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Determinants of patient's decision-making in seeking care when experiencing stroke-associated warning signs

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Abstract

Stroke strikes millions of people worldwide. It is categorized as one of the most alarming Non-Communicable Chronic Diseases (NCCDs) because of links to long-lasting disability or death. From the literature, it is known that a stroke patient's decision of seeking immediate medical attention when symptoms occur is connected with better clinical outcome. A descriptive phenomenological design explored 12 post-stroke survivors' experiences of their decisions to seek or delay care within the first three hours of symptom onset. Three themes emerged: Hindering Factors, Motivating Factors, and Stroke of Luck. Hindering Factors and Motivating Factors depicted core variables that either hampered or motivated health care seeking behaviors. The third theme, Stroke of Luck, highlighted the multi-dimensional impact of the stroke experience on survivors' life choices. Results from this study support expanded initiatives to educate the public on stroke symptoms through media platforms.

Keywords: Stroke; health care seeking behavior; post-stroke survivors' experience.

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1. Introduction

Approximately 97% of individuals over age 50 years are unable to identify stroke warning signs when they occur (American Stroke Association, 2013). Time is a critical factor in early stroke management. From the onset of clinical symptoms, individuals have a "golden window" of approximately three-hours to receive early treatment to reduce the severity of residual disability (Kleindorfer et al., 2008). Failure to recognize stroke warning signs by individuals, families, or observers may result in delays in receiving life-saving management within this timeframe (Fugate & Rabinstein, 2014). In previous research, the percentage of individuals presenting to a specialized stroke center within 180 minutes of the onset of stroke warning signs was estimated to be 30% to 60% (Moloczij, McPherson, Smith & Kayes, 2008). This indicates that at least 40% of individuals experiencing stroke symptoms fail to access health services within the recommended timeframe (Moloczij et al., 2008). Theoretical knowledge about stroke warning signs does not automatically lead the affected individual to react appropriately by seeking immediate medical attention. Health seeking behavior is a complex phenomenon that depends on individual risk perception more than theoretical knowledge about stroke symptoms (Teuschl & Brainin, 2010). Stroke patient's decision to seek immediate medical attention when warning signs occur is connected with better clinical outcomes; conversely, delayed decision to seek immediate medical attention was connected with poor clinical outcomes (Margaret & Loria, 2013). Uncovering an individual's experiences of their decision-making regarding seeking medical care in the first three hours of stroke onset will assist health care providers in developing intervention strategies. These strategies will help to remove barriers that prevent individuals from seeking immediate medical attention when stroke warning signs occur. Previous studies have overlooked factors contributing to the delay in seeking care, such as mass-media's role in raising individuals' awareness about stroke warning signs and patient's perception about stroke warning signs. The course of decision-making individuals employ when determining when to seek medical care once stroke warning signs occur has also been overlooked. Of equal importance, post-stroke survivors' reflection on their experience has not been examined. These gaps support the need for further research. Most importantly, the vast majority of the previous studies have overlooked examining the experience of stroke survivors who managed to seek a specialized medical care within the first three hours of stroke onset. Therefore, the purpose of this research was to explore the experience of post-stroke survivors and their decisions to seek or not seek specialized medical care within the first three hours of stroke onset.

2. Methodology

This study used descriptive approach to phenomenology. This research method supported the study's primary goal to explore the experiences of post-stroke survivors' experiences and their decision-making process in seeking health care within the first three hours of stroke onset. The participants were post-stroke survivors who attended a citywide stroke support group in Oklahoma City. Eligibility criteria for the study included post-stroke survivors who had been medically diagnosed with an ischemic stroke, who attended a citywide stroke support group, and were alert, oriented, attentive to questions, and could communicate appropriately during the informed consent process. Each participant supported that s(he) was independently able to conduct personal business and legal transactions. Participants were 21 years of age or older and able to communicate in English or Arabic. The exclusion criteria of the study included post-stroke survivors who were unable to respond to questions due to aphasia or speech difficulties, post-stroke survivors who had psycho-mental status impairments, and those who were younger than 21 years at the time of the research interview. Following approval by the University's IRB, participants were recruited. Participants were informed of the intent and purpose of the research and gave Informed Consent. Interviews were conducted at public libraries, community centers, or coffee shops selected by participants based and possessing the availability of facilities to conduct the research interview in a private and noise-free environment.

A 12-item semi-structured interview guide was developed to investigate post-stroke survivors' experiences, relative to their health care seeking behaviors within the first three hours of stroke onset.

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Ten demographic questions were included requiring information about age, gender, ethno-cultural background, residency, level of education, marital status, religious affiliation, status of the individual at the time of stroke incident, and health insurance availability. Information was asked about stroke type, timeframe for seeking medical attention, and receiving rt-PA treatment. Each interview session lasted 60 minutes and was audiotaped. Transcription of the interview occurred within two days from the interview and audiotapes were then destroyed.

Qualitative analysis was undertaken using the steps outlined by Giorgi (1985). Data analysis proceeded by first reading transcripts that had been transcribed verbatim from all 12 interviews. Several readings were necessary to fully appreciate the holistic experience of study participants. Key to this phase was being immersed in the data and understanding the experience as lived by the participants. After gaining an appreciation of the whole, transcripts were read again to identify meaning units. With meaning units determined, thematic meaning was clarified, and connections between units and the larger phenomena of the stroke experience and health care decision-making were established. At this point meaning units, discussed as themes from this point on, were examined once again for their psychological insight' (p.11) into the phenomena. and as a final step, a synthesized statement of the lived experience was developed. This study reports the thematic analysis of the data. Demographic data were analyzed by using the Statistical Package of Social Sciences (SPSS) (Version 16). Frequencies and percentages were the descriptive statistical parameters used to describe the study population.

3. Data Analysis

The first section of the findings discussion presents a detailed description of the study participant's socio-demographic characteristics and other related medical details. Two tables were created to describe extracted demographic details about the study participants. Table 1 shows the sociodemographic characteristics for 12 study participants.

Table 1. Frequencies and percentages of sociodemographic characteristics for study participant (N12)

Participant Characteristics	Frequency	Percent
Age at the time of stroke incident		
37-46 years	3	25.0%
47-56 years	2	16.7%
57-66 years	3	25.0%
67-76 years	4	33.3%
Gender		
Female	7	58.3%
Male	5	41.7%
Employment status at the time of Stroke incident		
Employed	9	75.0%
Retired	3	25.0%
Ethnicity		
Caucasian	7	58.3%
African American	2	16.7%
Native American	2	16.7%
Hispanic	1	8.3%
Marital status at the time of stroke incident		

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Single	2	16.7%
Married	8	66.7%
Divorced	2	16.7%
Status of the person at the time of stroke incident		
Alone	5	41.7%
Not alone	7	58.3%
Health insurance availability at the time of stroke incident		
Available	10	83.3%
Unavailable	2	16.7%

Table 2. Clinical information for study participants (N12)

Participant Clinical Characteristics	Frequency	Percent
Time frame for seeking medical attention		
< 3 hours	5	41.7%
> 3 hours	7	58.3%
Receiving recombinant tissue plasminogen activator (rt-PA)		
Received	1	8.3%
Not received	11	91.7%

4. Qualitative Analysis

Three major themes emerged from analysis process. The first theme, Hindering Factors, described factors that hampered participants from seeking immediate medical attention within the first three hours of stroke symptoms onset, which included four corresponding subthemes. The second theme, Motivating Factors, described factors that moved individuals to seeking immediate medical attention within the first three hours of stroke symptoms onset. While the third theme, Stroke of Luck, captured the impact of the stroke experience on the participants' subsequent life choices.

4.1. Themes of hindrance: Stroke perception

4.1.1. Stroke symptoms severity

In response to the question, "Did you think that you were having a stroke?" the majority of the respondents who had experienced less severe symptoms of stroke during the first three hours of its onset, answered "No." They explained this by saying that stroke as a health problem in their minds was a synonym of a severe, sudden, and devastating occurrence. All agreed that aforementioned mental image about stroke onset led to their hesitance to consider their less severe or slowly progressing symptoms as stroke related. Therefore, they decided that it was not worth seeking immediate medical attention.

Participant 12 reflected on her early moments of stroke incident as "I thought my symptoms could be anything but stroke...I thought that this light weakness is not related to brain malfunction...it just cannot be a stroke... that what was in my mind... apparently, I was wrong...".

4.1.2. Disbelief/denial

Regardless of the age of participants at the time of their stroke, thematic analysis demonstrated that none of the participants believed themselves to be old enough to be vulnerable to a stroke. In assuming this stance, participants rationalized their decisions of not acting immediately by not being able to attribute their symptoms to a stroke.

Participant 10 stated, "Being young... stroke was not in my mind... because stroke is a disease of older generations... that is why I ignored my symptoms for a while."

4.1.3. Media information and general knowledge about stroke

In response to the following questions, "Before you had your stroke, what symptoms did you think you would have if you were experiencing a stroke?" and "What symptoms did you actually experienced?" many of the study participants answered that their symptoms did not match what they knew about stroke. As a result, this mismatch did not activate their internal alarm system to seek help, so they decided to wait hoping that their symptoms would go away spontaneously. Participant 10 stated:

The stroke symptoms that I experienced were non-traditional...very different than what I have in my mind or what learned from the mass media about stroke warning signs, such as headache or extremities weakness...in my case, I was turning my head and go na na... nah...so my symptoms did not match with what I have in my mind about stroke symptoms...

4.1.4. Health as a secondary priority

The pace of modern life imposed significant challenges upon individuals. Many individuals were extremely busy fulfilling job-related commitments to the degree that all other important aspects of life, including, but not limited to, their health became a marginal consideration. This life style was visible in many of the study participants' testimonies. Several participants decided to ignore their stroke symptoms because they thought that they were too busy to seek immediate medical attention.

Participant 2 stated "I was scheduled to work at that afternoon... so that was also in my mind... as a chief engineer, I have to be there with my team... I was and still passionate about my work..."

4.2. Themes of motivation: Choosing to act

4.2.1. The urging of a valued individual

As shown in table 1, seven (58.3%) out of 12 participants were not alone when they experienced stroke symptoms. All agreed that being encouraged by family, friend, neighbor, or individual with health care expertise to seek immediate medical attention was the deciding factor in taking action. Having a friend, a family member, or a health care provider's input about stroke symptoms, had led them to seek medical attention and in some cases taking control and deciding on behalf of the participant to seek immediate medical attention.

Participant 9 affirmed "Beside my mom's insistence, our next-door neighbor who was a nurse, when she examined me she told my mom that she must call the ambulance immediately....she knew something was wrong."

4.2.2. Undeniable symptoms

For some participants, the severity of their symptoms was the pivotal characteristic in seeking care. Severe or sudden rather than mild or slowly progressing symptoms were a significant motivator to direct the clients seek immediate medical attention.

Participant 6 identified:

I experienced a very, very severe headache... very strong headache... on a scale of ten points... I would say it was ten in terms of its intensity... at that day I went to the bathroom and fall on the floor... and then immediately we... called 9-1-1... and when I said immediately ... I mean right away...

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2-3 minutes... um... my left armstopped working... I mean my entire left side of my body become weak... and my speech become slurred... I managed to make myself clear to my wife.

4.3. Themes of the stroke experience's impact on the participants' life: Stroke of luck

4.3.1. The learned lessons

Regardless of the clinical outcome, each participant expressed that (s) he had learned a meaningful lesson. In their reflections on their decision to seek or delay immediate medical attention, participants agreed that choosing to act can make a big difference between a full recovery, varying degrees of residual disability or loss of life. Participant 3 responded to the following question "as a stroke-survivor, what is the most valuable lesson that you learned from your experience?" as "The biggest take away from all of my treatment and all of my knowledge that I have learned since I had stroke and that is you have to act now!"

4.3.2. Gratitude

Regardless of the multi-dimensional consequences of stroke, many stroke survivors in this study reflected on their experience with stroke as being a positive change agent. In her response to "If you could turn the clock back in terms of your experience with stroke, what would you do differently?", Participant 7 confessed that after her stroke experience she became better in terms of keeping up with her medical regimen: she stated that "I'm regularly taking the medicine they gave me for my high blood pressure."

5. Discussion

Stroke perception was the overall theme under which four subthemes emerged. These were as follows: Severity of Stroke Symptom, Disbelief/Denial of stroke, Media and Personal Experience of Stroke Presentation, Health as a Secondary Priority. Whether consciously or subconsciously, each one of these themes was perceived as a hindering factor in the course action of seeking immediate medical attention within the first three hours of stroke symptoms onset. Severity of Stroke Symptoms was the major hindering factor. Participants perceived that a stroke is severe and sudden, rather than minor and slowly progressing. The consequences of that perception-based decision led to lost opportunities to receive medical intervention, primarily pharmaco-therapeutic treatment, within evidence-based intervention parameters. Researchers in one study found that medical attention was sought earlier when severe stroke-related motor symptoms were experienced (Zerwic, Young, Hwang & Tucco, 2007). Frequently, subjects' false interpretation or underestimation of their symptoms was behind their hesitance to seek medical attention (Wilson, Coleby, Taub, Weston & Robinson, 2014). With "perceived severity," individuals' symptom acuity failed to reach their perceived severity threshold (Champion & Skinner, 2008). Therefore, they dismissed the significance of their symptoms. Similarly, in another study, stroke patients with a higher sense of urgency due to their severe stroke-related symptoms were more motivated to seek immediate medical attention (Kitko & Hupcey, 2008).

Disbelief/Denial was another significant hindering factor involving denial and disbelief that their symptoms were stroke-related. In this study, all participants verbalized their belief that they were too young to have a stroke. This misperception was given to explain the delay in seeking immediate medical attention. Findings from other studies are mixed on the relationship of perceived susceptibility to stroke and age. Three studies have reported that they did not observe a relationship between the subject's age group and their medical care seeking behaviors in reaction to stroke symptom onset (Nedelchev et al., 2003; Zweifler, Mendizabal, Cunningham, Shah & Rothrock, 2002). In addition to the findings of the present study, Catalano et al. (2009), also reported that individuals experiencing stroke symptoms held the false perception of advanced age and stroke susceptibility (Catalano et al., 2009).

Media and Personal Experience of Stroke Presentation was the third subtheme identified that contributed to delays in seeking medical attention within the first three hours of stroke onset. This study found a discrepancy between participants' knowledge or perception about stroke symptoms and the actual symptoms they experienced. All the participants indicated that their stroke symptoms

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did not match the symptoms they knew about stroke. A similar conclusion was found in a recent study, in which study participants were unable to make the required connection between what they had envisioned as being stroke related symptoms and what they actually experienced (O'Connell et al., 2011). In another study, the researchers indicated that campaigns to raise awareness of stroke warning signs may have succeeded in increasing public knowledge about stroke symptoms and the necessity of seeking immediate medical attention. However, the campaigns failed to cover the non-traditional symptoms of stroke. This may lead individuals who experience non-specific or minor symptoms of stroke to ignore those symptoms (Robinson, Reid, Haunton, Wilson & Naylor, 2013). One way to raise awareness of non-specific stroke-related symptoms would be to redesign the symptom display in these campaigns to include less common stroke related symptoms and descriptors of stroke to include the words, language or vocabulary used by individuals who had suffered a stroke (O'Connell et al., 2011).

Health as a Secondary Priority was the final hindering factor that the thematic analysis captured. Putting work commitments as a higher priority than health was evident in many of the study participant's narratives. Many participants stated that their health could wait, but their work commitment was the first priority. Therefore, they decided to ignore or, in the best-case scenario, to postpone seeking health care until finishing their work-related commitments. These findings were supported by a study where participants described prioritizing routine responsibilities over their own health needs when making decisions of how to react to their sudden unexplained symptoms (Moloczij et al., 2008). Urging of a Valued Individual was captured in the study participants' narratives as a care-seeking factor. Having someone; a spouse, friend, neighbor, or individual whose opinion was valued, such as a nurse, with the individual experiencing stroke symptoms reflected positively in pushing them toward seeking immediate medical attention. In some cases, family members or friends took the initiative and contacted the emergency services based on their evaluation of the symptoms that the individual was showing or describing even if that was not welcomed decision.

In a study conducted to investigate the cognitive and behavioral aspects affecting early referral of acute stroke patients to a hospital, bystander response made a significant difference. Sixty-five per cent of bystanders correctly attributed observed symptoms to stroke and 75% of the bystanders decided to urge the individual to seek urgent medical attention (Shah et al., 2007). Similar findings have been demonstrated in several studies (Lacy et al., 2001; Mackintosh et al., 2012; Mandelzweig, Goldbourt, Boyko & Tanne, 2006). The current findings support that those living alone or being alone at symptom onset delayed seeking of medical attention. This too was supported in a previous study (Kitko et al., 2008).

Undeniable Symptoms emerged as a subtheme to describe the motivation to seeking immediate medical care. Whether they were able to define these symptoms as stroke related or not, study participants felt that seeking immediate medical attention was their only option with progression of symptoms. Similar findings were reported in a recent study when researchers found that immediate care-seeking behaviors in acute stroke patients was associated with traditional, undeniable, and sudden symptoms associated with the disease (Beckett, Barley, & Ellis, 2015). Similar findings were reported in older studies (Faiz, Sundseth, Thommessen & Ronning, 2014; Zerwic et al., 2007).

Stroke of Luck was the final theme that emerged from this study. This theme represented participants' meaning of the stroke experience on their life. Two subthemes were identified; Lessons Learned and Gratitude. The first subtheme of Lessons Learned reflected participants' awareness of the importance of seeking timely care when experiencing symptoms consistent with a stroke. These were evident in the narratives of all 12 participants, who stated that if this happened in the future they would seek immediate medical attention. This is congruent with previously published studies, which indicated that individuals with stroke history were more likely to seek medical attention than those without stroke history (Mackintosh et al., 2012; Williams, 2013). However, contradictory findings have also been reported (Lacy et al., 2001; Nedeltchev et al., 2003; Zweifler et al., 2002). When compared to first time stroke patients, patients with stroke history were not more motivated to seek immediate

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medical attention (Lacy et al., 2001; Nedeltchev et al., 2003; Zweifler et al., 2002). These conflicting reports might be viewed by the complexity of health-care seeking behavior is and cannot be attributed to a single variable (Mandelzweig et al., 2006). Therefore, successful interventions must be holistic and take into account personal, social, and cultural values.

Gratitude was the second subtheme in Stroke of Luck theme. Reflecting on valuing the stroke experience, many of the study participants acknowledged the positive impact of stroke experience on their life style choices. While it is true, that stroke can have a devastating effect on an individual's health and functionality (motor, emotional, and cognitive), it can also be a life changing opportunity to invest in a healthier life style (Watson, 2010).

Research has shown there is a significant reduction in mortality if stroke survivors engaged with more health oriented life style (Schonfeld, 2010). However, making needed life style changes can be difficult and rarely occur in a linear fashion. It is important for health care providers to recognize that the quality and speed of needed lifestyle changes are influenced by many factors that include the severity of post stroke condition, availability of resources, and the individual's attitude towards the adaption to presence of neurologic deficits (Buscherhof, 1998). Meleis and Trangenstein (1994) highlighted that personal meaning(s), expectations of the individuals, level of knowledge or skill, environment, level of planning, and emotional-physical wellbeing are major personal and environmental variables that can influence changes. Successful transition to reengage in a meaningful life despite having a stroke is not only about the patient him/herself; the family; resources availability; and the quality of health care system services. Rather, life post stroke is an integrated journey that connects all interested parties seeking to achieve a comprehensive reintegration of the stroke patient.

6. Implications of the Study Findings for Nursing Practice

The findings of the current research can be applied by nurses in achieving primary, secondary, and tertiary levels of prevention. Capturing post stroke survivors' experience in this phenomenological description is a valuable source of research-based data through which nurses can assess the core variables that determined individuals' health seeking behaviours. The outcome of this study will provide nurses with the essential research-based data that can enable them to develop better-informed primary, secondary, and tertiary prevention strategies. Nurses in public health and neuroscience arenas are challenged to redesign stroke awareness campaigns in a way that supports health-seeking behaviours regardless of age and raises awareness of stroke symptoms beyond current standards.

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