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## Life after stroke in Appalachia



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### ABSTRACT

**Objective:** The purpose of this study was to describe the structure of meaning in the experience of surviving stroke for adults living in Appalachia.

**Methods:** This qualitative phenomenological study includes a sample of 6 adult survivors of ischemic stroke who were discharged from either a community or university hospital to home in the Appalachian region. Data was collected through semi-structured interviews, transcribed, and analyzed thematically by two investigators. The explicated themes were verified by the survivors as representative of their experience.

**Results:** Five main themes emerged: 1) Frustration with new physical and functional impairment, 2) Negative emotions including anger, guilt, loneliness, and depression 3) Need for accessible support, 4) Longing for home during recovery and, 5) Stepping forward after stroke which included sub-themes of perseverance, acceptance, and retraining. Anger was described as contributing to delayed recover and emotional lability was described as a source of anger. The familiarity of home was viewed as key to reestablishing control over one's life. Survivors described how they developed perseverance to move forward and emphasized that willingness to participate in retraining led to adapting to impairments. Acceptance was described as letting go of prior expectations of self and others so one could live in the present.

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### 1. Introduction

Cerebrovascular disease was reported as the fourth leading cause of death for females and for older adults, and the fifth leading cause of death for all age adult males in the United States in 2014 [1]. Nationally, from 1996 to 2006, the stroke mortality rate fell 33.5% and the actual number of stroke deaths declined 18.4% (NCHS, CDC). Current reports estimate that the prevalence of stroke will increase by 21.9% by 2030 [2] and with the improved stroke survival rates, there is the potential for an increased population of ischemic stroke survivors who will be potentially living with serious, long-term disability [3]. The median survival time (in years) following a first stroke is: at ages 60–69: 6.8 for men and 7.4 for women; at ages 70–79: 5.4 for men and 6.4 for women; at age 80 and older: 1.8 for men and 3.1 for women (2001 SIPP: MMWR

Report). After stroke, women have greater disability than men (Roquer, Rodríguez-Campello, Gomis, 2003Stroke, 2003).

#### 1.1. Stroke and disability

Understanding experiences that influence stroke recovery are essential for planning interventions to meet the needs of stroke survivors. The effects of a stroke vary depending on the type of stroke, the location of the stroke in the brain, and the severity or extent of the stroke injury.

Nationally, from 1996 to 2006 the stroke mortality rate fell 33.5% and the actual number of stroke deaths declined 18.4% (NVSR) yet stroke remains a leading cause of serious, long-term disability in the United States [4]. The median survival time (in years) following a first stroke is: at ages 60–69: 6.8 for men and 7.4 for women; at ages 70–79: 5.4 for men and 6.4 for women; at age 80 and older: 1.8 for men and 3.1 for women (SIPP, MMWR). After stroke, women have greater disability than men [4]. A Michigan-based stroke registry found that 33% of women had moderate-to-severe disability at discharge compared with 27% of men. In an analysis

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of 108 stroke survivors from the Framingham Heart Study [5], 34% of women were disabled six months after their stroke compared to 16% of men.

Using Framingham Study data to assess disability in stroke survivors at six months post-stroke, Kelly-Hayes and colleagues (2003) reported that 43% of all elderly (aged 65 and older) survivors had moderate to severe neurological deficits and that women were more disabled than men. After controlling for age and stroke subtype, older age still accounted for the severity of the disability, and women were more likely to be older when they suffered a stroke. At six months post-stroke, 50% of survivors had some one-sided paralysis, 26% were dependent in activities of daily living, 30% were unable to walk unassisted, 35% were depressed, 19% had aphasia, and 26% were in a nursing home [6]. People residing in rural or remote areas may be limited in standard post-hospitalization care due, in part, to poor access.

Improving the transition of care for stroke patients from hospitalization through rehabilitation, recovery, and secondary prevention aligns with one of the major goals of the Division for Heart Disease and Stroke Prevention (DHDSPP) at the Centers for Disease Control and Prevention (CDC) and the Paul Coverdell National Acute Stroke Registry. The challenge is to find an intervention that can support patients post-Stroke during the critical first six months following hospital discharge. The purpose of this study was to describe the experiences of adults who had survived ischemic stroke and who were living in Appalachia.

## 2. Methods

### 2.1. Sampling and setting

Stroke survivors who lived in the Appalachia region, experienced recent occurrence of stroke, and were discharged from either a community or university hospital in the Appalachia region were invited to participate via letter in both this qualitative study and a larger quantitative study. Interested stroke survivors were asked to call the phone number provided and arrange a time for a phone interview.

### 2.2. Structure of the interview

The interviews were semi-structured and accomplished using talking points to begin discussion yet allowed the research assistant to encourage additional explanation through the use of open-ended questions about the stroke survivors' response. Talking points for the interviews were designed by the authors to discern meaning for the experience of stroke after discharge from the hospital. The six talking points that guided the interviews were:

- Describe for me what it was like to return home after your recent hospitalization for stroke.
- Describe for me how your life is different now than before your stroke.
- Describe for me new challenges that you are facing in your day to day life.
- Describe for me what healthcare providers could do for you now in your home to make things better for you.
- Describe for me how you see yourself healing from this recent stroke.
- Think about your mood since you arrived home from the hospital. Describe for me your mood.

In addition to responding to the talking points, participants were asked to elaborate their thoughts for a better understanding of their meaning. To ensure neutrality, consistency and quality of

the phone interviews, a research assistant (ANL) was recruited and trained to conduct the telephone interviews. Training for the interviews consisted of review of the talking points and repeated demonstrations of an actual interview with another author. The research assistant was neither an expert in stroke nor a participant in providing services for stroke thus was not influenced by any previous care or knowledge of stroke. The timing of the interview was dependent upon the schedule of the stroke survivor and of the research assistant. The interviews were conducted from August 2011 to September 2011. The average amount of time for a telephone interaction was 78.33 min.

### 2.3. Data analysis

Qualitative data was transcribed onto the computer during the interview and later analyzed thematically for meaning of surviving stroke. Two authors (ANL and LT) separately analyzed the transcribed data and then combined efforts to validate the themes. Codes were not developed in the process. After the five themes were established, they were verified with the interviewed stroke survivors. A qualitative research expert was recruited to examine and validate the analysis of the themes established and reviewed all themes and contributing text units for congruence. Any disagreement was resolved through discussion.

## 3. Results

Data saturation was reached with a total of six participants who ranged in age from 39 to 85 years of age (Mean age 47 years, 4 women and 2 men). Five participants had suffered an ischemic stroke and one had suffered a hemorrhagic stroke. The following five themes were explicated from the interview transcripts:

### 3.1. Frustration with new physical and functional impairment

A common message communicated throughout many of the interviews focused on the recovery process of stroke. Stroke survivors not only need to recover from the event of stroke itself, but also learn how to live with the new impairments placed upon their lives. These new impairments placed upon these stroke survivors caused psychological and emotional distress from the process of learning how to adjust. James explained: "It is like one of these books or movies; walk out of the door into a wholly different world". James suffered from extensive physical impairments from his stroke that touched every aspect of his life: "Anything from zipping up my jacket, getting from the store, help driving me, I don't know, it has been very hard". He noted that his frustration erupted when he had trouble with otherwise simple tasks like showering and undressing. Another difficult issue for James was realizing the limitations placed on him by the stroke: "I can't do things that I was able to do. I used to go camping in the woods by myself. Now I am not able to go to the bathroom without difficulty". Unsurprisingly, the interviews revealed that the severity of the physical and functional impairments appears to correlate with the degree of distress.

Barbara was hardly affected by her stroke long-term due to prompt diagnosis and rapid intervention. Thus, level of impairments and frustration she faced during the recovery process was minimal. Such a successful return to home life with little to no impairments stresses the importance of quick and accurate treatment of ischemic stroke. In contrast, Sara suffered a stroke that was untreated for days due to incorrect diagnosis of migraine. The extent of her physical and cognitive damages was vastly more extensive. Her vision drastically suffered after the stroke with one eye completely blinded and the other severely impaired. This

physical impairment combined with sequencing and memory problems presents daily frustrations: “It frustrates the hell out of me some days”.

As a pharmacist, Katelyn’s impaired analytical memory not only affected her home life but her work life as well. She had to quit her job because her deficits were so severe: “I am not good at math anymore and that was my forte. If I have to read something sometimes I have to re-read it numerous times. I am not on the ball anymore”.

Returning home from the hospital also presents a challenge for stroke survivors. With an unfamiliar new body, stroke patients and their caretakers must adjust the patient’s home environment to allow safe and functional inhabitation. James recalled the difficulty after discharge, “[It was] hard, we had a lot to do in the house ... put a shower in for me”. In addition, stroke survivors need to adjust to certain aspects of their home, like stairs, with these new physical and cognitive impairments. For Ashley, her physical and cognitive impairments made it difficult to use common home appliances and electrical devices. Such difficulties on a daily or even hourly basis proved frustrating: “There are five different places to touch on a stove to cook one thing. It made me mad every time I tried because sometimes I would miss it or hit another button.” These adjustments make the recovery process more stressful and difficult.

### 3.2. Negative emotions

As well as the effort of coping with physical, cognitive and emotional changes, stroke survivors also experience anger, guilt, loneliness, and depression. Unsurprisingly, most of the anger, depression and loneliness experienced by the six stroke victims interviewed was not derived from the occurrence of the stroke itself, but rather the result of struggling with a new identity. A life-long independent individual becomes suddenly dependent on others for physical and financial survival. Other emotional effects could be physiologically explained. Biological changes in the central nervous system can also be responsible for deriving some negative emotions. Regardless of the cause, negative emotional responses, such as anger, depression and guilt, after stroke is a shared message conveyed in the interviews.

#### 3.2.1. Anger

Experiencing a stroke is frightening for the victim and family members. This fear can translate into anger if the patient feels that they are being treated wrongly by healthcare professionals. Anger was a significant issue for Sara after her stroke. Part of her anger is directed toward the clinicians who incorrectly diagnosed her with a migraine: “I am very angry at the entire situation. I went to get help four times and was told to go home four times. Because of that, I missed the treatment window.” Behind this anger, there was also hurt. She had a significant amount of trouble retrieving treatment for her stroke recovery and felt abandoned by her providers: “I’m pissed off that I had to fight to get what I needed! I feel like the whole system let me down”. The experience of anger delayed the patient’s treatment and recovery after stroke. The mistrust of providers and difficulty obtaining treatment led Sara to eventually leave to be treated by a different hospital, whom provided better treatment. “I could pick up the phone and call them any time at home. Nurses called me every day for four days and checked in on me. I was very pleased.”

#### 3.2.2. Guilt

A sudden switch from the role of being an independent caretaker to a dependent ill person is not only a physical change but also an emotional one. James identifies himself as one who “never was dependent on others”. His stroke changed this role and now suffers

from guilt: “The hardest thing is letting other people do so much for me. I hate feeling dependent on others”. Katelyn also identified herself as an independent individual: “I prided myself on my ability to take care of myself ... And now all of the sudden I cannot even fold sheets because my right hand doesn’t work”. She has begun to let go of her guilt and ask for help. Katelyn described this process: “I am learning to ask for help. I read somewhere that if you don’t ask for help, you are prideful. It hit me in the gut. I couldn’t believe it at first, but now I can see that”.

#### 3.2.3. Loneliness

“I think the lack of socialization is the hardest part of stroke ...” (Katelyn). Stroke has the potential to isolate its victims. Some, like James, have difficulties with bodily functions that make it “embarrassing” and difficult to go out into public. Others, such as Sara, Timothy, and Katelyn are not able to drive, thus limiting the capacity to be involved in social activities. However, there are opportunities at home. Pets are a great source of comfort for some of the interviewed stroke survivors. Three stroke survivors mentioned the role of pets in their life after the stroke. Since these patients are unable to drive and constantly interact with other people, pets provide an outlet for patients to not feel lonely. Timothy talked about getting a dog after his stroke, “A treat to have ... He offers a lot of stability and has a lot of routine ... He stays with me all the time”. Ashley enjoyed the presence of her dog after stroke: “Regardless of where I am, he is right by me .... He doesn’t leave me alone”. Katelyn mentions that although pets do not replace human contact, they can provide an opportunity to meet and talk with other people: “I go on walks with my dog and I’m able to have social interaction with other people ... It does not alleviate the loneliness, but it does take up my time, which is great”. Although pets provide support in a unique way, some stroke survivors would like to be connected with others who deal with stroke. The local university hospital provides a stroke support group for stroke survivors and their families. Both Katelyn and James mentioned their desire to attend this stroke support group. James would personally like to hear the experiences of other stroke survivors: “It would be nice to talk to others who have been through it to hear their experiences”. The inability to drive is a main deterrent in attending: “I want to go to Stroke Survivor’s Group, but it is hard to get there.”

A strong social support system has the capabilities to increase quality of life in stroke survivors. Timothy was heavily supported by a social network of friends, neighbors, occupational therapy, physical therapy and even strangers: “I can see how people would degenerate and become suicidal if they’re debilitated. But that has never been an issue for me. I’ve never really had to reach out because they reached out to me”. Timothy had the potential to become easily isolated and very lonely. He was unable to drive after his stroke, the closest neighbor lived a mile away, and his extended family lived hours away.

#### 3.2.4. Depression

“The hard thing is knowing who you were before the stroke and knowing who you have become”. (James) A drastic change in identity is a common variable for patients who describe a depressive state after their stroke. For James, the physical limitations brought on by the stroke depressed him. As a previously physically active individual, it was difficult for him to adjust to the change of being physically disabled: “Sometimes I get really sad and cry when I can’t do something that I used to do”. As a self-defined workaholic, Katelyn had a difficult time adjusting to not being able to practice as a pharmacist. When told by her doctor that she could not work anymore after her stroke, she broke down: “I cried a lot ... I miss work and I miss people interaction”. On a different spectrum, emotional lability has been noted by one of the stroke survivors

after her stroke. When interacting with her family and care providers, Sara noticed that her emotions can uncontrollably shift from anger to depression: “I can be either totally weepy or totally pissed off ... I hate being out of control”.

### 3.3. Need for accessible support

Participants expressed dual perspectives about accessible support. These perspectives included acknowledging having support that was needed as well as identifying areas where support was needed or desired but lacking. One participant, Timothy, described having accessible healthcare support and social support. His neighbor, a registered nurse in between jobs, stayed with him when his wife went to work and acted as his advocate: “She was indispensable about intervening and talking to healthcare professionals. She knew the healthcare jargon”. Occupational and physical therapy workers drove to his home four times a week. In addition, members of his wife’s church would unexpectedly arrive and help with physical chores around his property without any expectations for him to attend church. Timothy would call his friends while home alone and built up relationships he never valued before. He praised the effect of the excellent support system provided to him after his stroke: “I had a phenomenal support system and I was fortunate in having the mechanism like Sara-Care and the neighbor that was a registered nurse, and even my wife’s church. They just rallied for me”.

In contrast, two interviewees spoke of needed support that was not available. They mentioned a desire to attend Morgantown stroke survivor group and connect with other stroke victims, but stressed the difficulty attending the session because they could not drive. Some of the interviewed stroke survivors were dependent on family or friends to drive them elsewhere. However, this method is not always dependable and it can be taxing upon caregivers. Another available support was public transportation. However, one participant, Katelyn, tried to utilize public transportation, but cognitive impairments related to the stroke hindered her ability to do so.

### 3.4. Longing for home during recovery

Ashley discussed her desire to return home during her hospitalization, “When I was in the hospital, I couldn’t understand why I had to stay there .... I wanted to stay home.” In a stressful new environment and situation, such as hospitalization after an acute stroke, people look forward to the familiarity of home and more importantly, the ability to control some aspect of their life. Katelyn wanted to return home to reestablish control over her environment and her doings: “Coming home was a relief because I could get up when I wanted to ... being able to drink a cup of tea whenever I wanted and stuff like that ... being able to be in my own environment”.

### 3.5. Stepping forward after stroke

When hospitalized for stroke, clinicians strive to stabilize the client’s condition for discharge. Outside of physical and occupational therapy, healthcare professionals rarely focus their attention on how the patient is going to recover or step forward after stroke. After discharge, stroke patients need to adapt to their physical and functional impairments. To do so, these stroke survivors had to develop a subset of psychological traits to cope with the realities of their current condition and quickly recover. Three sub-themes are included: perseverance, retraining and acceptance.

#### 3.5.1. Perseverance

“There is a lot I still want to do in life .... vacations ... camping. I don’t know how, but I am going to find a way” (James). After discharge, these stroke survivors went home with a new body, new mind, and new emotions. The first step in moving forward in recovery is making the decision to recover. Two options exist for them; persevere and try to adapt to their condition, or give up and cease adapting to their new condition. Sara emphasizes this in her own words: “Either exist or live. I choose to live”. In addition to the decision, attitude plays a key role in the recovery process. Katelyn stressed the importance of an optimistic attitude during recovery: “My mood has been pretty up-beat ... It is a very strong determinant .... If I was unhappy and miserable, I would be less determined to try different things”. Barbara persevered with the thought in mind that she was in control of her recovery: “I am the master of my own fate”. When the decision is made and the attitude of perseverance is developed, a plan then must be formulated to begin and continue through the process of recovery. This planning involves retraining.

#### 3.5.2. Retraining

To step forward from the stroke, stroke survivors must be willing to adapt to the impairments. A massive aspect of the recovery process is retraining. Adequate amounts of physical therapy and occupational therapy are an excellent means to accomplish this. However, part of this relearning comes from individual experience. For Sara, the retraining is not only physical but also habitual. With an impaired short-term memory and vision, she has difficulty finding items throughout her house: “You’ve got to put things back where you found it. It’s an effective strategy”. Timothy, who had a stroke that affected his equilibrium and peripheral neuropathy, found that he had to adjust how he accomplished chores around his farm and his house. He discussed how he adjusts working on a ladder, “Sometimes I have to look down and see where my feet are because I can’t feel them anymore. You just have to slow down and put your tools in pouches or something because you need both hands for the ladder”.

#### 3.5.3. Acceptance

Acceptance is a key factor in the retraining process. Expectations have to be reevaluated and examined in light of the new functional impairments. Timothy explains, “If you don’t get it done, then there’s tomorrow. That is the attitude you have to have or it will drive you crazy”. The other patients echo a similar message during the interviews: the ability to try again tomorrow or another day. Another facet of acceptance is refusing to be molded into another’s standards. Ashley offers a piece of advice she learned from experience after the stroke: “Don’t get up and dance and let people push you around”. Offering a different angle, Timothy describes a release from worrying about others’ expectations, “I don’t feel like I have to perform to somebody else’s standards. I can just drop the entire pretext. That is not important anymore, what other people think”.

With stepping forward also comes looking forward. At some point in their recovery, stroke survivors are able to think and make realistic plans for themselves. For Katelyn, working as a volunteer pharmacist at a local community health service for the homeless is a goal in the upcoming months. Although her mathematical skills were greatly affected from the stroke, she works hard for the chance to help others and regain the role she lost.

## 4. Discussion

The findings in this study describe physical, psychological, and social factors that occur subsequent to the experience of surviving stroke. However, our findings agree with the Clarke and Black

argument: "... the extent to which a disability restricts a person's sense of self as it contributes to his or her identity, is a principal pathway through which stroke affects quality of life" (Clarke et Black 2005). Our interview with James shows the truth of this line of reasoning. James labeled himself as a "workout monster", "independent", and a participant in outdoor and sport activities. After a physically debilitating stroke, he struggles with dependency and not being able to participate in his typical activities. His sense of identity was dramatically altered by the stroke, thus he notes a reduced quality of life. This finding indicates that it is very important for nurses who are caring for stroke survivors to understand the impact of stroke on unique individual identity. Assessing for function and role changes and devising a nursing care plan that emphasizes current abilities may be useful.

To our knowledge, this is the second qualitative studies focusing on the experiences of stroke survivors in Appalachia, a known area of stroke disparity [7]. In 2013, Danzi and colleagues described the experience of living with stroke from the perspective of stroke survivors and their caregivers who were living in Kentucky. The challenge of getting help in rural settings was also identified as problematic in this study [8]. Wood (2010) conducted a qualitative grounded theory study of 46 stroke survivors without aphasia and concluded that stroke survivors were challenged by their own expectations of themselves after stroke [9]. However, the study findings are in congruence with prior research in other populations. The importance of social support of friends and family for positive recovery after stroke has been emphasized and social connections have been determined to influence post-stroke quality of life [10] and deemed crucial in long-term post-stroke adjustment [11,12].

Nothing can entirely eliminate the frustrations experienced by a stroke victim with newly presented physical and emotional limitations. The psychological adjustment, shifting from independent role to a more dependent role, elicits negative emotions. Inter-professional teams that include expert psychological resources to appropriately assess and plan for ways to cope with the changes after stroke are an essential part of post-stroke care. The negative emotions associated with stroke have been studied using varied methodologies and with varying frequency. It is known that uncontrolled anger outbursts can occur in stroke patients' interactions with their caregivers. This is problematic because expressions of anger can be detrimental to building and maintaining social relationships and support systems. In a recent systematic review, it was concluded that more research is needed on the precise physiological mechanism of anger and stroke [13]. Loneliness has been understudied in the stroke population. However, a complimentary quantitative study that was conducted simultaneously with this qualitative study concluded that loneliness was related to every subscale of neurological quality of life for stroke survivors in Appalachia [14]. Few interventions are available for loneliness but a novel intervention, LISTEN, a loneliness intervention based on concepts from narrative therapy and cognitive restructuring, looks like a promising alternative and is in pilot testing with stroke survivors [15–17]. From a nursing perspective, it is critical to assess for negative emotions that may follow stroke. Currently guidelines suggest assessing for depression. It is possible that acknowledging anger early on in the recovery process and allowing patients to express frustrations could be instrumental to preventing anger-related outbursts.

Post stroke depression (PSD) occurs in up to 36.98% of stroke patients [18] and PSD significantly impacts quality of life [19]. It has been reported in the health literature that the most significant need for stroke survivors in the community is psychological support [8]. The psychoneuroimmunological paradigm could serve as a useful framework to study the interdependence between mental, physical, and psychological factors in the experience of stroke, and how

them impact overall health and chronic illness outcomes [20]. Since it is known that depression is associated with a chronic inflammatory biomarker profile [21], it will be important to understand the role of psychological factors in risk for subsequent cardiovascular events. Behavioral interventions for PSD have been successful [22] but may need to be adapted for the Appalachian population.

Limited access to care and support is a major challenge to living with multiple chronic conditions in Appalachia. Geographic distance to clinics and hospitals has been reported to impact attendance and chronic illness outcomes in this region of the country [23]. For survivors of ischemic stroke, this problem can be intensified if they are unable to drive a vehicle, leaving them dependent on others to travel to receive care. Interventions that include improved access to transportation could lead to improved outcomes post-stroke. Nurses who are caring for stroke patients should include an assessment of community-based accessible care programs and transportations prior to discharge. This is key because stroke survivors are likely to be suffering new impairments and therefore have not had to investigate or be aware of services in the surrounding communities. Referrals to these types of resources could facilitate access to needed support and diminish frustration.

The longing for home expressed by these study participants is likely an expression of true human need to be in a familiar environment as they recover from the major traumatic life event of stroke. Services like physical and occupational therapy and psychological counseling that are based in the home can more astutely assist the individual survivor with role alterations. Home-based physical and occupational therapy has been linked to improved patient physical outcomes [24]. When therapists are able to observe the patient's functional ability in the home environment, they are better able to tailor suggestions for overcoming difficult tasks to the real-world environment of the patient [25]. In recent studies, early discharge was associated with lower caregiver burden 12 months after stroke and cost analysis indicated no difference in healthcare costs between an early discharge group and a conventional treatment group [26]. Prior to discharge, it may be helpful for the family to work with the rehabilitation team so that family members can identify potential useful adaptations to the home environment. Implementing transitional care programs based in the home immediately after discharge has been reported to lead to improved function and fewer depressive symptoms [27]. Further research is needed to determine the outcomes and cost-effectiveness of transitional care programs or home-based interventions in rural settings, like the Appalachian region.

Successfully navigating the recovery process after stroke requires a positive psychological outlook for a stroke patient to actively participate in the process of physical, mental, emotional and psychological recovery. One qualitative meta-synthesis identified perseverance as key to community reintegration one year after stroke [28]. Acceptance has been determined to be important to stroke recovery [29] and lack of acceptance of disability may be linked to the development of PSD [30]. A systematic review of psychological interventions used post stroke indicated that the interventions can have an impact on mood and that interventions based on acceptance models may be helpful [31]. Connecting stroke survivors with existing stroke rehabilitation groups available in the community could lead to improved emotional and psychological recovery.

#### 4.1. Limitations

The small sample of patients was elected by convenience sampling, which may produce bias in our findings. Therefore, the generalizability of the findings is limited to the specific target population in Appalachia. However, this population does

experience known determinants of health such as poverty, limited access to care, and lower education that exist in many rural underserved communities.

#### 4.2. Future implications

Expanding what is known about effectiveness of post-hospitalization transition of care for improving stroke patient self-management would align with one of the major goals of the Division for Heart Disease and Stroke Prevention (DHDSP) at the Centers for Disease Control and Prevention (CDC). Home-based interventions tailored to the individual patient's level of activation (knowledge, skill, and confidence regarding the management of one's own health and healthcare) to support transition of care and to build capacity in the individual to self-manage his or her health and recurrent stroke risk factors and to reestablish partial or complete independence and improve quality of life could prove beneficial to this population and support stroke survivors during the critical first six (6) months following hospital discharge. Using home-based future implications include investigating the use of interventions to target the findings of this data. Interventions will need to include aims to lessen frustration, enhance connectedness, improve access to support, increase home-based services, and work with patients to enhance characteristics that enable a person to "step forward" after stroke.

#### 5. Conclusion

This study examined qualitative interview data relating to the long-term experience of stroke after discharge from the hospital. This study provides rich data describing the real experiences of surviving stroke, a true gap in the nursing literature. This enhanced understanding of the patient experience contributes to nursing knowledge about post-discharge needs for adult stroke survivors in Appalachia.

Stroke survivors described substantial impacts on the physical, cognitive, emotional and psychological well-being. After analytical analysis of the data gathered, five themes were created to explain the meaning of living with stroke after discharge from the hospital: frustrations with new impairments, negative emotions such as anger, depression and guilt, the need for home, the need for connection and accessible support, and stepping forward after stroke. Our findings indicate a need for interventions that target the predominant constellation of negative emotions that may be present during stroke recovery. In addition, enhanced awareness of limited transportation systems in rural areas and quicker and more frequent use of home-based services could impact post-stroke experiences. Future research that reflects the complex interactions of psychological state and physical functional ability could be useful in this population. Given that some behavioral health interventions and home-based programs have been studied, it is possible that comparative effectiveness trials could enhance the evidence base on stroke care. The knowledge gained from this project lays the foundation for the design and testing of interventions to address identified challenges for stroke survivors as they transition from hospital or post-hospital rehabilitation to home.

#### Author contributions

THEEKE conceived the study, secured funding for the study, was instrumental in the design of the study and participated in qualitative analysis and manuscript writing. LUCKE-wold conducted the study interviews, transcribed the interviews, participated in qualitative analysis, and manuscript writing. MALLOW participated in qualitative analysis and manuscript development. HORSTMAN

assisted with conceptualization of the study, participated in design of the study, facilitated recruitment of participants and assisted with qualitative analysis and manuscript development. THEEKE takes responsibility for the paper as a whole.

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#### Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.ijnss.2017.02.005>.

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