Experiencing acute stroke: the meaning of the illness for hospitalized patients*

VIVENDO O ACIDENTE VASCULAR ENCEFÁLICO AGUDO:
SIGNIFICADOS DA DOENÇA PARA PESSOAS HOSPITALIZADAS

VIVIENDO EL ACCIDENTE CEREBROVASCULAR AGUDO:
SIGNIFICADO DE LA ENFERMEDAD PARA PERSONAS HOSPITALIZADAS

Samia Jardelle Costa de Freitas Maniva[1], Consuelo Helena Aires de Freitas[2], Maria Salete Bessa Jorge[3], Zuíla Maria de Figueiredo Carvalho[4], Thereza Maria Magalhães Moreira[5]

ABSTRACT

The aim was to understand the meaning of the experience of the acute stroke patient. This was a qualitative study, based on the conceptual theory of symbolic interaction. It was conducted in a unit specialized in the treatment of stroke at a tertiary hospital in Fortaleza-CE and the ethical aspects were respected. The study included ten patients and data were collected through open interviews. The data were organized and analyzed according to enunciation techniques. The meaning of the illness experience was constructed based on the perception of the feelings that arose during the hospitalization and was characterized by fear of death and the sequelae of the disease; sorrow for the distance from home; relief, when a patient perceived an improved clinical course; and a desire to change one´s lifestyle. The experience of illness due to stroke is complex, as meanings are elaborated from the feelings, actions and behaviors of the subjects.

RESUMO

Objetivou-se compreender o significado da experiência vivenciada pela pessoa adoecida por acidente vascular encefálico agudo. Trata-se de estudo qualitativo, fundamentado nos pressupostos teóricos do interacionismo simbólico, realizado em uma unidade especializada no tratamento de acidente vascular encefálico de um hospital terciário, situado na cidade de Fortaleza, CE. Participaram do estudo 10 pacientes. A coleta de dados ocorreu por meio de entrevista aberta e os dados foram organizados e analisados segundo a técnica de enunciação. Cumpriram-se todos os aspectos éticos. O significado da experiência de adoecimento foi construído com base na percepção dos sentimentos surgidos durante a hospitalização, caracterizados por medo da morte e das sequelas da doença; tristeza pelo distanciamento do lar; alívio, ao evidenciar-se melhora do quadro clínico, e desejo de mudança dos hábitos de vida. Apreendeu-se que a experiência de adoecimento por acidente vascular encefálico é complexa, e nela os significados são elaborados com base em sentimentos, ações e comportamentos dos sujeitos.

RESUMEN

Se objetivó comprender el significado de la experiencia de la persona que padeció accidente cerebrovascular agudo. Estudio cualitativo, fundamentado en los presupuestos teóricos del interaccionismo simbólico, realizado en unidad especializada en tratamiento de accidente cerebrovascular de un hospital terciario en Fortaleza-CE. Participaron diez pacientes. Datos recolectados mediante entrevista abierta, organizados y analizados según técnica de enunciación. Se cumplió con todos los aspectos éticos. El significado de la experiencia del padecimiento fue construido en base a la percepción de los sentimientos surgidos durante la internación, caracterizados por el miedo a la muerte y a las secuelas de la enfermedad; tristeza por alejarse del hogar; alivio al evidenciarse mejoras del cuadro clínico; e intención de cambio de hábitos de vida. Se aprendió que la experiencia del padecimiento de accidente cerebrovascular es compleja; en ella, los significados son elaborados en base a sentimientos, acciones y comportamientos de los sujetos.

DESCRIPTORS
Stroke
Hospitalization
Nursing care
Interpersonal relations

DESCRITORES
Acidente vascular cerebral
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DESCRIPTORES
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[1]MSc in Clinical Care in Health from the Ceará State University. Nurse of the Stroke Unit of the General Hospital of Fortaleza. Fortaleza, CE, Brazil. samia.jardelle@gmail.com [2]Registered nurse. Professor of the Clinical Care in Health Academic MSc Course of the Ceará State University. Fortaleza, CE, Brazil. consueloaires@yahoo.com.br [3]Registered nurse. Professor of the Clinical Care in Health Academic MSc Course of the Ceará State University. Fortaleza, CE, Brazil. maria.salete.jorge@gmail.com [4]Registered nurse. Professor, of the Department of Nursing of Ceará Federal University. Fortaleza, CE, Brazil. zmfca@fortalnet.com.br [5]Registered nurse. Professor of the Clinical Care in Health Academic MSc Course of the Ceará State University. Fortaleza, CE, Brazil. tmmmoreira@yahoo.com

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INTRODUCTION

Suffering a cerebrovascular accident (stroke) constitutes one of the major causes of morbidity and mortality worldwide[1]. Considered the third most common cause of death in developing countries, it is the largest cause of disability among adults[2]. In recent decades, a growing body of knowledge has modified the traditional perceptions of stroke[3]. The evidence indicates that stroke is treatable condition for which acute care needs to be timely and effective to prevent brain injury. In this context, the patient should be offered a set of care generation technologies, including the support of specialized units and the use of thrombolytics[4], as well as subjective and transpersonal strategies to help the patient find meaning in the illness and suffering[5].

Faced with new perspectives in the field of cerebrovascular diseases, research in nursing focusing on clinical practice related to the illness from stroke can be identified among the themes studied by the profession, with the primary aim to improve the quality of care provided to these clients. Thus, the exercise of complete care requires theoretical and practical support from nurses that is not solely focused on the disease and therapeutic procedures but is also designed to meet the health needs of the patient and family. Given the close interactions with people affected by stroke, it is possible to appreciate that illness, because it occurs suddenly and unexpectedly, may triggers abrupt changes in the quotidian. Thus, the trajectory of life changes, including social and work activities are disrupted, and the result is hospitalization. It is therefore necessary for the healthcare professionals attending these patients, including the nurses, to understand the experiences involved in the disease process due to a stroke. Comprehension of the meanings attributed to this experience and the coping processes can provide nurses and other healthcare professionals with the subsidiary elements for human care.

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In illness due to stroke, meanings are produced through an interpretive process, in which the individual relates meanings about the illness, the symptoms, the complaints, care received through health services and the professional practices with the shared meanings endorsed by individuals in their social groups. Therefore, the meaning is a social construct formulated within and through interactive activities established by individuals and those who surround them[6].

Although many citations in the literature relate to the experience of illness due to a stroke, the majority of these studies focus on the perceptions of the relatives and caregivers[7]. Consequently, there is a lack of research that focuses on conceptualizing the illness experience from the perspective of the patient, as interpreted by using symbolic interactionism as the theoretical framework. Given this reality and motivated by the care provided by nurses in units specialized in treating the disease, the following questions emerged: How does the individual affected by stroke experiences the moment of illness and hospitalization? What are the meanings they attach to the stroke?

Faced with the situation mentioned above, to contribute to the improvement of nursing care to this population, the present study was proposed to conceptualize the meanings of the experiences of the acute stroke patient during the hospitalization period.

METHODS

This was a qualitative study based on the conceptual framework of symbolic interactionism (SI), which facilitates a comprehension of the conscious meanings embedded in life experiences related to the health-disease context. SI is a perspective of social psychology that emerged in the late nineteenth century, the greatest proponent of which was George Herbert Mead, who developed the central ideas of interactionism. However, Herbert Blumer systematically elaborated the theory based on the key analytic elements of Mead: self, action, social interaction, objects and joint action. Thus, it is a theory that addresses human behavior and social interaction[6].

Three basic assumptions underlie SI: 1) human beings act in relation to things, based on the meanings that the things hold for them. Such things include everything that human beings can observe in their physical environment, such as objects, people, institutions, ideas, activities and life situations; 2) the meaning of the things arises from the social interactions established by human beings with their peers; 3) the meaning attributed is manipulated and modified by the interpretive process, which is used by people to adjust to situations they encounter[6].

The study was conducted in a specialist unit for the treatment of stroke patients in a tertiary public hospital, located in the city of Fortaleza, Ceará. In the sector studied, 20 beds are available, (two of which are intended for patients who will undergo thrombolysis) in the acute stroke unit where neurointerventionist procedures are implemented. The participants of the study included 10 individuals with acute stroke, all with preserved cognitive and verbalization status, who were hospitalized in the above mentioned unit. For the cognitive evaluation, the validated Portuguese version[8] of the Mini-Mental State Examination (MMSE) was used. Data collection occurred from June to August 2011. The data collection technique

relied on recorded open interviews. Each interview lasted approximately 30 minutes. The guiding statement was as follows: tell me about your hospitalization due to the stroke. To ensure the anonymity of those involved, random fictitious names were adopted for each individual.

Upon the completion of data collection, the patient statements were analyzed by thematic category and enunciation analysis, which consisted of the following steps[9]: 1) Establishment of the corpus: The number of interviews to be analyzed was defined (n=10). The quality of the analysis substitutes for the quantity of material; 2) Preparation of the material: Each interview constitutes a basic unit. A comprehensive transcription of each unit was carried out, conserving as much linguistic and paralinguistic information (silences, onomatopoeia, speech disturbances and emotional aspects such as laughter, ironic tone, repetitions, lapses and others); 3) Analysis: In this stage, a thematic analysis was initially performed that, complements the analysis of enunciation, because thematic analyses do not take into account the dynamics and organization of the content. However, thematic analysis does include the frequency of the themes extracted from the set of discourses. Next, a logical and sequential analysis of style and the atypical elements and figures of speech was performed. For an improved comprehension of the analysis, the phenomenon in question was presented as follows: stating the experience of the illness due to a stroke.

The study fulfilled the ethical and legal requirements according to Resolution No. 196/96(10) of the Ministry of Health regarding research with humans, and it was approved by the REC of the study institution with protocol number: 030302/11.

RESULTS

The feelings experienced by the patients during the illness due to stroke were characterized by fear, sadness, bewilderment due to the unexpected appearance of the disease, and ultimately, relief and desire for change. The initial feeling of a fear of death was evidenced in the following statements:

> This disease is cruel (...), I'm afraid (...), it was an experience I never had in my life, a dangerous situation, we know that a person can die at anytime (Milton).

> I'm afraid, this disease almost killed me. I do not want to die so early, I thought I was going to heaven (Carlos Fred).

> It's a shock in a person's life, suddenly we become ill, with that agony, thinking I will die, it's horrible, I can not describe it (Sabrina).

The fear of their own deaths was felt strongly, due to the onset of disease. In the discourses, this sentiment was marked by an erratic style, in contrast to the linear style present in the rest of the discourse, and the discussion was marked by interpolations, silences and pauses, which slowed the progression of the speech and denounced the loss of domain. The speech was overtaken by the thoughts and opened a space for the upwelling of the emotions. Some subjects (Milton, Fred Charles, Sabrina, Simone) expressed this reaction through tears, or sometimes with contained crying. The fearful state signified apprehension in the face of real or imagined danger, fear and anxiety. This feeling emerged when the subjects were faced with a life-threatening situation.

In addition to this fearful feeling, apprehension was identified as being related to the sequelae resulting from the stroke and, in turn, the incapacity to perform work activities.

> Will I go blind, with this forgotten side not moving? (Ivone).

> I'm unable to work, my legs are weak (Carlos Fred).

> I have my work, my obligations, suddenly I had to stop work (...) (Sabrina).

Given the threat of dependence imposed by the possible consequences, discontent was also expressed. As a way of overcoming dependence, the subjects expressed a desire for autonomy, to demonstrate to themselves the importance of feeling active, even in the hospital environment.

> I do not want to be like a child, in the hands of others, if I can do it myself, I do it (Carlos Fred).

> I want to do things for myself (Milton).

The meaning of the fear of death, as well as the sequelae attributed to the stroke, also stemmed from the social interactions established by the subjects with people who are meaningful to them and who have experienced similar situations, given that meaning is a social product, formulated within and through interpersonal interactive activities[6]. The subjects put themselves in the place of others and imagined that they would go through the same suffering.

> People in my family have already died from this disease (Milton).

> My neighbor had this, she stayed in hospital for a long time and with a part of the body without moving, I imagined that I'd end up the same as her (Anahí).

Throughout the discourses, the appearance of the following expressions manifested in the form of lapses appeared in the speech without establishing a logical relationship to the other proposals. These patterns indicated the persistence of the refuted idea and conveyed the difficulties faced by the subjects in understanding what had happened and in accepting the disease.

> I never imagined myself having a disease like this! (Josué).

> I never thought it would happen to me (Fred Charles, Simone, Anahí).

These manifestations may indicate the subjects recognizing themselves as patients and visualizing their current hospitalization situations. Such inferences possibly result from the comments made by the people around them, including: the healthcare professionals providing care, the other patients who shared the place of hospitalization and the family members who accompanied the patients.

From the moment in which the subjects accepted the stroke as a real event in their lives, they started to seek explanations for the event and attempted to recognize the causal conditions that led to the emergence of the disease. Some subjects developed their own justifications, whereas others appropriated the fragmented information issued by the healthcare professionals to construct their explanations related to the stroke.

> I wanted to know why, if it was an anger I had (Josué).

> This that happened to me worried me, I do not know if it's because I have high blood pressure, does it have anything to do this? (Maria).

> I really want to find out why I had this, the doctor said I had this high blood pressure and high cholesterol business (Carlos Fred).

The excerpts of the discourses reveal that the subjects displayed a lack of knowledge regarding the stroke, as well as the risk factors for cerebrovascular disease. The group presented with hypertension in the majority of cases and, with difficulties related to adherence to medication, diet control and practicing regular physical activity.

The subjects also revealed a feeling of sadness when faced with the period of hospitalization, because they felt as if they were in a foreign place with strangers and they had to adapt to the hospital routine.

> It's hard to accept that I'm in a hospital bed, what I want is to be at home (Sabrina).

> For me it's very difficult being away from my home (Maria).

> We miss home (Anahí).

For some, this moment was characterized by a strong dislike, to the point of associating the hospital institution with a prison and viewing the patients as its prisoners. By ignoring the severity of the illness due to the stroke, the subjects did not comprehend the necessity of being monitored. Acknowledgement of themselves being confined to beds, with continuous monitoring of the vital parameters, was related to the loss of freedom. They aligned the hospitalization with suffering using the following logic: the hospital is prison. The prison is suffering. The hospital is suffering.

> I do not know how those prisoners manage, who spend years and years in prison, and me, after the few days that I'm here, I'm this way [sad] (Josué).

> It's very sad (...), it's a type of prison (...), to stay in a hospital is like being imprisoned (...), it's like being locked up(Carlos Fred).

> I'm here in this bed, with this pile of wires on top of me, unable to get myself up, it's really bad (Maria).

These statements, pregnant with meaning, denote the difficulty of the subjects in accepting their experienced reality. Regarding the distance of the family members during the time of acute illness, the subjects expressed a longing to be with their loved ones with a discourse marked by pauses and tears, signaling that contemplation of the subject awakened profound sadness in them. Furthermore, they reinforced the perception of isolation due to the hospitalization.

> I miss my daughters, my husband, my grandchildren [crying] (Maria).

> Here I'm different [crying], I'm far from my family, my home, it is very sad (Josué).

However, not all study subjects perceived the hospitalization as linked to sadness, pain and suffering. Unlike the others, two subjects expressed that they were happy with the hospitalization. After the initial shock due to the onset of the signs and symptoms of stroke, a re-signification of the hospitalization process was noted.

> I'm feeling great staying here in hospital, I'm feeling wonderful, it seems like I'm on vacation (Ivone).

> I'm happy here, it's not difficult for me to stay here (Anahí).

As evidenced in the statements of Ivone and Anahí, the hospitalization period gained a positive meaning, based on the recognition of this period as a time when they were free of domestic obligation, while concurrently receiving the necessary care. By exploring the discourses, it was evident that they were active people, responsible for all household chores in their homes.

During the hospitalization, the subjects experienced visible improvement in the signs and symptoms of the stroke. As a result, the feelings of fear, anguish and grief that were triggered at the beginning of the disease process were re-elaborated and gave way to relief. Given this improvement, they began to behave differently with regard to the illness situation.

> I'm better, I'm healthy, I already have to vacate the space for others who need it (Carlos Fred).

> I'm feeling pretty good, now I'm improving (Ivone).

> I've already recovered a lot, compared to the day I arrived (Sabrina).

The perception of clinical improvement indicated to the subjects that their physical integrity was preserved. This was reinforced when the subjects identified the functional progress in the bodies for performing basic activities, such as walking, feeding themselves, and performing personal hygiene without assistance. The desire of the subjects to regain the autonomy of their lives was emphasized. By viewing the neurological improvement

of the other patients, they also desired this outcome for themselves and began to believe that they were capable of experiencing such recuperation.

The shift in emotions motivated by the improvement from the stroke, through the re-signification, allowed the subjects to comprehend the illness situation different perspective: the occurrence constituted an awakening. It became possible to reflect on the current health status, as well as the identification of attitudes considered harmful to health. Based on these considerations, the subjects felt responsible for what had happened.

> I was very extravagant, like greasy food, salty food (Carlos Fred).

> I didn't care, I didn't accept advice from anyone, I thought I was superman (Milton).

> I think that the stroke was due to a lack of care for myself, not the medicines [for blood pressure] I took (Simone).

At this time, the experienced situation was perceived to be a positive force that could activate beneficial changes in the way the subjects dealt with their health. The subjects admitted their contributions to the occurrence of the disease including recognition of their inattention to health and lack of preventive care, and they began to see the experience of illness as a provider of change.

> Now I will change many things, I'll have to change my habits, the sedentary lifestyle that I was leading (Milton).

> It served as a warning, because now I'll have to change all my eating habits (Anahí).

> Now I'll be someone else, I will take care of myself, go for walks, take care of food, take my medicine (Simone).

The promise of a lifestyle change was motivated by the fear of disease recurrence, as can be observed in the discourse of Simone:

> I will not falter in any way, so I'm not at risk of having this again (Simone).

In this way, the subjects reported the specific modifications they intended to perform. However, it is unknown whether they managed to accomplish these goals. These attitudes related to how to future actions reflect their intentions, given that the subjects were hospitalized.

DISCUSSION

For hospitalized individuals, the phenomenon of stating the experience of illness due to a stroke presented itself as the need to express the feelings arising from the onset of the illness manifestation and the hospitalization process. The meaning of the illness experience was constructed based on the perception of feelings that emerged from the initial moments, when the clinical signs and symptoms appeared, from seeking medical attention and from the beginning of hospitalization. However, the experience was not restricted to self-reflection, given that interactions with the hospital environment and with other individuals were also integrated.

In support of these findings, data from another study indicates that hospitalization is experienced personally as well as collectively, according to individuals` previous cultural references, values and experiences. By listening to the patient, a polysemic construction is realized. Thus, the meanings of the illness process and hospitalization are components of the social reality produced within a context, and this reality, interacts with different personality variables to influence the actions of the individuals caught in that particular situation[11-12].

The onset of the disease often causes suffering. Facing overwhelming situations in which death emerges as a possibility may supervene the inevitable associations with suffering, pain and vulnerability, thereby perpetuating the fear inherent to the illness[13]. It is distressing for human beings to be conscious of their finitude[14]. The fear expressed by the study subjects constituted conscious elaborations that resulting from social interactions and self-interactions. These interactions led the individuals to perceive themselves from the outside, to put themselves in the position of others[6], and to signal the severity of illness due to the stroke.

Hospitalization is a stressful event, characterized not only by fear of the unknown that arises from the signs and symptoms of disease, but also by the consequences arising from this situation, such as the distance from family members and the interruption of routines and social roles[15]. In the case of stroke, another important aspect is added: that of physical disability. In this context, studies warn about motor and cognitive deficits responsible for the lack of independence and autonomy of the patients, who must come to rely on the aid of others[2,7]. The physical disability restricts their actions, and ultimately, it also compromises their abilities to decide how and when they want to perform a certain activity. In turn, these restrictions make it difficult to cope with the disease process[16].

Individuals who suffer a stroke become vulnerable and are exposed to situations that change the way they see themselves and construct their identities[17]. In the case of the study subjects, some individuals showed themselves to be active and independent people, whereas others were engaged in the full productive phase of life and assumed responsibility to provide for their families, theses activities maintained the sense of self. This interactionist concept refers to the definition that individuals have of themselves[6]. Despite being hospitalized and limited by physical disabilities, the individuals wished to control, direct and manipulate their own lives, thereby highlighting the concept of human action.

The study subjects used expressive and dynamic mechanisms to expose and analyze their problems. The

perception of the negative aspects related to the stroke, characterized by the fear of death and of the sequelae, demonstrates that the meaning attributed to the disease refers to a life-threatening situation. This development interferes in the coping process[6,17], which consists of the activity of human beings to act in accordance with what they encounter in their lives, with their actions constructed by the ways they perceive, evaluate, and interpret salient details and by the type of projected courses of action they plan.

The hospitalization was perceived as a time of isolation and loneliness during which subjects were deprived of contact with their family members and the domestic environments of their homes. The illness leads the patients to a loss of familiar boundaries. Thus, the emotional suffering caused by the illness and hospitalization awakens a sense of displacement that demands a protective environment capable of providing stability and refuge[14]. Studies show that, in the imagination of the patient, the hospital is recognized as a threatening place and a generator of suffering[11,18]. Symbolic elaborations of patients who associate the institution with the prison environment have been encountered [11], similar to the findings of the present study. However, to give sense to the things, it is necessary to relate two dimensions: what we encounter and what we choose. Therefore, the same moment may present with divergent meanings when experienced by different people, revealing that the human experience, marked by interpretations of the world, does not have a linear trajectory[14]. In this context, the presence of the family members beside the patient may signify confidence and a reduction of anxiety prior to the hospitalization process. The links established between individuals in their primary social group, when broken, can trigger profound pain and the need to elaborate the feelings to face the situation[18]. After all, for most people, the family is a powerful source of support, related to both the formulation of affective bonds and the references of support and safety.

The neurological improvement experienced by the subjects facilitated the re-signification of living, to the point of accepting the illness as an event that served to alert them. That is, it was transformed into an opportunity to adopt healthy lifestyles and take more effective control of the stroke risk factors. It is not easy to find meaning in life in hospitalization situations, especially when faced with critical conditions. However, these circumstances provided the opportunity for intense internal reflections and, in many instances, triggered significant changes in the lives of those who experience them[14].

From the data presented, a discussion of the experience of illness due to stroke is essential for the healthcare for this clientele. When sick, individuals not only require professionals to evaluate their symptoms, but they also seek care to rebalance themselves as they are faced with new feelings awakened by the suffering. Thus, understanding the subjective aspects reveals that illness due to stroke is rich with meaning. Therefore, for authentic and human care, healthcare professionals, including nurses, need to consider these nuances in their daily tasks.

CONCLUSION

Comprehension of the experience of patients hospitalized for stroke is a fundamental experience required in the planning and execution of nursing care. Care begins with the perception of the health needs, which are included in an integral care plan, to minimize the suffering that is experienced and verbalized by these individuals. By giving voices to the subjects and pondering their experiences with stroke-related illness and hospitalization, it was possible to outline the meaning of such situations in their lives. Distinct meanings have been attributed to the experience and may be characterized by fear of one´s own death and of the sequelae and disability of the disease; sorrow due to the distance from one´s home and loved ones; perplexity regarding the disease occurrence; relief, with the evidence of a patient´s clinical improvement; and the desire for change, with improvements in one´s lifestyle habits to help prevent a recurrence. The illness experience is unique and individualized. Each individual interprets illness in the light of their values, which are constituted by self-interaction and by social interaction with their peers. The feelings were continuously modified and re-signified throughout the hospitalization process.

It should be understood that this study presents limitations with respect to the sample size. Therefore, no generalizations or comparisons between populations can be made. It is noteworthy that this study sought to deepen the issues inherent to the illness due to a stroke. Therefore, it does not lose its potential to provide an incentive for future studies. It is hoped, in turn, that this work contributes to the context of nursing practice and research, as well as provides subsidies for the professional practice of the nurses that work with these clients. Likewise, it aims to explain the methodological route followed so that other researchers may confirm or refute the findings.

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Correspondence addressed to: Samia Jardelle Costa de Freitas Maniva
Rua Alan Kardec, 606 - Apto. 301 – Montese
CEP 60420-630 - Fortaleza, CE, Brazil