Original Article

Survivors' perspective of life after stroke

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ABSTRACT

This aim of this interpretive case study was to understand meanings of the experience of illness from the perspective of eight survivors of stroke. Data were collected by means of semi-structured interviews and qualitative thematic analysis. The experience of stroke generated negative feelings such as fear of death, disability, loss of autonomy and inability to work. Social support of family and religion was essential to cope with the changes in everyday life and inefficiency of the health care network experienced by the participants. Lack of guidance was identified, especially from nurses, for home care of patients. The results of the study suggest the need to strengthen health education on predictive symptoms of stroke, awareness of the impacts of this disease on the life of survivors, and the need for multidisciplinary health care teams to encourage proactivity of survivors' family members.

Descriptors: Stroke; Rehabilitation; Qualitative Research; Chronic Disease; Patient-Centered Care.

INTRODUCTION

Cerebral vascular accidents (CVA), commonly referred to as strokes, are the leading cause of death and disability in adults worldwide(1-3). It is estimated that of the 74% of people who survive a stroke, 57% will need care from family members(4).

Studies indicate that despite sophisticated health care technologies, recovery after stroke is complex and involves biomedical, social and psychological aspects related to health, well-being and quality of life(5-6). Most survivors and their families face daily demands of care related to increased level of dependency and complex care needs, in the face of physical, cognitive and emotional disabilities caused by a stroke(4-5,7).

Stroke is an event that suddenly changes the lives of victims and their families. Scientific evidence points to the need to establish health system interventions that promote continuity of care after the acute phase, with emphasis on the period of rehabilitation and social and community reintegration(6-7).

Therefore, it is important to investigate the process of rehabilitation for people who have survived stroke, considering the high overall prevalence of this disease and its impact on quality of life of survivors and their families. This requires comprehensive health care actions that empower and enable victims of stroke to achieve and maintain their best levels of functionality(6).

One recent systematic review on the overload experienced in treatment of stroke showed that this burden can be influenced by aspects related to the micro and macro levels of health care systems, and may vary among different locations. The authors indicated the need to understand the experience of patients undergoing treatment of stroke in different cultural contexts(5).

The development of people-centered studies is recommended to understand the global challenges associated with continuity of care among health care services and the social and cultural environment experienced by patients. This understanding may be important to identify the trajectory of the illness and aspects related to management of health care after stroke, thereby contributing to generate people-centered outcome measures that will be used by public health care managers and professionals(5).

Thus, the aim of this study was to understand the meanings of the experience of illness from the perspective of survivors of stroke.

METHODS

This was an interpretive case study focused on the experience of the disease from the perspective of survivors of stroke, who were treated in a hospital unit of the Brazilian public Unified Health System (SUS, as per its acronym in Portuguese), in the interior of northeastern Brazil, from January 2011 to December 2012.

Participants met the following inclusion criteria: being 18 years old or older, having a medical diagnosis of stroke, and being a resident in the municipality covered by the study.

Initially, a survey was carried out for potential participants by means of hospital records in the hospital unit, and 37 people that survived stroke and met the inclusion criteria were identified. Through telephone contact, 28 of the 37 individuals were excluded due to moving to another city (14), difficulty communicating (13) and death (1). One person was excluded because they did not want to participate in the study (1).

For definition of the participants, the criteria of intentional sampling and theoretical saturation were adopted(8). The sample group was made up of eight people who survived stroke.

Data were collected from January to December 2013, by means of semi-structured, individual, face-to-face and in-depth interviews. All interviews were conducted at the participants' homes, and were based on a script that included socio-economic characteristics and health care conditions of the person who survived stroke. The guiding questions of the interviews were: what happened to you on the day of the stroke? How did you feel about this experience? What helps you cope with this process? How was your life after the stroke? The interviews were recorded by audio or handwritten, based on the participants' consent, and subsequently transcribed in full.

The number of interviews per participant was defined in the simultaneous processes of data collection and analysis, considering the time in which the phenomenon was described in-depth(8-9). Theoretical saturation was achieved with the completion of 12 interviews, with a minimum duration of 30 minutes and a maximum of 55 minutes. The realization of more than one interview for some participants was due to the need to revise gaps in the data collection, deepen and check the preliminary analysis with each participant, in order to ensure methodological rigor in qualitative studies(9).

The interpretive thematic analysis was conducted in a simultaneous and continuous process of data collection, by means of the following steps: familiarization with the data, identification of codes, grouping of codes into thematic categories, review of the categories, definition and final naming of categories, and drafting of the description and interpretation of the meanings expressed by participants in each category(10).

To ensure reliability of data analysis(11), three criteria were used: 1 - recording of the interviews and checking of transcripts made by the first two authors of the study; 2 - confirmation with participants on the descriptions at the end of the interviews; 3 - throughout the process of data analysis, codes and thematic categories were checked among the members of the research team. The whole process of interpretation was conducted collectively, through discussion, revision and reworking of the descriptions and interpretations.

The study was approved under protocol no. 305,390 by the Research Ethics Committee of the Pontifical Catholic University of Goiás, and adhered to the legal ethical recommendations of the Brazilian legislation for research involving human subjects. The identities of all participants were kept anonymous, and each signed a free and informed consent form.

RESULTS

Three men and five women participated in the study, whose mean age was 54 years, most of whom were married and had children. Most participants had less than one year of education, and a monthly family income of between one and two minimum monthly wages. Only two participants returned to work after suffering stroke. Two participants retired, one due to permanent disability and the other due to age. The others cited bureaucratic difficulties to obtain the right of retirement.

Interpretative analysis of the **experience of illness**, experienced by people who survived stroke, was marked by situations of fragility of care, especially on their return home from hospital. All participants confirmed that the stroke was a traumatic and unexpected event, which provoked feelings of fear, hopelessness and lack of preparation to recognize the symptoms, or know what to do when they occur.

Most of the participants said that they had, at some point, sensed that something was wrong, but thought *"at the time it was a [minor] detail and would get better"*. On the day of the stroke, the perceived symptoms were described as *"a headache", "leaning of the mouth to one side," "speaking with difficulty", "seizure" and "numbness in the arms and legs*".

With the clinical changes cited above, the participants, when forwarded to the hospital care network, experienced lapses in health care, including delay in care, lack of qualified personnel to perform important exams such as tomography, and assistance with welfare benefits.

Following hospital treatment for stroke, most of the participants returned home with clinical changes such as hemiparesis or hemiplegia, and became dependent on others to perform activities of daily living. The participants expressed fear and concern of becoming dependent on others for simple activities of daily living such as feeding, as well as fear of other health complications such as death. These feelings generated a sense of hopelessness among participants due to the disabilities imposed by the illness.

Being paralyzed, the feeling was helplessness! [...] that feeling that I lost everything, and I'm not going to get out of this! [...] It was a feeling of death! That was the worst feeling [...]! (P5).

In my head, I thought: [...] will I have to stay like this forever? Like this? Depending on [others]? (P6).

I want to do the things that everyone else does for me! [...] They do my laundry, bathe me, dress me and feed me. I keep remembering that I didn't need this [help]. *[...] Everything I eat has to be well cooked, well mashed, because if there is any bran in my mouth, it doesn't go down! [...] If I drink water, I get scared of choking. [...] At night, I use a diaper because I don't sit! I don't want to wake anyone up at night to catch me, and urine is leaking all the time! [...] It feels hot! It's really bad, but it's necessary! If I used the toilet it would be better, more comfortable! (P4).*

Lack of work and/or financial limitations were the predominant problems among the study participants. The impact of physical disabilities transcended the care of everyday activities, and had an impact on the participants' economic situation. Most participants cited "fear of losing social security benefits", "interruption of activities", "lack of work", "slow return to activities", "interruption of activities before the usual time" and "desire to work".

I want to work and I can't! I miss work. (P2).

The issue of work has worsened! [...] I stayed at the bar until 2 in the morning! [...] Today I close and sleep earlier, because I'm afraid I will have another stroke, I'm shaking! (P3).

In addition to lack of work, two participants said that the stroke had negative impacts on their social life: "*life got bad*", "*I get in the way of my family's leisure*" and "*I don't like not being able to travel anymore*".

I walked, I travelled, and today I can't! [...] because of the stroke! [...] If I need to go to the street, to the bank and hospital, the girl [daughter] needs to go more than I do! I can't go out alone! I used to do everything I needed to by myself! I didn't depend on anyone! (P1).

Because of the hardship imposed by illness, the participants counted on support of family members to help them and perform activities of daily living. This experience awakened feelings such as: *"fear of falling and not healing", "anxiety", "dependency on others", "loss of liberty"* and *"sadness"*.

The social support of the family, as well as belief in God and spirituality, were considered important to overcome this phase.

The presence of these people was critical to improvement of the clinical and emotional states of the participants, who said that help occurred through conversation, presence of friends, outings, attention to small wishes, and changing the environment of the house for added comfort.

This situation strengthened family bonds and embracement due to proximity, care and expansion of love among the family. According to most participants, faith in God was crucial to overcome the disease. The participants said that in this moment of distress, they *"cried out to God to free me of the disease",* believed that *"God would make it better"* (the illness), and *"felt that God would save"* their health.

The participants also depended on the formal support of professionals at the public health care units. The main resource available and used was physical therapy, which most of the participants mentioned in their interviews, with both positive and negative evaluations, both in regard to the service itself or access to it.

What helped me was a long period of physical therapy! [...] On days that I stay seated for long periods of time, my legs and arms get worse, but if I do physical therapy it improves 100%! (P6).

However, one participant stated that although this service was offered by the city, they experienced difficulty in scheduling sessions, even with the referral in hand. For this reason, sometimes this individual had to pay for this service with their own money.

[...] I did physical therapy just once here at home [...] All from the hospital! [...] but they didn't come again! [...]! (P4).

Other services such as provision of medication and scheduling of exams were also mentioned by three participants. Of these, two participants said that they were able to access drugs easily at the basic health care unit, which helped to control their hypertension. Two participants cited delay in scheduling exams, even those deemed essential, such as tomography.

If I'm worried about my blood pressure, I have it [basic health care unit]! [...]! When my medicine is almost running out, I run to get more! For us to get the prescriptions and go to the doctor, which before was difficult, today is not! [...] The family health care unit (FHU) is one of the things that has helped everyone a lot! (P1).

He [the doctor of the FHU] requested a Doppler ultrasound, an electrocardiogram and a CT scan. I scheduled the first two quickly [within one month], but the CT scan could only be done with a neurologist's report. [...] it took a long time! [...] Three months, but some people waited eight months! (P6).

[After the first stroke], the neurologist evaluated the CT scan, and said that I needed to do another scan two days later! [...] I was discharged, the CT scan was not done, and I was referred to a neurologist by the basic care unit! [...] But there weren't any available times! (P8).

The participants' statements on life after stroke showed how much this illness negatively impacted their lives. Physical restrictions caused changes not only in activities of daily living, but also self-esteem, ability to work and, consequently, in their social and financial life. Despite the difficulty in scheduling physical therapy and accessing other resources such as drugs, the participants valued these forms of support from the SUS.

DISCUSSION

This study enabled understanding of the intense experience of illness by people who survived stroke, based on their descriptions of the physical, emotional, social and economic repercussions of this event. Description of these different, interconnected dimensions makes it possible to more clearly understand the complexity of health care demands of patients who have suffered stroke, from the acute phase to the rehabilitation period.

The results showed the need to sensitize the public to the proper understanding of the signs and symptoms of stroke, in order to prevent it. In addition, the need was observed for popular education for early recognition of the signs and symptoms of stroke and immediate seeking of health care, because inadequate knowledge has hindered prior access to available care(12).

Many people tend to underestimate the first signs and symptoms of serious illness, which interferes with their seeking out health care. Late recognition of these signs and symptoms compromises chances to save their life and, in cases of stroke survival, chances of minimizing disabilities resulting from this illness(12-13).

Stroke survivors have their well-being and functionality compromised, impacting their ability to perform activities of daily living(4,7). It is estimated that in the age group greater than 50 years, stroke is the cause of disabilities that represent 40% of early retirements and, furthermore, about 40% of deaths that occur in Latin America happen during the most productive years of the victim's life(14).

Disabilities resulting from stroke generate dependency, and, on average, 44% of people do not return to work after the event, and require some type of aid in performing basic activities of daily living(15-16). Loss of productivity and difficulty developing work activities are notable impacts. Frustrations and decline in subjective well-being result from loss of social status and relationships(17-18).

Researchers show that difficulty returning to work is not the only impact of stroke. Other significant difficulties experienced by survivors of stroke include remaining in the labor market and difficulty accessing financial and social welfare resources to maintain care treatment(15).

Stroke survivors' difficulty working and contributing financially to the household puts strains on family members, who assume costs of food, clothing, improvement of the living environment to attend to the victim's physical disabilities, and in particular, additional health care expenses, in addition to other unforeseen expenses(5, 7,13,18).

The situation of dependency undermines the emotional stability and identity of stroke victims, evoking feelings of futility and failure. The person feels sad, hopeless and less interested in activities that were once enjoyable, slowing the process of recovery of physical and mental health(4-5,7,19).

These feelings from functional disability also affect stroke survivors' social life, causing overload for caregivers(4-5,7,16). However, the desire to restore autonomy to their lives was also notable among the study participants, when bolstered by formal or informal social support(17,19).

Family and religious support were important coping strategies, and may have been the driving forces for restoration of health of some participants, given the precariousness of health care units in guaranteeing continuity of care at home.

Scientific evidence indicates that the more social support stroke victims receive, the better their perceived quality of life will be, along with better results related to the individual's ability to cope and adapt to changes in their daily life that result from the stroke(20-21).

Religion and spirituality support the hope for improvements that can be achieved by faith. Religious activities usually improve an individual's quality of life and reason for living, and religion has been positively associated with better physical and mental health after stroke(15,22). In this context, integration of family and faith in God were key components for emotional support and to improve the ability to cope with illness(20-21).

Precariousness of care was present, especially at the time of providing directions related to continuity of care at home and in the community context, which should be started in the hospital environment(4,6,19). It was found that the current care model has not yet incorporated guidelines related to rehabilitation and health promotion for adaptation and maintenance of well-being and functionality(21), focusing also on curing the disease and not on the care of individuals and their families, who receive little support from health care professionals in the rehabilitation period(19-20).

The moment of transition of care from the hospital phase to the home occurred in isolation, and patients and their families resolved the demands of care independently, without professional assistance from the SUS(4,7,17,19). In this scenario, patients and families in need of information are at the mercy of a weak and fragmented public health care network, and are at risk of experiencing adverse events which may lead to complications and readmissions throughout this process(4,5,22-24).

The participants were not satisfied with access to rehabilitation interventions after hospital discharge, and mentioned that they experienced restrictions to continuity of care in the community context. This aspect was also evidenced in studies conducted in developed countries that identified fragmented care, lack of continuity, communication, coordination and integration of health care services, and absence of, or difficult access to, rehabilitation services in the community context(23-24).

Effective rehabilitation should involve a biological and psychosocial assessment, with a set of interdisciplinary measures that aim to empower families of stroke survivors to minimize the chances of new episodes of this illness(6-7,23). The rehabilitation period has been neglected by the health care system, and educational interventions, when they occur, have been superficial, without considering the specific needs of each person and their family nucleus(7,17,19,23). That denotes weakness in fulfilling the principles of universality and equity of the Brazilian public health care system, which significantly impedes stroke survivors' effective reintegration into their social and community lives after hospitalization(6).

Researchers describe that this is a serious problem in developed countries, and a real tragedy in developing countries, which face problems related to underutilization of health infrastructure and scarce resources (human and material)(25). In this sense, inefficiency in the mode of production of care tends to result in delays in follow-up and monitoring of care, difficulty referring people to different levels of health care, errors and other undesirable adverse events leading to deficits in resolution, and the consequent general disillusionment and dissatisfaction of people, families and communities(25).

CONCLUSION

Public policy advocates a model based on prevention and promotion of health by means of popular health education, multidisciplinary care for intervention in the clinical picture of stroke, and rehabilitation of disabilities, with formal social support to families, strengthening its partnership in home care.

The findings of this study showed a dichotomy between the effective employment of the guidelines of public policies in the care process, rehabilitation of people who survived stroke, and the reality experienced by these people and their families.

This study observed that the population still lacks knowledge and awareness about the risk factors for, and impacts of, physical, social, psychological and financial disabilities from stroke, which may represent an individual's negligence of their own health, and lack of support from other professionals, especially nurses as comprehensive care managers.

The family is essential for access to health care services, and to guarantee maintenance of care; however, this care occurs in an isolated manner. Therefore, the health care network must encourage support for family members and better utilize their potential to provide care, as well as reorganize the flowchart of care in order to ensure the effective action of health care services to attend to the population.

The production of positive results of care after stroke requires that health care systems are organized in an integrated manner, and ensure continuity of care involving people-centered interventions (individual, family and community), in the different production scenarios of care, through the integrated performance of health care professionals.

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