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Duality between following and giving up: feelings experienced by disabled patients after brain vascular accident

ABSTRACT | Objective: to identify and describe feelings experienced by disabled patients after a stroke. Method: Qualitative research, developed with six users of a physiotherapy school clinic, located in Vale do Paraíba, in the interior of São Paulo. For data collection, semi-structured interviews were applied, which were transcribed and analyzed according to the content analysis framework proposed by Bardin. Results: After thematic analysis, the data were grouped into three central categories: Feelings and emotions perceived after a diagnosis of stroke; Difficulties and limitations faced after stroke; Perceptions, coping strategies and post-stroke experiences. Final Considerations: It was evidenced that the way each person faces the disease and the limitations resulting from it, however, will depend on the unique attributes and the meaning given to the event, as well as the support and encouragement received from the family and the possibility access to health resources.

Keywords: Stroke; Adaptation; Nursing care; Feelings.

RESUMEN | Objetivo: identificar y describir los sentimientos que experimentan los pacientes discapacitados tras un ictus. Método: Investigación cualitativa, desarrollada con seis usuarios de una clínica escolar de fisioterapia, ubicada en Vale do Paraíba, en el interior de São Paulo. Para la recolección de datos se aplicaron entrevistas semiestructuradas, las cuales fueron transcritas y analizadas de acuerdo al marco de análisis de contenido propuesto por Bardin. Resultados: Tras el análisis temático, los datos se agruparon en tres categorías centrales: Sentimientos y emociones percibidos tras un diagnóstico de ictus; Dificultades y limitaciones enfrentadas después de un accidente cerebrovascular; percepciones, estrategias de afrontamiento y experiencias posteriores al ictus. Consideraciones finales: Se evidenció que la forma en que cada persona enfrenta la enfermedad y las limitaciones derivadas de ella, sin embargo, dependerán de los atributos únicos y del significado que se le dé al evento, así como del apoyo y aliento que reciba de la familia y del posibilidad de acceso a recursos sanitarios.

Palabras claves: Accidente cerebrovascular; Adaptación; Cuidado de enfermera; Sentimientos.

RESUMO | Objetivo: identificar e descrever sentimentos vivenciados por pacientes incapacitados pós Acidente Vascular Cerebral. Método: Pesquisa de abordagem qualitativa, desenvolvida com seis usuários de uma clínica escola de fisioterapia, localizada no Vale do Paraíba, interior de São Paulo. Para a coleta dos dados, aplicou-se entrevistas semiestructuradas que foram transcritas e analisadas conforme o referencial de análise de conteúdo propostos por Bardin. Resultados: Após análise temática, os dados foram agrupados em três categorias centrais: Sentimentos e emoções percebidas pós Diagnóstico de Acidente Vascular Cerebral; Dificuldades e limitações encaradas pós Acidente Vascular Cerebral; Percepções, estratégias de enfrentamento e experiências pós Acidente Vascular Encefálico. Considerações Finais: Evidenciou-se que o jeito como cada pessoa encara a doença e as limitações dela decorrentes, no entanto, vão depender dos atributos singulares e do significado conferido ao acontecimento, assim como do apoio e estímulo recebidos por parte da família e da possibilidade de acesso aos recursos de saúde.

Palavras-chaves: Acidente Vascular Cerebral; Adaptação; Assistência de enfermagem; Sentimentos.

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INTRODUCTION

It is estimated that the Cerebral Vascular Accident (CVA) or also called Stroke, is one of the major public health problems, nowadays with a high rate of morbidity on a national

and international scale, due to focal neurological impairment or global. Cardiovascular diseases, which include stroke, make up the most evident cause of death in all of Europe, including Portugal. Considered a silent, disabling pathology, which is characterized by transient or definitive deficit, caused by alteration of cerebrovascular circulation, resulting in the cessation of blood flow by arterial obstruction by thrombi or emboli, which limits the supplement of oxygen and nutrients in a certain area of the brain, responsible for the main causes of hospitalizations and for causing irreversible damage which can affect the subject's quality of life, requiring accuracy in the

identification of signs and symptoms for direct intervention ^(1,2)

According to its classification, stroke is divided into hemorrhagic caused by the rupture of small cerebral arteries that cause oxygen deprivation to neurons and, consequently, neuronal death. Another form is the Ischemic Stroke, motivated by the deficit or block in the cerebrovascular blood flow, which occurs due to clots or atheromas, the latter being the most frequent and with the best clinical prognosis, both hindering the person's return to daily activities and generating an impact on personal, family and social life, transforming everyday life. ⁽³⁾

In this perspective, the stroke constitutes a group of neurological disorders with etiologies and well diversified clinical pictures that, in the great majority of the times, can cause death or dysfunction, for example: aphasia, blindness, tactile, perceptual, mental and cognitive alterations besides physiological alterations and motor and behavioral limitations, which can generate different sequels from patient to patient, even if they are in very similar situations, which, due to these obstacles, start to depend on the help of others. ⁽⁴⁾

Approximately 75% of stroke survivors have hemiplegia, defined as weakness or partial paralysis on one side of the body, which, in most cases, is increased by spasticity. Both negatively affect functional performance and safety in dynamic activities such as walking, given this context that imposes several changes in the patient's lifestyle, being necessary to reframe individual experiences, and learn to live with the disease and/ or sequel, since only 10% of these individuals evolve without motor deficit or with minimal deficit without impairment of functionality in their activities of daily living (ADL's). ⁽⁵⁾

Given this aspect, the perception and feelings regarding the stroke sequel, can be considered one of the most suffered and comprises several aspects related to health, with the inclusion of information about the disease, as well as its symp-



Although there are quotes in the literature about the experience of illness due to stroke, it is observed that most investigations focus on the perception of family members and caregivers, therefore, there is a lack of studies aimed at experiencing the illness from the perspective of the victim of a Stroke.



tom, possible causes, long-term evolution and implications, taking into account individual and collective behavior and experiences. ⁽⁶⁾

However, for decades, this disease has affected new people every day around the world. It impacts the health of the population at a global level, constituting the main cause of neurological disability by compromising vital motor and cognitive functions. ⁽⁷⁾

In this context, nursing has an important action and must act in an appropriate, planned, qualified and humanized way, co-participating with the family, discussing the need to adapt to this new reality, in helping to cope and adapt the individual to this condition, in accordance with their limitations, in the daily challenges often encountered, such as "hands, legs and eyes", respecting and knowing their point of view, the way they see themselves, and then trying to be empathetic, understanding them and meet their needs, helping to educate themselves with this "new" reality. ⁽⁸⁾

Although there are quotes in the literature about the experience of illness due to stroke, it is observed that most investigations focus on the perception of family members and caregivers, therefore, there is a lack of studies aimed at experiencing the illness from the perspective of the victim of a Stroke.

Given this reality, the study starts with the following question: What are the feelings experienced by patients after sequelae caused by the Stroke? Seeking to better understand the arrangements of individuals who survived the stroke, given the duality between following or giving up imposed by the current condition of life.

However, the present investigation aimed to identify and describe feelings experienced by patients incapacitated by stroke.

METHOD

Article extracted from the Course Conclusion Paper entitled "Spirituality and the Perception of Disabled People

After Brain Vascular Disease", presented to the Nursing Graduate Department at Escola Superior de Cruzeiro/ ESC, Cruzeiro, São Paulo, Brazil. 2019.

This is a research of a descriptive and exploratory nature, with a qualitative approach, guided by the tool used for reporting the data collection COREQ (9), developed in a clinical physiotherapy school, which belongs to a Higher Education Institution located in a small municipality in the region known as Vale do Paraíba in the interior of São Paulo, Brazil, which serves people referred from Primary Health Care (PHC).

Participated in this study patients seen in the neurological physiotherapy sector of the school clinic chosen for the transferring field, regardless of the time of the post-stroke injury, of both sexes, over 18 years old and who were willing to formalize and accept to join the study, which occurred by signing the Free and Informed Consent Term, providing information relevant to the research, and by signing the Authorization Term for the Use of Voice Image and Sound for Research Purposes.

The sample was chosen at random, so that the study population was represented by people assisted during the second semester of 2019 in the months of September to October.

As inclusion criteria of this research were invited individuals affected by Stroke, conscious, lucid, oriented and verbalizing; who had some kind of motor, cognitive, sensory or visual sequelae; and

those who agreed to participate in the study. There was no exclusion criterion.

The procedure for data collection was carried out by means of a semi-structured questionnaire prepared and applied to the participants by the authors themselves, containing closed questions, referring to the sociodemographic profile such as: sex, age, marital status, religion, time of diagnosis and stroke type and consists of guiding questions such as: Describe for me: What feelings did you experience after the stroke? What difficulties do you face in your daily life after the stroke?

The average time of the interviews was 15 to 20 minutes, held mainly in the afternoon, considered the time of greatest flow of attendance at the school clinic. With a view to privacy, the approach took place individually, in a private room at the institution, at an agreed time in advance and the speeches were captured by an audio recorder and with the prior consent of the patients.

After the end of the interviews, the data were transcribed and analyzed according to the methodological framework of content analysis, in accordance with the steps proposed by Bardin, who, according to the author, this process composes a set of procedures that analyze the subjects' communication, based on systematic objectives of exposing the content of the messages in this way, harmonizes an accurate observation about the messages and the understanding of the in-

terviewees' conducts, providing greater scope on their perceptions. ⁽¹⁰⁾

Therefore, the analysis is organized in the stages of pre-analysis, exploration of the material, treatment of results, inference and interpretation, working on speech, specifically the practice of language, trying to know what is behind the words about which they express, at a given time. ⁽¹¹⁾

The determination of the number of participants followed the criterion of thematic saturation of the information.

To ensure the anonymity of the participants, speeches were protected and referenced using an association between letters and numbers. The letter P for Patient was used followed by an Arabic number corresponding to the order of the interview (Example: P1 to P6).

The research is in line with the ethical-legal criteria established by Resolution No. 510/2016, of the National Health Council, which deals with research on human beings. It was also appreciated and authorized by the manager responsible for the researched higher education institution, just as the project was submitted and approved by the Research Ethics Committee via the Teresa D'Ávila University Center - UNIFATEA- Lorena, São Paulo, Brazil, under the opinion number 3.554. 261 and Certificate of Presentation for Ethical Appreciation: 19925019.9.0000.5431 on September 4th, 2019.

RESULTS

Six (100%) users of the services offered by the school clinic who were undergoing neurological physiotherapy treatment participated in the study after a diagnosis of stroke.

Information regarding the participants' sociodemographic characterization is described in table 1.

The results of the present study indicate that only one participant (16,6%) was male, highlighting the predominance of females.

Considering the age group it was possible to observe that the average age of

Table 1: Sociodemographic data of the study participants, in a physiotherapy school clinic, in the interior of São Paulo, Brazil. 2019.

Participants	Sex	Age	Marital Status	Religion	Stroke type	Diagnostic Time
P1	F	44	Divorced	Evangelical	AVC I	4 years
P2	M	69	Married	Catholic	AVC I	2 years
P3	F	70	Widow	Catholic	AVC I	2 years
P4	F	36	Divorced	Evangelical	AVC I	10 years
P5	F	56	Married	Evangelical	AVCI	13 years
P6	F	70	Widow	Evangelical	AVC I	4 years

Source: Research data (2019).

the participants varied between 36 to 70 years, with greater concentration in the age groups of 69 to 70 years.

Regarding marital status, two respondents who correspond to (33,3%) claimed to be divorced, two (33,3%) declared to be widowed. In other words, women who lived in their homes, without partners or spouses, prevailed and only two (33,3%) were married and in a stable relationship.

When asked about the diagnosis and type of stroke, there was a predominance of (100%) among the six surveyed, with an Ischemic Stroke (I-stroke) report and with time between 2 to 13 years of coping with the disease .

Taking religion into account, four (66,6%) followed Protestantism, two (33,3%) professed the faith through Catholicism, all reported being doctrinal practitioners. In this way, we can infer that the study participants perceive and understand the importance of the religious and spiritual aspect in facing the adversities of life.

After thematic analysis, the data obtained were grouped into three central categories and their thematic units, which are: Feelings and emotions perceived after a diagnosis of stroke; Difficulties and limitations faced after a stroke. Perceptions, coping strategies and experien-

ces after a Stroke, as shown below and summarize, in a synthetic way, the themes and units of meanings explained in the interviews:

1st Central Category of Analysis: Feelings and emotions perceived after diagnosis Stroke

In this category, the participants reported changes and feelings experienced after communicating the medical diagnosis of stroke, and showed emotions initially characterized as sadness, hopelessness and worry.

Apparently, they are able to recognize the negative effects on their physical and mental health, as was very well exemplified in the following statements:

"[...] Difficulty walking, eating and talking, it was a difficult experience" (P1)

"[...] I felt afraid, worried and wanted to cry. It was a bad experience and feeling" (P2)

"[...] I I felt sad" (P3)

"[...] I was very weak and emotionally shaken, because I did everything and had to fight to be able to recover" (P5)

It is noticed that as a result, many be-

come insecure, with the feeling of being a nuisance in the lives of those who help them, and have a feeling of guilt, fear and bitterness.

Some interviewees in the study described experiencing episodes of continued discouragement, but at the same time there were feelings of strength and hope to live, followed by courage to face the adversities of life, these are feelings that go through daily, according to the statements that follow:

"[...] I felt sad, but I didn't lose hope" (P1)

"[...] I woke up in the ICU and I couldn't move my right side, the doctor explained that it was because I had an ischemic stroke, in addition to the aneurysm, I felt sad, but I am grateful to God for being alive" (P4)

"[...] I felt nothing and faced it" (P6)

It is noted that the patients used optimism, courage, confidence and gratitude when overcoming the difficulties imposed by the sequel of the Stroke.

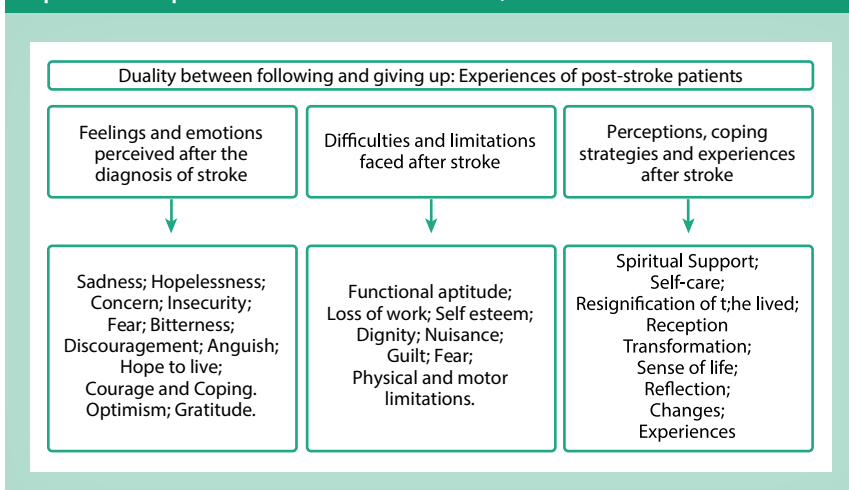
They also verbalized questions related to Divine power and its wisdom as faith, in addition to the ability of positive thinking to influence the disease process.

2nd Central Category of Analysis: Difficulties and limitations faced after stroke

In the statements collected, it is observed that the limitations are not only related to the damage of functional aptitude, but also to the loss of work, self-esteem and, in a way, dignity towards the family. The need to care for other people, especially the family, was highlighted.

In this context, it is part of the daily life of the person who is incapable and, often, to carry out activities that were previously done independently and now need to rely on the goodwill of family members, caregivers and even strangers. As a result of this, many become insecure, with the feeling of being uncomfortable in the lives of those who support them, and bring

Figure 1 - Diagram of the duality between following and giving up, based on the experiences of patients after a stroke. São Paulo, Brazil. 2021.



feelings of guilt, fear and anguish. In this sense, the speeches of the participants highlight this issue:

"[...] Difficulty walking, eating and talking"(P1)

"[...] I had difficulty moving my arms and legs" (P2)

"[...] Difficulty getting my daughter tidy" (P3)

"[...] It completely changes people's lives, but I'm taking it anyway" (P4)

"[...] I was in a wheelchair, wore diapers, didn't comb my own hair, I don't speak properly, but I'm a lot better compared to before. It was very hard and I didn't expect it. I was a very active person, I worked and now my limitations are many" (P5)

"[...] It changed my life a lot" (P6)

However, knowing how to live with feelings of physical limitations, total or partial dependence on loved ones and the absence of autonomy, can be a complicated challenge. In the reports, the patients interviewed claim to resent this limitation to perform daily activities, referring in particular to activities of daily living (ADLs). It is even a relative incapacity that leaves them fragile and powerless in the face of society.

3rd Central Category of Analysis: Perceptions, coping strategies and experiences after stroke

It is observed that patients used the main strategy of coping focused on the problem with spiritual support. In other words, the individual makes an effort to act in the situation that caused him restrictions and tends to transform the existing difficulty, developing new self-care skills to follow his life journey. The testimonial, below, illustrates this:

"[...] It was bad because I can't do anything else. But I got really attached to the spiritual part to over-

come the challenges" (P3)

"[...] It completely changes people's lives, but I'm taking it anyway. My husband left, left me and separated from me, I live with my mother along with my daughter (P4)

"[...]It was very hard and I didn't expect it. I was a very active person, I worked and now my limitations are many" (P5)

"[...] It changed my life a lot" (P6)

It is clear that the experiences lived by the participants, through the reports, showed the resignification of what was lived, to the point of welcoming the illness as an event that served to strengthen them. In other words, it has become an opportunity to find meaning in life.

However, these circumstances provide intense internal reflections and, in many moments, provoke significant changes in the lives of those who experience them.

DISCUSSION

Taking into account that the occurrence of Stroke has shown a predominance in female people,⁽¹²⁾ as it also occurred in this study, therefore, the women affected have a lower quality of life than men, probably due to the functional impairment that limit manual dexterity for domestic services, in this context the professional occupation outside the home stands out, as they are the principally responsible for tasks, often carried out exclusively by them; this source of stress is associated with the age factor and predisposes to a greater onset of stroke after menopause, making the female population more vulnerable to cardiovascular and cerebrovascular diseases.⁽¹³⁾

Faced with a population aging scenario associated with Chronic Noncommunicable Diseases (NCDs), which currently constitutes a public health problem, there is a relevant relationship between the onset of stroke in this age group, occurring a

marked increase, preferably from the sixth decade of life onwards, doubling every decade.⁽¹⁴⁾

Corroborating this result in view of the life expectancy of the general population, in recent years there has been a concomitant increase in the prevalence of NCDs, which are important risk factors for stroke in the world, coming in line with the literature,⁽¹⁵⁾ which states that 70 to 80% of strokes are of the ischemic type, being considered the most common, while 9% are hemorrhagic and arises as a result of arterial block.

In this perspective, a research carried out in Italy points out that the prevalence of impairment and the change of status or loss of occupational identity due to cognitive impairment after a stroke, has been identified as one of the significant sources for a person's imbalance, because the decline in quality of life, or even the impossibility of performing routine activities and as probable dysfunctions and disability retirement can prevent the person from returning to the level of adaptation prior to adversity.⁽¹⁶⁾

It is also relevant to discuss the religiosity variable, considering that for the interviewees, the religious aspect emerges as a positive association between religion and prosperity, which corroborates with the results of other surveys.^(17,18) According to the same authors, this positive association is justified due to the individual and collective connections that such activity provides. In addition, it provides support in the face of daily difficulties, coping with diseases, especially those of a chronic nature and overcoming the loss of close people.

Still in this context, religion also promotes social interaction and support between the family and other members of society. Religion and spirituality are both beneficial to family members and patients who live with the sequelae of stroke.⁽¹⁹⁾

In the investigation of feelings, emotions, the perceptions experienced by the participants were synthesized in a few words, such as: sadness, hopelessness,

fear, the desire to cry, feeling bad, discouragement, contempt, negative experience, anguish and concern, in view of this situation, it is natural to have these yearnings, as they are going through a turbulent and adaptation phase.

In terms of hopelessness and emotional instability, these represent the complaints most commonly experienced by the interviewees, being described as feelings that arise as a feeling of incapacity that causes the disruption of functional life, sleep disorders, changes in eating with excessive and sudden increase or weight loss, lethargy, lack of motivation, social isolation, tiredness, self-loathing and suicidal ideas are some of the signs that may indicate the depressive process caused by coping with the post-stroke period. On the other hand, the damage to brain structures can also contribute to and be responsible for some of the emotional changes.⁽²⁰⁾

The participants made it possible to unveil the experience in the existential sphere in the face of suffering as something inevitable in people's lives, making it impossible not to have the freedom to face it, since the human being needs the tension to re-signify his existence and the responsible non-positioning in the face of anguish causes the being to be lost, adrift and unconformed, but it is necessary to face suffering in the face. It is noteworthy, therefore, that the human being should not live a meaningless life, on the contrary, he should seek, take refuge and redefine this feeling every day for a fuller and happier life, even in adverse circumstances.⁽²¹⁾

These emotional changes must be taken into account, since the individuals are fragile and intensely unhappy with the situation of dysfunction of their own personal image, as a result of what they have endured, causing a low self-esteem, personal devaluation, accompanied by a feeling of inferiority to other people, can be part of the daily lives of these individuals.

Therefore, the results obtained through the interviews indicate that the main difficulty after a stroke was in the motor

sphere, referred to by deficit in walking, speaking, moving the arms and legs, along with limitations of functions that used to be part of activities of daily living, such as eating, dressing, grooming, bathing, using the bathroom and walking, pointing out radical changes in lifestyle.

Another factor of difficulty that patients encounter is the dependence on others to perform routine tasks, it is worth mentioning that patients need to get used to their new reality, which is now present in this patient's life path, however, knowing how to live together with physi-



It should be noted that discussing the experiences of illness due to stroke is essential for the health care of this clientele. Because, when falling ill, the subject does not only require professionals to examine their symptoms, but also seeks care to rebalance in the face of new feelings awakened by suffering



cal restrictions and lack of autonomy can be challenging.

It should be noted that discussing the experiences of illness due to stroke is essential for the health care of this clientele. Because, when falling ill, the subject does not only require professionals to examine their symptoms, but also seeks care to rebalance in the face of new feelings awakened by suffering⁽²²⁾.

Considering that nursing care is fundamental starting in the health process, both physical and emotional, where each patient will have their treatment directed until recovery. It has the role of promoting dignity, preserving balance, and recovering human totality. The representation of the participants about the change in their lifestyle indicates the need to conserve with as little stress as possible, and as a consequence interfere in their state of emotional well-being, when referring to the fear and sadness caused by the post-stroke impact.

In this perspective, the family is seen as a part of the sick person, experiencing anguish, fear, separation and behavior change, the study raised the issue of abandonment by some revealing that they live alone and that their spouse separated after the diagnosis of stroke, family support and well-being generated by family and friends has been fundamental for adhering to the process of recovery, acceptance and coping with this reality.

The limitation of this study is related to the non-generalization of its consequences for the entire population that faces the sequelae caused by the Stroke, since it is mentioned in a small group of patients, with the production of data in only one scenario. However, it was possible to highlight aspects related to the feelings of people who face the duel between following and giving up after a stroke. Another obstacle was the low number of participants and the regionalization that in urban metropolises may differ from the data revealed in this study.

Nevertheless, the results allow for a qualitative and in-depth discussion of

the information involved, which can be applied to people who experience situations similar to those of the research participants.

CONCLUSION

It became evident that the way each person faces the disease and the limitations resulting from it, however, will depend on the unique attributes and the meaning given to the event, as well as the support and encouragement received

from the family and the possibility of access to health resources and professionals who discuss and report on the subjective issues surrounding the disease and obstacles, in addition to guiding and assisting in recovery, reframing and/ or adapting to lost functions.

Thus, the in-depth knowledge of those who perform this role is essential for the preparation of quality and effective nursing care planning, with a view to the needs to guide the development of public policies that meet the real needs of these

people, since the stroke is considered a public health problem.

Developing this study leads us to reflect on the consequences of the illness of a person with sequelae due to stroke, which made us more human and committed to social reality.

The results obtained and the knowledge achieved in this study, will contribute to future research and will serve as a guide for health professionals, caregivers and family members about the feelings and difficulties experienced by individuals after a stroke. 🐦

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