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## Care path of person with stroke: from onset to rehabilitation

*Percurso da pessoa com acidente vascular encefálico: do evento à reabilitação*

*Camino que recorre la persona con accidente vascular encefálico: desde el acontecimiento hasta la rehabilitación*

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### ABSTRACT

**Objective:** to describe the care path of the person with stroke goes through and to identify the important events in this path. **Method:** qualitative descriptive exploratory research, using the semi-structured interview technique based on Meleis's Middle-Range Theory. The sample was composed of 13 people who became dependent after a stroke and were admitted to two hospital units in the region of Vale do Ave, Portugal. Data were collected between January and October 2013. Content analysis was used to analyze the data. **Results:** The data revealed that the person's care path goes from recognition of the symptoms to preparation for hospital discharge. Adapting to the new situation of dependence brings the need for new competencies. **Final considerations:** The research aims to contribute to the improvement of nursing care regarding care for people with stroke including onset, recovery and rehabilitation, and home care. **Descriptors:** Stroke; Disabled Persons; Nursing Care; Rehabilitation; Rehabilitation Nursing.

### RESUMO

**Objetivo:** Descrever o percurso da pessoa com Acidente Vascular Encefálico e identificar os acontecimentos significativos neste percurso. **Método:** Abordagem qualitativa e natureza exploratória- descritiva, valeu-se da técnica de entrevista semiestruturada baseada na Teoria de Médio Alcance de Meleis. Participaram 13 pessoas que se tornaram dependentes devido à Acidente Vascular Encefálico e recorreram a duas Unidades da região do Vale do Ave, Portugal. A colheita de dados deu-se durante Janeiro a Outubro de 2013. Para análise dos dados foi utilizada a análise de conteúdo. **Resultados:** Os dados revelaram que o trajeto da pessoa vai desde o reconhecimento dos sintomas até à preparação da alta hospitalar. A dependência traz a necessidade de adquirir competências para se adaptar à nova situação. **Considerações finais:** Espera-se contribuir para a melhoria dos cuidados de enfermagem no atendimento das pessoas acometidas com Acidente Vascular Encefálico, desde o acometimento, recuperação e reabilitação, até aos cuidados domiciliares. **Descritores:** Acidente Vascular Cerebral; Pessoas com Deficiência; Cuidados de Enfermagem; Reabilitação; Enfermagem em Reabilitação.

### RESUMEN

**Objetivo:** Describir el camino que recorre la persona con Accidente Vascular Encefálico e identificar los acontecimientos significativos de ese camino. **Método:** se trata de un abordaje cualitativo de naturaleza exploratoria- descriptiva, con técnica de entrevista mixta basada en la Teoría de Mediano Alcance de Meleis. Participaron 13 personas que se volvieron dependientes debido a un Accidente Vascular Encefálico y recurrieron a dos Unidades de la región del Valle del Ave, Portugal. La recolección de datos se realizó durante el período comprendido entre enero y octubre de 2013 mediante el análisis de contenido. **Resultados:** Los datos rebelaron que el trayecto de la persona comienza con el reconocimiento de los síntomas y se extiende hasta la preparación del alta hospitalaria. La dependencia hace surgir la necesidad de adquirir competencias para adaptarse a la nueva situación. **Consideraciones finales:** Se espera

contribuir para la mejoría de los cuidados de enfermería en la atención de los pacientes con Accidente Vascular Encefálico, desde el acontecimiento, durante la recuperación y la rehabilitación, hasta los cuidados domiciliarios.

**Descritores:** Accidente Vascular Cerebral; Personas con Deficiencia; Cuidados de Enfermería; Rehabilitación; Enfermería en Rehabilitación.

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## INTRODUCTION

The Cerebrovascular accident (Stroke) is an incapacitating disease that can lead to death and requires quick identification and immediate intervention. The number of people having a stroke has increased<sup>(1)</sup>. In Brazil, between 2008 and 2011, there were 424,859 hospitalizations of elderly people due to stroke, with a mortality rate of 18.32<sup>(2)</sup>.

Cardiovascular diseases, including stroke, are the most relevant cause of death across Europe, including Portugal<sup>(3)</sup>. In this country, stroke remains as the main cause of morbidity and potential years of life lost among all cardiovascular diseases<sup>(4)</sup>. stroke is the second leading cause of death and disability, usually leaving many physical, mental and social sequelae and restricting functionality, especially in activities of daily living (ADLs)<sup>(5)</sup>.

Population ageing and a progressive increase in functional dependence, especially after a stroke, implies an increase in additional care needs. For this reason, consumption of health care services has increased, since the majority of hospital discharges are of people over 65 years old who need not only an intervention to cure an acute situation but also a new approach, person-centered, integrating health and social security systems to support their needs in basic life activities and in care related to rehabilitation and reintegration<sup>(6)</sup>.

Functional incapacity causes difficulties that depend on the area affected, the level of the injury and the individual capacity for recovery. These difficulties interfere in the quality of life and impact daily life of the person affected and the family. The degree of disability determines the care dependency and, consequently, the challenge presented to the caregiver/family<sup>(7)</sup>.

At the onset of signs and symptoms of a stroke, health services must be contacted urgently. In Portugal, the *Instituto Nacional de Atendimento Móvel de Portugal*<sup>1</sup> (INEM) should be contacted through the number 112, and, in Brazil, the *Serviço de Atendimento Móvel de Urgência*<sup>2</sup> (SAMU) through the number 192. Both provide first care and transportation to the most appropriate hospital unit. When the time between onset of signs and symptoms and arrival at the hospital is shorter than 4.5 hours, it allows the administration of acute phase therapy, such as thrombolysis, reducing symptoms and sequelae after the stroke, in case this is an ischemic stroke<sup>(8)</sup>.

In Portugal, when the thrombolysis performance is possible, people are referred to stroke Units, located in central and district hospitals. The units are networked, allowing patients to start treatment in a special unit and continue their care in

another unit (in their area of residence), when it is clinically possible, enabling the special unit to receive other patients<sup>(4)</sup>.

In Portugal, stroke Units have a specialized multidisciplinary team that works coordinately to meet the patients' needs. Physicians, Nurses, Rehabilitation Nurses, Physiotherapists, Speech Therapists and Social Assistants are part of the team<sup>(9)</sup>. This team initiates rehabilitation after the stroke as soon as there is hemodynamic and neurological stability.<sup>(10)</sup>

Returning home, the prospect of care diverges from the one provided at the hospital, and this is the beginning of the transition from the hospital healing process to the home care process. The transition is the passage from one phase of life to another in face of different conditions or status in a particular social context<sup>(11)</sup>.

The transition is not only an event, but the personal reorganization and redefinition to incorporate changes into the patient's life<sup>(12)</sup>. Authors also mention that transition is not only the changing process, it also includes the psychological process that is involved in adapting to the transition events<sup>(13)</sup>. Its importance lies in the knowledge acquisition and acceptance of new roles in the process. In this transition moment the family has to deal with changes in the functional abilities and the body image of the survivor. The caring process in this transition depends on the society's and family's culture. Each family conceives the care that has been designed throughout history within their knowledge, habits, customs, language, beliefs, family environment and relationships network with the patient<sup>(14)</sup>.

Health professionals, especially Rehabilitation Nurses, play a key role with people who become dependent after a stroke by developing and implementing a self-care training program in order to adapt these people to mobility limitations and to maximize their autonomy<sup>(15)</sup>.

Dependence limits the person regarding their self-care, family role and social and work participation, consequently impairing quality of life<sup>(16)</sup>. The nurse's role is fundamental because it is this professional's responsibility to guide, educate and supervise the care provided.

Rehabilitation Nursing has three main objectives: maximize self-determination, restore functionality and optimize patient's lifestyle choices<sup>(17)</sup>. The specific competence of the Rehabilitation Nurse is providing care for people with special needs, helping them to return to a full life<sup>(15,18)</sup>.

Currently, the prospects for the person with stroke are more promising, but ensuring quality rehabilitation involving patients and relatives is necessary. An encouraging environment and a multidisciplinary team available to the caregiver and to the patient

1 This is a National Mobile care institute in Portugal

2 This is a National Mobile emergency care in Brazil.

are fundamental for a successful rehabilitation. The family's involvement and the assurance of a permanent education to the caregiver/family and to the patient are fundamental. This contributes to a better quality of life for both the patient and the family.

Dependence after a stroke has a strong impact in the life of the person and the family, which justifies the study of this issue in a region of northern Portugal. This research arose during a Master's Degree in Rehabilitation Nursing due to an interest in understanding and analyzing the process experienced by people who transition from autonomy to dependence after a stroke. In this article, we only assess the health-illness transition after a stroke, the situational transition is not explored.

One of the strategies to face the health care challenges related to the population with stroke is to assess the in-depth description of this process for the development of a nursing care plan<sup>(14)</sup>.

Based on the above, this article aimed at knowing the care path of the person with stroke and identifying the meaningful events in this care path. Here, the care path is understood as the trajectory covered from the onset of the symptoms of the stroke until rehabilitation. This research is one of the results from the master's degree dissertation about Rehabilitation Nursing at the School of Nursing of Porto, in Portugal.

## METHOD

### Ethical aspects

The research met national and international standards for research ethics involving human subjects. The project was submitted to the Research Ethics Committee of the Hospital Administration Council, approved under the protocol number 52/2012. The participants who accepted to participate signed a Consent Form (CF). Anonymity was maintained using alphanumeric identification (I-interviewed, followed by a number from 1 to 13).

### Theoretical and methodological framework and study type

The methodology that guided this study was an explorative and descriptive qualitative approach, aimed at understanding complex phenomena related to the care path of the person with STROKE.

The theoretical and methodological framework was the Afaf Meleis' transitions theory, detailed below.

The three domains of the COREQ were followed: research team and reflexivity, study design, and data analysis and reporting<sup>(19)</sup>.

### Study scenario

The research was conducted at stroke Units in the Ave region of northern Portugal. The stroke units are composed of multidisciplinary teams working within the hospital institutions, responsible for the care in the acute and post-acute phases. Its purpose is to promote care and initiate treatment and early rehabilitation.

### Study participants and data source

People who had a stroke and became dependent participated in the study. The sample consisted of thirteen people from the Vale do Ave region, that were admitted to two stroke units between the 1<sup>st</sup> and 10<sup>th</sup> day after the stroke occurrence

- acute phase. The participants were selected intentionally, with the help of health professionals in these units. In order to find the participants, the professionals from these stroke units who worked directly with the patients were contacted to indicate which patients met the inclusion criteria: diagnosis of a stroke of the middle encephalic artery between the 1<sup>st</sup> and 10<sup>th</sup> day of its occurrence, causing functional dependence. Exclusion criteria were: diagnosis of multifocal stroke, with aphasia or disorientation. The possible participants indicated were contacted personally by the researcher and invited to participate in the research. The reasons and objectives of the research were explained. After acceptance, the interview was scheduled.

### Data collection and organization and research phases

For the data collection, the in-depth semi-structured interview was conducted by the researcher herself, and additional information was provided by the health professionals responsible for these people in their respective Units. The information requested from the professionals was related to the degree of functional dependence of the participant.

The interview consisted of twenty open questions with a script divided in three moments: the first one consisted of questions focused on socio-demographics and family conditions; the second was the assessment of the dependency through the Barthel Index; and the third one contained the central questions of the research, also organized by areas: conditions of transition, dependence and preparation for the return home and personal, family, social and professional roles.

The theoretical framework that supported the elaboration of the interviews was Meleis' middle-range Transitions theory<sup>(20)</sup>. The three domains of this theory (nature of transition, conditions of transition and patterns of response to transition) allow the identification of the possible patterns, properties, personal, social and community conditions, and the transition process and results, with the objective of developing and implementing a nursing care plan. Meleis' middle-range Theory of Transition provides a better understanding of the transition process, since through a more complete and in-depth view of the post-stroke transition it is possible to establish guidelines for nursing practice, allowing nurses to use strategies that facilitate the transition to dependence after a stroke, according to individual needs, difficulties and concerns.

Previous interviews were conducted to explore and confirm the existence of difficulties encountered in the interview with these people and to serve as training for the investigator. The interviews were recorded in a digital recorder, after authorization of the interviewees and had duration of approximately 40 minutes. They were conducted in a private space provided by the health service. Each interview was transcribed and assigned a registration number according to the order in which the interviews were conducted.

### Data analysis

Content analysis was used to analyze the data<sup>(21)</sup>. The interviews were read in depth, and the categories emerged. The analysis and interpretation of the information obtained consisted in the cut-off points of the transcriptions and

codification and categorization of the information found. The relevant categories emerged were related to the moments of onset of stroke, the stroke itself and after stroke. The emerged categories were: signs and symptoms of stroke, transportation to the hospital, adaptation to the situation of illness and dependence, integration in the hospital, preparation for discharge and awareness of changes in personal, family, social and professional life.

## RESULTS

Seven of the participants were female and six were male. Their ages ranged between 48 and 76 years. Level of education ranged from illiteracy to 9<sup>th</sup> grade, and most of them had completed the 3<sup>rd</sup> year of primary education. Only one of the participants did not present a risk factor for a stroke. The others are either hypertensive, diabetic, obese, with atrial fibrillation, hypercholesterolemia or have alcoholic or smoking habits. The Barthel Index used to assess the degree of dependence of the participants showed a greater number of moderate dependence. Three participants presented mild dependence, seven presented moderate dependence and three presented severe dependence.

After the stroke the person transitions from a state of health to a state of illness and dependence to which they must adapt, and they have to go through the process of rehabilitation trying to regain independence. This justifies the need for help and support from family and caregivers, in order to better adapt and accept the new disease and state of dependence.

This process happens in an unexpected and abrupt way, without perceiving any prodrome, as reported by the participants:

*[...] out of nowhere. (E1)*

*[...] I woke up like this. I was washing my face and saw a different face. I wanted to talk and I couldn't. (E4)*

The stroke occurs at any time of the day or night, during any activity, any day of the week. There is no way to determine if there is a period with higher frequency of occurrence:

*On Monday morning, I was lying on the couch. I got up and was dizzy and my hand was stuck. (E6)*

*This happened at 2 in the afternoon, I was working. (I13)*

*I was in bed sleeping and it happened out of nowhere. (I1)*

The initial symptoms are not perceived as serious. They are seen as something that is not right, without considering the extent of the problem. There is no association with the stroke:

*I started with headaches. (I1)*

*I started feeling that I not seeing well [...]. (I5)*

*[...] I picked up my clothes to go to the bathroom to take a shower and when I laid my clothes on the bath I felt ill and I thought I'm not well, I'll go to bed. I got out of the*

*bathroom, got into the laundry room and felt I was going to fall. I leaned against a piece of furniture, felt a weight on this left side, fainted and fell. (I3)*

*[...] I was working, I went to the warehouse to look for material and when I left the car I started to feel my leg escape, but I ignored it.. (I13)*

The failure to perceive the severity of the symptoms and the lack of association with a serious health problems result, sometimes, in people not asking for immediate help and waiting for the problem to improve by itself.

*On Tuesday afternoon, my sister-in-law came by my house and I told her I couldn't move this arm. (I6)*

Others, upon the identification of the symptoms, call family members, neighbors or health professionals in an attempt to seek help:

*I called my daughter. (I5)*

*[...] I came crawling to my room and told my husband I wasn't well. (I12)*

*I called out my sister who lives over my house. (I4)*

*I called the doctor to come. (I6)*

*I went downstairs and called the firemen. (I7)*

*[...] the neighbor called me and I told her I wasn't well. (I11)*

The transportation used depends on the help request. It is the ambulance if the person requests for medical services and the family car if the person calls a relative. Health services are more mentioned regarding transportation. In one of the cases, the person walked to the health unit:

*They called the fire department, called the ambulance and I came to the hospital.. (I1)*

*I called my son and he brought me here in his car. (I8)*

*[...] I came to the health center on foot cause it's close by. (I13)*

In summary, the person does not give proper attention to the stroke symptoms, associating them to a simple health problem. When they realize that the problem is more serious, they ask for help from relatives, neighbors, or even health services, and are immediately transferred to hospital institutions, staying hospitalized for varying periods.

During the transition process after the onset of the stroke, the person has to adapt to the different hospital environment and routine, created by health professionals to the group of hospitalized people, without considering the individual needs. In addition, the stroke creates completely new physical difficulties and obstacles, which the person will have to experience and deal with:



*It was difficult to be in here, entering the hospital for me is an obstacle, I am used to move a lot and I am imprisoned in here. (I13)*

*The STROKE is very complicated. (I12)*

*We have to live one day at a time. (I1)*

*I have no strength in this hand. I see poorly with this eye. (I4)*

During hospitalization, people with stroke already begin rehabilitation, which consists in restarting activities related to self-care, cognitive-motor training, body balance, proprioception and daily activities, under the responsibility of rehabilitation nurses. At this moment, these people show a will to learn. They look for information regarding their situation and what they must do to improve, actively participating in the rehabilitation process, in an attempt to regain their independence:

*[...] I want to learn to walk again, see if my legs can get better, if I can balance myself standing without falling. (I1)*

*I hope they help me to become as independent as possible. (I7)*

The participants identified their acquired competencies in several domains related to self-care, motor activity and proprioceptive sensitivity, which met their needs and expectations regarding health care. From the reports, it was observed that Rehabilitation Nurses were the ones who taught and trained them in the following areas: bathing, going to the toilet, eating, and walking:

*I find the exercises they make us do positive; training how to bath. (I3)*

*The nurses help me to take a shower on my own [...]. (I4)*

*Today they helped me to go to the bathroom, it was the first time I got up and started walking. I was very happy to go there and take care of myself. (I8)*

*I can already eat by myself [...]. (I1)*

*Today I walked, I was standing by the bed, and a Nurse helped me walk. I walk, but only with support. (I6)*

*If I can hold to the nurse I walk fine, if she leaves me I fall, I can't balance myself. (I1)*

Even after stabilization of the stroke, returning home is an event that really worries the person and the family, since the confrontation with the incapacities generates insecurity and uncertainties:

*I'm not ready to go home. Not now, I'm not sure. (I6)*

Since the stroke is an incapacitating disease that leads to a state of dependence, there is a need for continued care after

hospitalization. When the person feels able to return home or has family support, they decide to go to their own home; some of them, in order to not be alone, go to their children's home or don't know where to go. There are also situations in which the family and the person choose to go to a Continued Care Unit, in order to recover faster and become independent as quickly as possible. Continued care is a network of palliative and rehabilitation care that includes hospitalization and home and outpatient care, with a proper team for these purposes.

*When I leave here I want to go to my home. (I13)*

*I was in my house and I lived alone, I was doing well. But now my children said that I won't go to my house. I still don't know with which child I'm going to live. (I8)*

*Next month I don't know where I'll be. My house has lots of stairs. Perhaps I will go to the continued care or to my attachments that are ground-floor. (I3)*

*When I leave here I'll go to the Riba D'Ave Hospital for Continue Care or another one which is available. (I1)*

Family life is strongly affected by the disease and by the dependence it causes. There is a reorganization of family life, with a care overload for some family members. On the other hand, the imminent feeling of loss and the need for care aroused by the disease tends to strengthen ties and to bring closer people distant from the family nucleus:

*They will check with each other what to do [...] now we have to be looking after our mother. I have confidence in my children. (I8)*

*The good relationship with my daughter and grandchildren will continue, but my daughter will be jeopardized [...] she already has a lot of work and now me. (I3)*

*My family life will be better. I have a 33-year-old daughter and she had not spoken to me for a while, now, after this illness, she does. (I2)*

Rehabilitation Nurses are regarded as health professionals with an essential role in this transition process, since in addition to facilitating self-care for the post-stroke person and family, they also stimulate as much independence as possible, without replacing the person in the activities in which they are autonomous, promoting the adaptation of the patient and family to the external environment, eliminating barriers to the satisfaction of needs and mobilizing community resources for the purpose of their reintegration into the social, economic and cultural environment.

The care path of the person with stroke starts from the lack of knowledge and negligence of the signs and symptoms, and goes through a necessary urgent hospitalization, the sequelae and dependence caused and a long period of recovery, with the family's support. There is a radical change in a short period of time.

**Chart 1** – Care path of the person after a stroke

1) stroke appearance *			
Sudden onset, any time of day		Early symptoms and evolution of the stroke* identified by the person, family and witnesses	
2) During stroke*			
Contact after identifying the symptoms – Relatives, Firefighters, Health professionals, Neighbors, Boss		Transportation to the hospital after identifying the symptoms - Car, Ambulance, On foot	
3) After stroke*			
<b>Adaptation to a state of illness and dependence</b> - Positive and negative feelings; Awareness of the change; Acceptance of the health situation; - Transition conditions - Facilitators/Inhibitors - Concerns - - Personal - Relatives	<b>Hospital Integration-</b> Perception of the health team; Professional Relationship; Constitution of the multidisciplinary team; Perception, expectations and satisfaction regarding health care	<b>Preparation for discharge and return home</b> - Involvement of the person in Rehabilitation; Domain of new competences; Perception of the return home and the future; Family support	<b>Destination after discharge-</b> Home (own home or children's home); Continued Care Unit

Fonte: Adaptação de Faria, 2014.

Nota: \* AVE – Acidente Vascular Encefálico

## DISCUSSION

This research investigated the care path of the person with stroke in the acute phase, based on the Transitions theory, uncovering some aspects of this care path. These aspects are encountered through people with stroke cared for in a stroke unit, which limits the study since other places of care are not contemplated. The research is also restricted to the first days after stroke, meaning that other studies are needed to extend this period, since the sequelae resulting from this condition are long lasting.

The research points out important elements for the care of this population, outlining the main issues related to the moment of the event and the first care. These information improve nursing work regarding health promotion, protection and care of these people.

Regarding the age of the participants, this research is based on recent studies that indicate that the cumulative effects of aging associated with an increase in the number of risk factors and their natural progression substantially increase the risk of stroke, and that every 10 years after age 55 the risk of stroke doubles<sup>(1,22-23)</sup>. In addition to this, there are the risks found in the study population.

Lack of knowledge or negligence regarding signs and symptoms of a stroke can lead to a delay in seeking medical care, with consequences for post-stroke treatment, decreasing the probability of minimizing sequelae. The degrees of

dependence found are in accordance with other studies<sup>(24-25)</sup> which report that one-third of the stroke survivors present moderate to severe dependence, requiring permanent care from third parties. From the statements, we found that the families of the participants take very different structural and relationship configurations, including those that presume comfort for family integration and those that presume difficulties in the return home.

The findings show the care path of the transition process, outlining the transportation to the hospital, adaptation to the situation of illness and dependence, hospital integration, preparation for discharge and changes in personal, family, social and professional life. The stroke occurs suddenly with symptoms that last more than 24 hours, including: un-coordination; unilateral or bilateral sensory impairment; aphasia/dysphasia; hemianopia; conjugate deviation; apraxia of acute onset; ataxia of acute onset, perception deficit of acute onset<sup>(5)</sup>.

This study was also compatible with other researches which found that some people do not identify the signs and symptoms as an alarm of a stroke. However, approximately 33-50% of people recognize their own symptoms as a stroke<sup>(9)</sup>. Stroke prognosis depends, among other issues, on how quickly it is treated, which explains the need for early intervention<sup>(9)</sup>. Stroke treatment after detection of signs and symptoms should be an emergency. As such, it is of utmost important to quickly contact Emergency Medical Services, since the longer it takes, the higher are the chances of brain loss. Therefore, the main objective of a stroke pre-hospital phase is to avoid delays. Recognition of signs and symptoms by the individual, relatives or witness is essential for the prognosis. However, only about 50% contact the Emergency Medical Services, according to the authors. The main causes for the delay in contacting medical help are lack of knowledge of the symptoms of a stroke, not recognizing their severity and also denial of the disease and hope for the suppression of these symptoms<sup>(8)</sup>.

Time between onset of stroke symptoms and diagnosis/treatment is important to reduce mortality and morbidity. Decreasing this time is a priority in all stroke programs, especially when regarding ischemic stroke, since the therapeutic window for thrombolysis is in the first 4.5 hours after onset of symptoms<sup>(8,26)</sup>. Thrombolysis is essential since it may reverse the symptoms, resulting in few or no sequelae. These findings are in accordance with the research<sup>(9)</sup> which states that the medical care is rarely sought by the patient him/herself and mostly by a family member, not providing the patient access to health care in the fastest way.

Transportation to the hospital by ambulance or emergency medical services is the fastest way<sup>(9)</sup>. A study indicates that in the transport to the hospital the person already experiences a process of mourning their losses<sup>(27)</sup>. The person goes through four stages: initially through a phase of shock, then denial, awareness and finally adaptation.

The shock phase takes place right after the first care and corresponds to a state of confusion where the person cannot perceive the importance of the event. At this stage the person disconnects from the outside world in an unconscious attempt to protect their body image.

Caring is the purpose of the nurse's job. Educating for self-care is within their professional training and it is the nurses' role as caregivers and educators. They assume the role of "bridge" between patient and family, as well as between hospital and home environment. The hospital discharge does not imply total recovery and therefore, they should assure the continuity of care, either through the family or health institutions, these actions are essential so that the patient can be reintegrated with the highest degree of independence in the community. The Rehabilitation Nurse is responsible for helping the person and family with the discharge plans, educating the caregiver and other important people and planning the patient's continued care and reintegration into the community<sup>(15)</sup>.

In the 2006 Helsingborg Declaration, one of the goals set by the WHO, to be achieved by the year 2015, is the continued access to organized care from the acute stage to rehabilitation, with the objective that over 70% of the surviving patients are independent in their ADLs within 90 days after the stroke<sup>(2,28)</sup>.

After discharge, 88.3% of people who had a stroke remained in the same family nucleus, but the future is uncertain for 46.78% of them<sup>(4,29)</sup>. The analysis shows different care paths of people with mild dependence in relation to those with severe dependence. Participants with more severe dependence choose to be reinstated in Continued Care Units until they become more autonomous after discharge from the hospital, while participants with mild to moderate dependence go to their homes or to their children's homes after discharge. The need for a redistribution of roles and responsibilities among members of the family and the changes in daily life routines are unavoidable situations<sup>(30)</sup>. Regarding the transition process itself, the participants expressed: awareness of the change; verification of changes and differences in personal, social, family and professional life; involvement in the rehabilitation process through participative rehabilitation and pursuit of information. The critical events identified in this transition process were the adaptation to the situation of illness and dependence, the integration in the hospital and the preparation for the return home.

Some conditions eased the transition, such as the observation of clinical improvement; a good relationship with health professionals, especially the nurses; the support of family members through hospital visits; and the presence of every human and material resources during hospitalization. Some conditions hindered the transition, such as how the person felt about being away from home, the sensation of psychological

limitations, the loss of appetite, the limitations resulting from the stroke and the difficulties felt to adapt to the new conditions. The family also had difficulties adapting and accepting the new condition of their loved ones.

Regarding answer patterns, the process indicators found were: positive and negative feelings; interaction with health professionals; understanding and facing the new situation; the return home and prediction of difficulties in the future; and the development of trust and coping with the support of health professionals who provided knowledge of the disease and prepared the return home. The results indicators found were the acquisition of new self-care, motor activity and proprioceptive sensitivity competencies, the attribution of meaning to the life after illness and the awareness of changes in family, social and professional life.

Rehabilitation Nurses are regarded as health professionals with an essential role in this transition process, since in addition to facilitating self-care for the post-stroke person and family, they also stimulate as much independence as possible, without replacing the person in the activities in which they are autonomous, promoting the adaptation of the patient and family to the external environment, eliminating barriers to the satisfaction of needs and mobilizing community resources for the purpose of reintegration into the social, economic and cultural environment.

### Study limitations

The research was carried out in a region of northern Portugal, so the profile of the inhabitants of this region may have influenced the results. However, the overall findings are in accordance with the reality observed both in Portugal and in Brazil. We also point out that we only follow the person's post-stroke care path in the acute phase, between the first and the tenth day after the stroke, so the experiences of post-stroke dependence after returning home are still to be explored.

### Contributions to the Nursing area

This study has contributed to increase the knowledge of Nurses, especially Rehabilitation Nurses, regarding the person's care path after a stroke. People are unaware or overlook the signs and symptoms of stroke, leading to delays in seeking medical help and decreasing the probability of minimizing sequelae. Therefore, Nurses urgently need to educate people about the signs and symptoms of a stroke and instruct people on how to seek for medical help. Nurses must also keep up with the concerns and difficulties of post-stroke patients and their families, since adapting to the situation of dependence and the return home is a moment of great anguish. Nurses must ease reintegration to the community, by adapting the house to the dependency situation, removing architectural barriers or guiding the person for self-care and rehabilitation in continued care units.

### FINAL CONSIDERATIONS

The health transition care path is described starting from the detection of the initial symptoms and evolution of the stroke, going



through transportation to hospital, hospitalization and preparation for discharge. Integration into the hospital environment and routine is not easy for patients, but a positive relationship with healthcare professionals facilitates this transition process.

Nurses and, particularly, Rehabilitation Nurses meet the needs expressed by the subjects, being responsible for training both patient and caregiver in adaptation competencies and also for adapting the house according to the patient's

situation. However, the person still worries and predicts future difficulties that must be resolved.

The feeling there is much more to be investigated remains, but we believe we have helped the construction of knowledge regarding the transition of the person who becomes dependent after a stroke and therefore improve Nursing knowledge and their care practice. However, the situational transition reported by the study participants should be further explained.

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