Title: The Lived Experience of Stroke Survivors Transitioning From Hospital to Community: A Proposed Study

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Abstract Summary:
Stroke, a major cause of disability and death, affects 800,000 people in the US annually. Little is known about the lived experience of stroke survivors as they transition to the community. The proposed study will explore this phenomenon to inform healthcare providers about best practices in meeting stroke survivor needs.

Learning Activity:
| LEARNING OBJECTIVES | EXPANDED CONTENT OUTLINE |
Understand the significance of stroke for patients in the US.  The scope of stroke in the US; racial, ethnic, and gender disparities; the outcomes of stroke; co-morbidities

Recognize the challenges experienced by stroke survivors and their caregivers as they transition from the hospital to the community.  Communication; continuity and coordination of care; non-adherence to medical regime; autonomy; caregiver burden

Abstract Text:

Title: The lived experience of stroke survivors transitioning from hospital to community: A proposed study

Problem: Stroke affects 800,000 people annually; it is the fifth leading cause of death and the first leading cause of adult disability in the United States. Because of longevity, women have more strokes than men; and, African-Americans are more likely to be affected by strokes than other racial groups in the US. Care for stroke continues after inpatient hospitalization and requires coordination of care and follow-up in order to prevent complications and improve the quality of life of stroke survivors and their informal caregivers. Unfortunately, little is known about the lived experience of stroke survivors, especially among racial and ethnic groups, as they transition to the community. The proposed phenomenological study aims to better understand this to redesign transitional care.

Purpose: To explore the lived experiences of stroke survivors and their informal caregivers as they transition from the hospital to the community. Understanding this phenomenon will help inform nurses and other healthcare providers about best practices in meeting patient and informal caregiver needs.

Literature: Research about patient and caregiver experiences for chronic diseases and health issues requiring rehabilitation reveal that there are gaps in care following the acute phase of an illness and hospitalization. Key challenges in the transition of care include informational, management, and relational continuity. Studies also reveal coordination issues with the staff, patient/family, and with organizations resulting in problems such as missed appointments and non-adherence to medical regimes. Patients have reported losing autonomy in their care once they were seen in an outpatient clinic, deferring to staff judgment to plan care, though self-care is encouraged to improve quality of life of survivors. Research suggests that there are challenges to quality of life, significant patient depression, reduction in survivors’ psychosocial functioning, non-adherence to prescribed medical and rehabilitation regimes, and difficulties assuming self-care and activities of daily living. There is a paucity of literature specific to stroke survivor and informal caregiver experiences transitioning from hospital to the community.

Methods: This study seeks to search for themes in the transition of care for stroke survivors and describe the effect of the lived experiences of these survivors. The proposed study will use an exploratory, phenomenological design. A convenience sample of adult stroke survivors and their informal caregivers will be recruited from an acute, urban hospital that serves a predominantly black population. After IRB approval, potential study participants will be identified through medical records and referrals from physicians and nurses. Potential study participants will be contacted if they meet the inclusion criteria. Inclusion criteria are (i) incidence of stroke within the last two years, (ii) their having had at least one scheduled follow-up visit, and (iii) ability to communicate in conversational English or Haitian Creole. Interested patients will be contacted by a trained research assistant who will explain the study and obtain informed consent. Data will be collected utilizing semi-structured in-depth interviews, which will include topic areas such as: experiences moving from the hospital to community; use of resources; scheduling and coordinating care; preparation for self-care or caregiving; and, education. Patient demographics will be taken at the conclusion of the interview. Research assistants will conduct 30- to 60-minute interviews with each study participant in their home, by telephone, or in the clinic. All interviews will be audio-recorded as described in the consent. At the conclusion of each interview, the interviewer (research assistant) will summarize the interview to be sure that all sentiments were accurately recorded.
Data Analysis: Audio recordings will be transcribed with patient identifiers omitted from the transcription. Three research participants will each review the transcriptions, code segments of data, and label them into categories. As a research group, categories will be compiled into key themes and sub-themes and the frequency of responses will be analyzed using descriptive statistics. Demographic data will be analyzed using descriptive statistics.

Implications: A summary of findings from this study will be shared with stroke survivors and informal caregivers in the community to verify the meaningfulness. The findings will also be shared with nurses doing discharge planning, primary care providers and other providers in the community so they may better understand the experiences of their stroke survivor patients and informal caregivers. Armed with a better understanding of the lived experiences of stroke survivors transitioning from hospital to community, health care providers, stroke survivors and informal caregivers can develop better patient/family-centered guidelines for safe, quality care transitions.