Abstract

Background: By 2030 there will be approximately 7.6 million stroke survivors (SS) in the U.S. yet comprehensive transitional care (TC) for stroke is not widely available. Stroke strikes without warning and leaves in its wake a "storm" of uncertainty for SS and caregivers (CG) as they encounter a myriad of unmet physical, mental, emotional, and financial needs that are not wholly addressed by passive health care delivery systems. Needed is a stroke specific transitional care model that bridges this storm to active delivery of SS and CG post-acute care. Naylor's Transitional Care Model (NTCM) has not been examined for how it can frame comprehensive stroke care. The purpose of this study was to solicit SS and CG descriptions of TC experiences to inform the NTCM with refined operational definitions and exemplars specific to stroke. **Methods**: Focus groups conducted for this qualitative descriptive study were guided by interview questions based on the eight NTCM operational definitions. Data were analyzed using inductive and deductive qualitative content analysis methods. **Results:** Post-acute stroke care does not comprehensively meet the needs of SS and CG. Participants described TC deficits across all eight NTCM components. Two new subcomponents that could be applied for a stroke specific NTCM emerged: psychological and transportation challenges. **Conclusion**: Unmet needs identified by SSs and CGs were used to extend NTCM specific to the stroke population and to develop the Recommendations and Exemplars for Stroke Specific Comprehensive Transitional Care Delivery (see Supplementary Digital Content). Researchers and practitioners can use the findings to develop and deliver more comprehensive TC to SS and CG.

Introduction

Stroke is the leading cause of preventable and long-term disability in the United States, affecting approximately 795,000 persons annually, culminating in approximately 7.6 million stroke survivors (SS) in the U.S.[1] By 2030, the socioeconomic burden of stroke is projected to cost $240.7 billion.[2] Although remarkable achievements have been made in acute stroke care,[3] stroke transitional care (TC), which bridges in- and out-patient settings and community resources, lags behind acute care advancements. SS and CG perceive the aftermath of a stroke as a storm of uncertainty[4] fraught with unmet physical, psychological, emotional, social, and employment and financial needs. [5, 6] These major deficits in comprehensive stroke care persist despite 1) ample evidence that SS and their CG face ceaseless long-term challenges[1, 5] after stroke, 2) recent guidelines calling for stroke to be managed as a chronic condition[5] and 3) the development of novel models to care for the growing number of people living with stroke[7, 8].

Factors accounting for the gap in post stroke care are complex and include the current health care industry emphasis on stroke as an acute care disease,[5, 9] policy that does not favor formalized TC,[10] and prior stroke TC studies that suffer from intervention heterogeneity and poor implementation fidelity.[11] Despite inconsistent findings from TC studies, TC remains a promising approach to guide post-acute stroke care. TC that is designed to ensure continuity of care, create safe transfers across providers and settings, reduce readmissions, emergency room visits, and improve activities of daily living is a worthy goal, given its success in other chronic conditions.[12, 13] Stroke TC could address the storm of SS and CG unmet needs to positively impact recovery.[5, 9, 14]

To date, there has not been a systematic and comprehensive study of the application of transitional care model (TCM) components in the stroke population; we sought to address that gap. After a thorough review of TC models, we determined that Naylor's Transitional Care

Model (NTCM)[15] was the best framework for this study because it has been widely tested for efficacy,[16] effectiveness,[17] and has been translated into different populations and settings.[18] Testing of NTCM via randomized controlled trials in different populations led to the eight comprehensive, effective, and operationally defined NTCM components[15]: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. The purpose of this study was to solicit SS and CG descriptions of TC experiences to further inform the NTCM with stroke specific operational definitions and exemplars specific to stroke.

Methods

We used a qualitative descriptive approach, which supports a straightforward and pragmatic collection of stakeholder descriptions that are useful in developing a program or intervention.[19] The study was approved by the University's Institutional Review Board. Using purposive and snowball sampling techniques[20], SS and CG were recruited from community stroke groups in a southwestern city. Potential participants were screened for cognitive ability to independently respond to interview questions by using the Telephone Montreal Cognitive Assessment (T-MoCA), a valid and reliable tool for establishing cognitive impairment.[21] Inclusion criteria were English-speaking and reading adult SS or CG, T-MoCA score over 18, and SS discharged from inpatient setting to home. Excluded were individuals (a) receiving hospice care, (b) actively participating in another study, (c) unable to sign informed consent form, and (d) self-reporting a TIA without corresponding stroke.

Adequate sample sizes for qualitative descriptive designs varies, ranging from six to fifty-two participants and are influenced by the quality of data collected.[22] The gold standard for qualitative sample sizes is data saturation attainment.[23] For focus groups, data saturation is

generally attained within 3-5 meetings.[24] The goal for this study was to recruit 15-20 participants (SS and CG) for 3-5 focus groups.

Informed consent was obtained, and participants provided demographic data (see Table 1). Focus group data were collected using established techniques[25] consisting of asking a topic question, followed by probing question(s) drawn from TCM operational definitions (see Supplemental Digital Content (SCD)).[15] To support SS and CG candid descriptions of experiences, participants self-enrolled into their choice of five focus groups: SS-only (1 group), CG-only (1 group), and all-comer SS CG groups (3 groups). Focus group interviews were audio recorded and transcribed verbatim, using participant codes instead of actual names. The PI verified the focus group transcriptions by checking them against the recorded interviews. Data were managed with ATLAS.ti version 8.1.

SS and CG data were collectively analyzed, consistent with the holistic approach of NTCM, using inductive and deductive qualitative content analysis methods.[26] The units of analysis were meaningful segments consisting of words and phrases.[27] For deductive analysis, a priori codes informed a categorization matrix whereby each code corresponded to a NTCM component. Data that did not correspond to the matrix were inductively analyzed using open coding and abstraction.[26] Themes that emerged from inductive analysis were compared to the categorization matrix for correspondence as sub-components for NTCM components.

To ensure trustworthiness[28], the PI and a second investigator independently analyzed the data and met weekly to discuss and reach consensus. A third investigator independently verified the codes and emerging subcomponents. Two participants read summary statements and confirmed that the statements adequately represented their perceptions.

Results

During a two-month period, 27 potential SS and CG participants were referred by local stroke support group leaders. Eight potential participants did not enroll due to: ineligibility (n=1), unable to reach (n=1), scheduling or venue conflict (n=4), and health challenges (n=2). The remaining 19 SS and CG were consented and participated in the study (Table 1).

Table 1 lists the sample and focus group characteristics. Participants had a mean age of 67 years (SD 11.3). Overall, most participants were white (79%), female (53%), and retired (74%). The average number of months since stroke onset was 26.2 (SD 18.8).

Table 2 provides SS and CG descriptions and salient quotes pertaining to the eight NTCM components.[15] Stroke-specific TCM operational definitions and exemplars for the components are provided (underlined) in the Supplemental Digital Content (SDC). A summary of these descriptions is presented below.

Patient and caregiver engagement

Patient and caregiver engagement pertains to the efforts of health care professionals and systems to support individual's needs, capabilities, and care outcomes while facilitating caregiver in their role with shared decision-making.[15] Participants described needing information, communication, and one point of contact to facilitate engagement with providers. Barriers to engagement included work-life-health competing demands, financial stress related to unemployability and health care costs, unmet self-care needs, and the need for caregiver assessments for suitability and capability ("He just didn't have the tools [for caregiving]").

Complexity management

Complexity management pertains to anticipating problems, delivering holistic and person-centered care, managing complex physical, emotional, and social needs, effective medication management, and a comprehensive care plan integrated with adherence strategies.[15] Participants described the following problems: medication management, social isolation, financial security, lacking family support, and SS and CG comorbidity management. Participants described medication management as a "scary and overwhelming" process.

Complexity management subcomponent: psychological challenges

Psychological challenges emerged as a subcomponent within Complexity Management. Participants described psychological challenges as complex mood, behavioral, psychological, and personality changes that persisted long term after the initial stroke and negatively affect all other challenges associated with their stroke. For example, one CG described that after the stroke "All the psychological stuff started to happen. . .". CG noted that psychological challenges such as personality changes can affect intimate partner relations as this CG described, "This is like a Martian. This is not my husband.". Participants described a gamut of emotional states ranging from questioning if death might have been better than living with stroke, to feelings of anger, frustration, and dangerous impulsivity.

Patient and caregiver well-being

SS and CG well-being describes recognition of and holistic response to stressful experiences while supporting quality of life.[15] Participants described coping skills for independence, support and guidance, and life balance. One CG described: "I feel guilty about this, but I just lay in my room, put my earbuds in, and listen to music or watch movies . . . lay there and just close my eyes . . . I have to completely shut down or it's too stressful."

Patient and caregiver well-being subcomponent: transportation challenges

Transportation challenges emerged as a subcomponent within Patient and Caregiver Well-being. A SS described transportation challenges, including having his driver's license revoked, and not understanding how to use public transportation ("I know nothing about busses.") and ride sharing applications ("There's no phone number for me to call them."). Some SS completed formalized training, while others resumed driving without training or relicensing, "I had to learn how to drive on my own, sneak out on the streets and stuff". Participants described frustration surrounding the additional burden posed by needing to ask for or provide transportation.

Patient, caregiver education

Education involves interactive teaching, involving caregivers in decision making, management of worsening symptoms, and community resource referrals.[15] Participants described the need for continual, incremental, and iterative access to multi-modal and aphasia-targeted content, use of scaffolding techniques, visual images and a dedicated contact person and feedback loop. "…I couldn't even look at the materials . . .I was in such shock" described one SS, while another commented, "we finally got some reading material . . .but [SS] has aphasia."

Care continuity and accountability

Care continuity and accountability includes clinician, team, and organizational management of care continuity.[15] Participants described troublesome barriers including lack of timely access to general health care and stroke specific follow up care, and an absence of referrals to community services. They commented on the complexity of the health care system as a barrier and the need for advocacy to negotiate it, along with a tailored care plan and support

when discharged from inpatient facility to home. One SS recommended "mentors being involved on a monthly basis for the first six months, maybe longer."

Recommendations for Stroke Specific Comprehensive Transitional Care Delivery

As a result of this study, we used TCM operational definitions and exemplars that are specific to stroke transitional care to refine the NTCM and develop the Recommendations and Exemplars for Stroke Specific Comprehensive Transitional Care Delivery (see SDC).

Discussion

This study was conducted in response to our own practice observations and after a thorough review of the literature, both indicating that improvements in stroke transitional care are urgently needed. Neuroscience nurses are the first line of defense to guide SS and CG through poststroke recovery[29] and are best positioned to develop, lead, and deliver stroke TC[30]. We posit that to ensure active, comprehensive delivery of post-acute stroke care, tailoring the widely tested NTCM components[15] to a patient population which has experienced a stroke, is an important first step. By using NTCM as a guiding framework for this study and eliciting community dwelling SS' and CG' transitional care experiences, we identified (a) unmet needs across all eight components, (b) multiple stroke specific exemplars for each TCM component operational definition, and (c) new subcomponents *psychological and transportation challenges*. Exemplars and new subcomponents identified in this study can be used to inform development of a comprehensive stroke specific TCM.

Findings from this study parallel the findings of other studies and guidelines[5]. In a systematic review[31], investigators report that each SS has 2-5 unmet needs in these areas: physical health, activities and participation, environmental, attainment of services, information, therapy, transportation, and personal care. Our study uniquely makes these unmet needs explicit

in the context of NTCM as described in the Recommendations and Exemplars for Stroke Specific Comprehensive Transitional Care Delivery (see SCD) across all eight components and new subcomponents *transportation and psychological challenges*.

Our results echo those of Pindus et al.,[9] and Ramazanu et al.,[4] regarding the passivity of post-acute stroke care whereby SS and CG describe feeling uncertain; abandoned and marginalized by care systems. We add specific exemplars for how to shift from passive to active post-acute stroke care: one community point-of-contact, a closed feedback and communication loop, patient advocate, management of SS and CG multimorbidity, among others. A recent systematic narrative review[32] and scoping review[6] similarly identified unmet health needs, challenges with finances, returning to work, community reintegration, suboptimal CG support, psychological challenges, and the need for transportation assistance. Overall, SS and CG experienced fluid and changing needs during different phases of recovery, highlighting the urgent need for a comprehensive NTCM for stroke. Our results provide clear recommendations to support providers, health care professionals, SS and CG in meeting these challenges while identifying additional NTCM subcomponents, *transportation and psychological challenges,* to guide comprehensive stroke TC. Both subcomponents, if not addressed by stroke TC, interfere with optimal safety, recovery, and quality of life.[3, 33] In designing a comprehensive stroke TCM, it will be useful to draw upon the multiple exemplars and subcomponents from this study.

Limitations

SS and CG responses may have been limited by a priori categories corresponding to TCM components. The assumption was these components reflected the totality of their experiences. However, this potential limitation was balanced by the identification of a broad range of unmet needs. Further, the participants read TCM operational definitions for each

component that were a paragraph in length, which may have resulted in abbreviated lay-person translations. Lastly, all participants resided in a medium size urban setting, were mostly white, and no stroke survivors under age 48 years participated. These factors may influence the transferability of the findings.

Conclusions

The major finding from this study is that stroke survivors and caregivers identified unmet needs across all eight components of the NTCM. Additionally, stroke-specific unmet needs in several subcomponents were recognized by the participants. The findings provide support for expansion of the NTCM to reflect post-acute stroke care. The findings also support the idea that stroke should be considered a chronic condition and that novel models of TC should be developed to address SS and CG living with stroke. We recommend tailoring a comprehensive stroke TC program that builds on the NTCM components to include stroke-specific components that identify a broad range of unmet and changing needs of SS and CG. The clinical practice question of who will and can provide stroke TC services in the short- and long-term remains unanswered and must be addressed in future studies and discussed across various disciplines, professional organizations, and policymakers.

Acknowledgements:

Drs. Renz, Hirschman, Shaid, and Naylor at the University of Pennsylvania School of Nursing.

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