a private home-body; I'm sure he's trying everything he can do to come home."

Overall, survivors felt vulnerable with a loss of privacy and embarrassment of showing emotions in the rehabilitation center. As noted by Brann et al. (2010), this type of vulnerability is challenging as many stroke survivors struggle with their emotions. Individuals acknowledged

this vulnerability of emotions but wanted to wait to get home to a place where they could be themselves or show emotions in the privacy of their own homes. While only two women were survivors, only male survivors or female caregivers mentioned this theme. The male participants in this study are more traditional who may value privacy and limit the sharing of feelings in public settings.

### **Excited Anticipation of Going Home**

Sometimes the anticipation of getting home was not based upon the need to accomplish something, but just the excitement or hope of being able to go home. One female survivor exclaimed, “I’m tired of being here though I know I need to get better – but I can’t wait to get home again – I just can’t wait to be home.” Another male survivor stated, “I really was not sure if the day would come for me to go home. The power of prayer is an amazing thing – I hoped and prayed but could not believe I was really going home.”

Caregivers also felt the anticipation of their loved one coming home. One female caregiver stated the following:

Overwhelming. From the worst possible way that it could be with a bleeder to ‘Oh my God, he’s going to come home!’ I mean that was just incredible to watch the whole thing – I didn’t think he would ever be able to go home.

Another caregiver said, “I know they kept saying he will be able to come home, so I kept waiting for the good news. Finally, it came – I could not believe he was coming home.”

As Olofsson et al. (2005) discovered, for patients, wanting to come home overshadowed everything else. In this study, participants were grateful that the survivor could return home, and regardless of what lay ahead, getting home was paramount. Overall, this theme reflected statements of hope, thankfulness, and relief from both survivors and caregivers about the news of

going home. In some statements, participants demonstrated the resilience of strength and spirit when waiting for the news of the survivor coming home.

### **Nervous Preparation for Home**

While the above theme identifies excitement for being home, survivors and caregivers experienced the juxtaposed feeling of real and perceived anxiousness of preparing to go home, which was overwhelmingly the largest of the themes identified by participants. This uncertainty occurred due to medical and financial decisions, the lack of preparedness of the caregivers, the preparation of the physical house for the survivor's discharge, and relational uncertainty. One caregiver shares her concern for her husband going home and the frustration of the system coupled with a lack of financial and physical preparedness:

He was told he had to go home. When he went to the rehab he could not even hold his head up, and then the insurance company told him he had to go home after 90 days, we could not afford long-term care, so he had to come home...I could not believe they were making us leave. I don't know the first thing about caregiving – I could kill him! But I could not tell him that because he wanted to be home, so I just didn't tell him some things – we had to try to find other cheaper therapy. There was no point in getting him upset about money problems when his primary concern was just trying to get up to go to the bathroom. He just needed to get home first and then worry about the rest. But yeah – I was scared for him to come home.

In these instances, the caregiver had to make decisions without consulting the survivor. Some concerns were not even communicated with survivors, at least not in the immediate transition. As Pawlowski (2006) noted, caregivers who once could talk to the survivor about several topics may now share limited and surface-level information. Caregivers in this study did not want to worry

or upset the survivor with matters regarding relational issues or money problems, creating an internal tension for caregivers. Caregivers were conflicted with the delicate balance between a survivor's right to know versus the need to know regarding decisions made on behalf of the survivor.

Concerning preparedness, another caregiver stated,

I was so focused on getting him home that it didn't hit me what that meant until we were home. I felt so unprepared to be his caregiver, and now we were all alone at home. He is a bigger guy, and I have some health issues as well. I needed better preparation before I left the hospital for what would happen when we got home.

One male caregiver exclaimed his nervousness for caring for his loved one at home. This notion reflected lack of preparedness as well as lack of confidence and relational implications.

I am a little scared – I'm not a good cook – she has always taken care of the house while I was outside on the farm. She's going to be home in a wheelchair, and I'm going to have to ask her how to make supper. I'm afraid I will let her down with taking care of her, like I'm letting down the team.

For many, physical and emotional protection of the survivor was evident but created additional burden and emotional stress for the caregiver. Caregivers overall felt underprepared for taking care of their family member. While practitioners do their best to prepare survivors and caregivers for discharge, becoming a caregiver is a sudden role for most individuals, and caregivers typically feel ill-prepared for providing quality care to the survivor (Baumann, et al., 2014; Cameron & Gignac, 2008; Krishnan et al., 2017). As noted by these participants, unpreparedness was with physical care, domestic tasks, as well as emotional and relationship concerns. Thus, more than just immediate physical needs require attention in caregiver



preparation.

This realm of uncertainty and unpreparedness also was common among survivors. The preparation of going home created anxiousness for most, despite wanting to go home. A final notion of being nervous for the transition, which was frequently commented on from participants, included managing the physical space in the house. As one male survivor stated,

I was nervous to go back home, our bedroom is upstairs in an old farmhouse, and I knew there was no way I could make it up those stairs. The kids and neighbors helped to remodel the house quickly to get it ready for me downstairs, so the living room became my bedroom for a while – welcome home – just change your jammies in the picture window, but I was grateful everyone helped out so I could go home – really grateful!”

Overall, due to the acuteness of strokes, the home preparation creates great uncertainty associated with safety (Meijering et al., 2016; Taule & Raheim, 2014), as well as emotional concerns for survivors and caregivers. Participants in this study were concerned with accomplishing daily living needs and performing new roles. These concerns affected the role-identity changes of how each party would manage the balance between physical recovery and adapting to a modified home with modified responsibilities. Taule and Raheim (2014) discovered that it is challenging for survivors to balance the shift in roles, self-identity, and personal expectations.

With overall results, a particular pattern among themes was the juxtapositions, or tensions, experienced among participants. While survivor and caregiver felt similar tensions, a few nuances existed. For example, a tension existed between the positive excitement and motivations to go home, and the expressed feelings of uncertainty and unpreparedness from survivors and caregivers. Caregivers seemed to have more uncertainty of being prepared for the

survivor's homecoming. Also, the tension of sharing information, or keeping information from survivors emerged as more of a tension expressed by caregivers. While survivors are nervous about coming home, they may not realize the extent of internal tensions felt by the caregivers. Such tensions increase the emotional strain and may impact decisions taking place during this transitional period. Past research (Brann et al., 2010; Pawlowski, 2006) has examined dialectics and strategies for managing tensions among stroke caregivers and stroke survivors, respectively. The research concludes that many of these tensions are normative in the recovery process and should be shared with survivors and caregivers to reassure them that their feelings are common throughout this process. Health care professionals should also be aware of, and communicate, such tensions to individuals to help ease the uncertainty and prepare individuals for this home transition.

### **Discussion**

Overall, the goal of this article was to extend stroke recovery research by examining the significance of home communicated by stroke survivors and their caregivers during the short-term transition of stroke recovery. Five themes emerged from the data: marker events as motivation, comfort of home and family, physical and emotional privacy of home, excited anticipation of going home, and nervous preparation for home. The first four themes communicated patterns of motivation and hopefulness of being home. The final and most prevalent theme reflected the uncertainty and unpreparedness on the part of the caregiver and the survivor. Results and conclusions have theoretical, methodological, and practical implications for understanding the importance of home for stroke families.

## Theoretical Conclusions and Implications

**Transactive model of person-environment relationships.** First, results contribute to the transactive model of person-environment relationships by examining how the physical, social, and personal dimensions can be used more specifically in a health care context. The functionality of the physical dimension of home for the short-term transition was significant for survivors and caregivers. Crow (2018) and Cecil et al. (2012) indicate that in the short-term, survivors prioritize physical needs over psychological needs. The focus on immediate functioning for these survivors did take precedence but not without communicating concern for adept ability to care for the physical needs. Taule and Raheim (2014) also indicate that the effects of strokes for the survivor are more evident upon returning to home and realizing the extent of loss of freedom related to driving, hygiene, and daily activities. For these participants, they soon realized that accessibility and safety issues were apparent. The home required modifications before discharge, as well as after discharge, based on emergent lack of physical ability of survivor. Interestingly, modifications also had to be done because of the caregiver's lack of physical ability or health restrictions to help the survivor with daily activities. Implications of this dimension could include additional concern for the effects of the physical environment for both older survivors and caregivers. The functionality of the survivor is critical, but care and safety for the caregiver are just as vital.

Concerning the social dimension of home, placement of the survivor at home was important for family members fulfilling family roles. Going home meant more opportunities to be with family and play out the roles within the family unit. Survivors wanted to attend events or accomplish goals. One participant even noted that grandchildren were scared to visit the rehabilitation center, which created the motivation to get home. The goal is to recover in the

home (Taule et al., 2015), but limited research has identified the impetus or the motivation for going home. These results provide implications surrounding the motivation behind survivors wanting to go home. Health care providers could take more time to communicate with survivors and caregivers to seek out goals and the motivations in efforts to help guide the recovery process.

Related to the social dimension is the nature of emotional and physical support, and social needs being met for the survivor (Meijering et al., 2016). For these participants in the short-term transition, both emotional and physical support from family members emerged as being essential for recovery. While no participants mentioned support outside of the family during this transition, additional research suggests that social isolation from friends and external support networks is common for long-term stroke survivors (Egbert et al., 2006; Pawlowski, 2006). It would be interesting to note the timeframe in which this shift from family to external networks becomes apparent, or missed, by survivors in the recovery stages. At what point do survivors receive or want company from friends and social networks, and at what point do people stop coming by to visit?

In addition to survivors, caregivers also need support, as caregivers suffer from stress and emotional and physical well-being (Alpert & Womble, 2015; Lopez-Espuela et al., 2018; Wittenberg-Lyles et al., 2014). Within this short-term transition, some caregivers were concerned with their physical ability and unpreparedness to be a caregiver, though most of their stories had a focus on social support for the survivor. Being home and receiving support from family was necessary for the survivor, but caregivers were less concerned about support for themselves. Overall, more work in social support research within the social dimension could contribute to this immediate short-term transitioning to determine the timing of, and amount of, support needed for both survivors and caregivers.

Results also reflect the personal dimension. As noted, concerns of hurting their loved ones, physically and relationally, were personal to each participant. These concerns were different from just the physical home but focused on how being home impacted other aspects of their lives and daily routine. For some, it was difficult to let go of the domestic or outside activities; for others, it meant learning domestic responsibilities. For these participants, age may have added some to the concerns of their abilities. As noted, these new roles become more difficult as couples enter elderly stages of life (Pawlowski, 2006). Bigonnessee et al. (2014) also state that older adults take pride in taking care of their homes. For these elderly survivors and caregivers, they had concerns about fulfilling these prideful physical and domestic obligations. Not being able to do so was a loss of independence.

Overall, these conclusions have additional implications for this model. Prior research has been primarily in housing literature and lacks “the subjective meanings” connected to declining health and environmental challenges individuals face (Oswald & Wahl, 2005, p. 21). In this study, participants created personal meaning as they communicated their needs and apprehensions surrounding their changing health conditions and nervousness for going back home physically. Discovering these interconnections between the physical, social, and personal dimensions of home for both stroke survivors and caregivers demonstrate the heuristic application of this model beyond its original scope. Health care professionals could use this model to communicate more effectively with families in their preparation for this life transition.

**Narrative theory.** Second, we can draw conclusions and implications from the narrative theory. Participants engaged in sensemaking and rationalizing what was happening in their lives through narrative storytelling. As called for by Harter and Bochner (2009), Burke (1954/1984),

and Charon (2001), participants tried to make sense of the uncertainty in their lives through stories. While the safety of the survivor and the physical dimension were important for participants, additional information uncovered by participants' stories revealed particular needs far beyond the practical necessities or clinical observations. For example, survivors wanted to get back home but knew that passing a particular level of physical therapy was a determining factor and shared their motivation to reach that mile marker. For others, they described their need for privacy or explained why they were nervous for caregiving, or how they were feeling about effects on the relationship. Participants' narratives reflected a temporal sequence of events as they focused on the past, resilience to keep trying, authentic concern for transitioning to home, and anticipation for the future. Such underpinned feelings and emotions can only be identified by listening to others. Their stories were not bound in biomedical explanations but co-created as part of the whole story of their lived experiences.

These conclusions have implications for the continued need to use the narrative approach when working with health care patients. Using narratives and genuine communication with patients and their families could help practitioners and family members alike understand the concerns and needs of stroke survivors and caregivers. Participants might not have otherwise identified particular anxieties and motivations to be home without narrative approach. If we are to understand stroke families to prepare them for recovery and provide optimal social support, more qualitative research, and communicative medical narrative approaches by scholars and health practitioners, is warranted. We need to focus more on the whole person and see how they are connecting their past with their current motivation and experiences, as well as their hope for the future.

## Methodological Implications

Though not paired as partners, this research does examine both survivors and caregivers within the same study, and results indicate that survivors and caregivers, for the most part, were feeling similar perceptions. As Brann et al. (2010) argue, understanding whether survivors and spouses experience similar feelings can help increase relational functioning. Also, as called for by Gaugler's (2010) review of stroke research, this study examined the retrospective longitudinal experience of those in their environment rather than a clinically-generated population. This naturalistic approach may have encouraged participants to be more open and honest with their responses, as they were not in a hospital setting or connected to any clinical registry. The retrospective approach may have also led to more reflective responses (Creswell, 2012; Faircloth et al., 2005), as individuals were able to recall introspective memories they may not have otherwise been able to do in real-time in the clinical setting. Also, much of their communication was in present-tense language as if reliving the experience during the interview process.

## Practical Conclusions and Implications

**Gendered care.** Results also have implications for gendered care related to stroke. Emotional privacy was more important for men than women. Men stated that they did not want to express their emotions publicly in the health care facilities, but they appeared comfortable expressing their emotions privately during one-on-one research interviews. Also, while only two women survivors were in the study, only men mentioned the feeling of embarrassment when they were in the hospital or rehabilitation center. In addition, only women caregivers were concerned about their husbands' privacy. One explanation for these behaviors is the cultural and gendered enacted roles expected in society for how men and women display their feelings. Traditionally, men are socialized to be strong, independent, more physical, and suppress feelings

of weakness and emotion (Greenglass, 2001). Women are taught to express feelings and interpersonal needs and focus more on others in relationships (Greenglass, 2001). While these behaviors may not be as stereotypical in our contemporary society, this older traditional population, for the most part, adhered to these gendered role behaviors in expressing emotions.

When it came to specific caregiving behaviors, these participants had to enact opposite traditional roles and were apprehensive in carrying out duties. For example, women caregivers were apprehensive about physically helping, and caring for, their husbands with daily needs. Male caregivers were concerned with accomplishing domestic chores and letting down their partners about the emotional and relational side of care. Gendered differences did not emerge in any other themes. Both men and women seemed to have similar anticipations and motivations for going home.

Understanding these differences has implications in how to communicate with, and prepare stroke survivors and caregivers for the transition to going home. While following some traditional gendered roles and behaviors, we cannot assume such patterns exist across contexts. For example, as noted, men seemed willing to be open about and share their emotions in the research setting where they felt comfortable in their own homes but communicated their apprehension of exhibiting emotions in health care settings. It would be interesting to know whether men would be willing to share this information in typical clinical health-related appointments or whether this information is only shared in a more narrative medicine approach, as co-created one-on-one in these research interviews. Also, for caregiving, men and women felt high anxiety performing opposite gendered-role behaviors. Knowing these differences could lend itself to multiple methods of communication with stroke survivors to fully understand their needs and concerns.



**Health care professionals.** These results have additional practical communicative value for health care professionals regarding caregiver and home preparation for stroke families. Throughout the interviews, both survivors and caregivers indicated that they wished they had been asked more questions or given more clarity on the transition preparation. It is typical to talk with the survivor, but as caregivers have the unique perspective of knowing the stroke survivor best (Krishnan et al., 2017), they should be considered more fully in the health care decision-making process for the optimal outcome of the survivor. Communication between health care professionals and family members could include more emphasis on the personal and social dimension and preparation for home in this immediate short-term transition. Conversations related to home beyond the clinical and physical could more adequately motivate and prepare survivors and caregivers for going home.

### **Limitations and Future Research**

Though these data provide a new understanding of stroke recovery, limitations, and future research need to be addressed. First, while data came from survivors and partners from the same relationships, responses were not paired with each other. Direct analysis of such pairings would enhance understanding of the relational dynamics of recovery. Second, involving other family members in the research could enrich the process. Much of the research, including this study, focuses on survivors or caregivers, but limited research examines other familial relationships. Such research would perhaps help explain perceptions of others, and what others are experiencing regarding communication and relational functioning during recovery.

Given the nature of the data collection (via snowball referrals), this study included those from the same geographical, cultural, and gendered background. While purposeful for this study to include those in a rural setting, this study cannot generalize to other settings. Individuals also

were from the same cultural background. In many cultures, it is customary, and sometimes even expected, for family members to be the caregivers for family members. It would be interesting to learn if the same perceptions of home or immediate social support exist across different geographical and cultural boundaries. The participants were heterosexual, primarily male survivors and their respective married partners. Narratives from various gender identified participants would enrich our understanding of the lived experiences of stroke families.

Results also warrant future research. While research on the dimensions of home initially began for understanding older adult housing needs, these dimensions seem to have a direct connection for stroke survivors and caregivers. More work could be done to formalize this line of research in the various health communication contexts. Also, Metts and Asbury (2015) call for more emotion research within the family. They argue that emerging theoretical work on emotions is being done but “the role of communication in eliciting, managing, and expressing emotion is critical to our further understanding of family at all levels” (p. 51). With these survivors and caregivers, emotion played a role in self-identity and vulnerability of survivors. Marcheschi et al. (2018) also argue that research largely ignores this link between the personal emotional connection of home and the stroke survivor. Finally, the relational dialectical theory could be expanded to examine paired survivors and caregivers to further aid in understanding similar and different tensions among both survivors and caregivers collectively.

Overall, this research has examined the narratives of stroke survivors and caregivers about the importance of home during the short-term transition from a health care facility to going home. Though perceived as hopeful for recovery, this transitional period requires considerable physical and emotional adaption from the survivor and caregiver and has communication implications for healthcare teams in preparing families for going home. With the continued

increase of strokes each year, this research remains critical for scholars, health practitioners, and families.

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