

## ORIGINAL PAPER

## Exploratory Study of Patients' Life Situation after a Stroke

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### Abstract

**Background.** Brain diseases are a major health issue in modern societies, leading to multiple losses and disruptions.

**Objective.** Based on the question “*Are stroke patients' quality of life and well-being also influenced by hospitalization and its duration and nature?*”, this study aimed to characterize the patients' life situation upon returning home, assess the illness and recovery process, and understand how stroke patients experience hospital stay and discharge.

**Methodology.** Qualitative, descriptive, exploratory study, using semi-structured interviews with a nonprobability sample of recent stroke patients.

**Results.** Data were presented using three different approaches: a brief socio-demographic characterization; a description of the general meaning captured; and a detailed assessment of the themes identified. Mean age of 71 years ( $71.3 \pm 10.4$ ); an average of 690 days since the ischemic episode; length of hospital stay between 9 and 61 days ( $\bar{x} = 21$  days). Interviews were conducted in distinct contexts. The mRS and BI scores revealed significant functional preservation. Different experiences were found regarding the “length of hospital stay”, availability, attitude towards disease, recovery and after-effects, lifestyles, regaining control, and family involvement. The importance given to body functioning, organic dimension, and presence of pain are underlined. As aspects of quality of life, participants underlined the family unit, discrimination and “weight of the gaze”, and support network and its importance. Positive judgments were made and critical aspects were identified, such as fear and anxiety about the future. Hospitalization was perceived as necessary, while discharge triggered positive emotions and relief, despite being a source of concern and fear.

**Conclusions.** In this study, patients expressed pain, discomfort and depressive mood (despite their good functional recovery). Small changes in their personal, family and social routines were significantly valued. Despite criticisms, patients assessed the care process as positive. Hospitalization was understood as virtuous, and discharge, though desired, was anticipated with concern and fear.

**Keywords.** Stroke; ischemic stroke; hospitalization process; discharge, stroke survivor's experience; length of stay.

### Introduction

The brain has always moved large sums of money and prepares itself to be the subject of more in-depth research, funded by millions, in a joint transnational effort towards a deeper and more comprehensive understanding of how it works, given its intrinsic complexity. This is valid for the brain as a healthy organ... it will

certainly be so as an unhealthy organ. “*The brain is the intellectual excitement for the twenty-first century*”, Bill Newsome said (Abbott, 2013, p.273) when challenged to take on such task for the twenty-first century.

Another neuroscientist, K. Kording, underlined how impressive and capable this wonderful human organ is as it “...*produces in 30 seconds*

as much data as the Hubble Space Telescope has produced in its lifetime.” (Abbott, 2013, p.273).

On the other hand, “*brain diseases are one of the major health issues in modern societies*” and their current high costs will substantially increase over the next few years, particularly due to the increased prevalence of nervous system disorders resulting from increases in life expectancy. (Malva & Bernardino, 2010, p.24)

Among brain diseases, this study highlights the cerebrovascular diseases, which have led us to this vast field of work. The scientific community, health policy decision-makers and citizens have already gathered much knowledge about stroke. However, it still remains a huge challenge for them, because it is a devastating event that has catastrophic consequences for those who survive (Minzenberg, 2010). Stroke occupies the top places in mortality and morbidity statistics.

With a significant worldwide impact, it occupies a prominent position in the ranking of causes of disability-adjusted life years (DALYs). [Lopez & Mathers (2006) cited by Langhorne, Sandercock & Prasad (2009)].

The functional aspect emerges as the most visible and often most dramatic stroke dysfunction. The possibility of recovery after stroke varies (among other factors) according to the nature and extent (or severity) of the initial disorder. Dobkin (2005, p.1677), citing Hendricks et al. (2002), mentioned that “*35 percent of survivors with initial paralysis of the leg do not regain useful function, and 20 to 25 percent of all survivors are unable to walk without full physical assistance*”. While citing other sources, the author added that, six months after stroke, 65% of patients cannot incorporate the affected hand into their usual activities. As a result of these and other examples of impaired function, the author mentioned that the priority targets in rehabilitation strategies should be aphasia, self-care and functional use of the arm, walking, exercise and strengthening.

Still, is it possible to speak of functional disorders without relating them to dimensions that are initially less likely objectified such as the quality of life and well-being dimensions, or even stroke-related pain symptoms/ manifestations? As an important and cross-sectional phenomenon, pain will influence functionality and the perceived quality of life, and it may be

the motto for negative feelings and emotions of unhappiness. In a literature review article on the subject, two psychiatrists address the matter in an instructive way; by citing other sources, they assume that “*pain as a stroke sequel is an often underdiagnosed and underrated condition*” and that, “*although there are few studies on their actual incidence, the notion that pain is a common problem in stroke patients results from clinical practice*” (Gaspar & Antunes, 2010, p.38). In reference to various other studies, they provide some possible explanations for its devaluation and claim that “*the importance of understanding and treating pain after a stroke is related to the fact that pain is associated with a higher prevalence of depression and impairment of the quality of life of both patients and their families/caregivers, which is a limiting factor of an active participation in a rehabilitation program and leads to worst functional outcomes*”. (*idem*; p38)

Based on the question “*Are stroke patients’ quality of life and well-being also influenced by hospitalization and its duration and nature?*”, this study analyzed some stroke-related aspects through the discourses and perspectives of the patients themselves. Thus, as specific aims, this study aimed at recognize:

- 1 – The patients’ situation upon returning home after having had a stroke;
- 2 – The process of illness and recovery after a stroke;
- 3 – How stroke patients experienced hospital stay and discharge.

### **Background**

As we know, “*brain diseases are one of the major health issues in modern societies*” (Malva & Bernardino, 2010, p.24), occupying a prominent position in the ranking of conditions leading to disability-adjusted life years/years of potential life lost: DALYs/YPLLs (Langhorne, Sandercock & Prasad, 2009).

Patients experienced disruptions in their living standards, functional capacity, quality of life, and objective and subjective well-being. Back in 1997, the real dimension of the problem was already under discussion (Gonçalves & Cardoso, 1997, p.543), and stroke prevalence was analyzed in a population sample by gathering the participants’ personal health

records, particularly those including history of stroke and vascular risk factors.

Despite the advances made during the first decade of the twenty-first century, in Portugal, “*cerebrovascular diseases and cardiac ischemic diseases remained the leading causes of preventable years of potential life lost (YPLLs) through health care.*” (DGS, 2013). According to alerts from the Portuguese Stroke Association, a stroke occurs every five minutes (SPAVC, 2013).

Portugal is the Western European country with the highest rate of stroke mortality. Statistics referring to its incidence, prevalence and case-fatality were also worrying (Correia, 2006).

Although some of the documents consulted seem contradictory, which is clearly related to the scales and the perspectives of analysis, it is worth remembering Oliveira (2012) on the magnitude and repercussion of strokes in Portugal. The author states that they represent a scourge “*due to their high incidence, considering that in the so-called developed countries - Europe and the United States, Canada, etc. – they are the third leading cause of death and permanent disability while, among us, they are the first leading cause. Official figures show that, in 2009, 14.285 people died of stroke (6.127 men and 8.158 women)*” (Oliveira, 2012, p.263)

With a time frame up to 2015 (Helsingborg Declaration, 2006), a major objective was set out for these patients, particularly with regard to rehabilitation. The aim is that 70% of survivors regain independence in activities of daily living within three months after a stroke (Kjellström, Norrving & Shatchkute, 2007). This path is being unevenly constructed in the various European countries, aiming at offering the best health-related response to populations.

As recommended by the scientific community, the responses to stroke victims shall always and primarily be made available in a particularly rapid manner and, preferably, through an organized care service concentrated in appropriate units, i.e., stroke units (ESO, 2014). This will be the purpose of hospital admission, though discharge should also be an organized and coordinated process, thus providing a response to several domains of the problem, in particular the provision of different technical assistance and referral (which is often essential) to a care network which ensures the continuity of care.

This had also been found in the study of Hakim & Bakheit (1998) who analyzed the factors with the potential to extend the length of hospital stay among stroke patients.

More recently and still examining the same factors, a strong predictive relationship between the severity of episodes (NIHSS score) and the length of stay in the “acute phase” and in total stay (considering the implemented rehabilitation program) was observed and confirmed. Similarly, other factors were confirmed to extend or shorten the length of hospital stay, such as pre-stroke dependency on activities of daily living, some specific NIHSS items, and pre-stroke dementia (Appelros, 2007).

Other factors were highlighted with regard to the American reality (Hanchate *et al.*, 2013) where aspects such as race, ethnicity and socio-economic status are associated with these patients’ length of hospital stay.

Either through empirical observation in clinical settings, either through personal testimonies (Olofsson, Andersson & Carlberg, 2005), it is also known that, when hospitalized and undergoing a therapeutic process, many patients feel a strong desire to return home.

### Methodology

This is a qualitative descriptive exploratory study, using information collected from semi-structured interviews, with a non-probability sample (n=12) of recent stroke patients who were duly followed and assessed (at admission, at hospital discharge, after 1 month and after 3 months).

Within the scope of a broader study (n= 110), the following inclusion criteria were established: being the 1st ischemic stroke; previous level of functioning (mRS)  $\leq 2$  points; being more than 18 years of age; and speaking Portuguese. The interviewees’ clinical records were consulted and their clinical situation was, therefore, characterized.

The content of the answers, given to simple and direct questions, was analyzed using Bardin’s methodology (2013). Given the predominantly qualitative approach, the hypothetical inference derived from the available *corpus* could only be based on the “*presence of the index (theme, word, character, etc.!) and not on its occurrence rate in*

each individual communication.” (Bardin, 2013, p.142).

Twelve interviews were conducted. Patients were previously contacted by telephone. The study and the therapeutic process were duly contextualized, and the participants' necessary cognitive skills and response abilities were assessed. Data were recorded in individualized field notes which were written immediately after each interview. The respondents gave their consent and their anonymity was guaranteed.

## Results

The available data are presented in three different, yet complementary approaches: first, a brief socio-demographic characterization of the informants and explanation of the contexts where the interviews were conducted; then, a general description of their meaning; and finally, a more detailed summary of the analysis, which will be divided into five themes.

In January 2014 (at which time the interviews were conducted), the respondents' mean age was around 71 years ( $71.3 \pm 10.4$ ). Between 347 and 779 days ( $\bar{x}=690.3$  days) had elapsed since the stroke and the total length of stay ranged from 9 to 61 days, with a mean of 21 days.

As field notes resulting from observations made in each visit, it ought to be said that the interviews were carried out in different venues, either chosen or suggested by the patients themselves or their family members (e.g.: at home – in the kitchen, living room – or in the day center, in outdoor patios, on the street, in staircases, coffee shops, restaurants,...), at different times of the day and, in some circumstances, only after two or three visits to the site.

Particular emphasis was always given to the respondents' needed and desired privacy. During the interviews, patients were performing routine tasks, such as cooking, ironing, taking a walk, sitting in the day center. Two patients (former smokers and alcohol consumers) had resumed their smoking habit only in a furtive way, though they had completely quit drinking alcohol.

In functional terms, patients scored between 0-3 in the modified Rankin scale (mRs) and between 100 - 85 in the Barthel Index (BI), as recorded in their clinical files.

As global and generic ideas resulting from the empirical material collected through the interviews and their processing, the aspects described below illustrate the population under study. They often translate the sociocultural reality itself, as well as the subjects' personal relationship with health-illness issues.

Therefore:

- With some exceptions, patients avoided talking about the disease process, both the period before and during the disease; they were concise.
- The length of hospital stay was perceived by some patients as a difficult time, whereas others considered it to be good, even highly virtuous.
- Perhaps as a precaution, as mistrust or as a result of intense concerns, which are characteristics aggravated by the current socio-economic crisis, it was sometimes quite difficult to talk/chat with some patients and their families. Long explanatory processes were needed and, even then, they were strongly reluctant to share information, and showed little availability. The occasional “blocking” of access from the patient's spouses was also clear, and even more evident from the wives towards their husbands, who were now in difficulties.
- During the process of interviewing patients, with an average of 690 days after a stroke, completely opposite situations were found in patients' relations with the health care services, i.e. from patients who were dependent on these services, focusing almost entirely on the appointments, rehabilitation/physiotherapy treatments (which, according to their opinions and testimonies, were rarely up to their expectations) to patients who had moved on with their lives and for whom stroke was part of the past and almost forgotten.
- Family reorganization processes were also observed in response to the new problems brought about by the physical/motor difficulties which many patients experience.
- A reference should be made to the comorbidities mentioned and verified (depression, diabetes, domestic accidents: falls, wounds) during some interviews and in the preparatory visits.
- Special reference should be made to male patients, not too old, who addressed their current

sexual-related issues which they did not have prior to the stroke and considered to be directly related to it.

- A situation shared with patients (and relatives) is related to the “robbery” of which they were victims (given their age, dependency and difficulties, etc.) on the part of relatives, children, grandchildren. This situation, which was a unique case in terms of its size but not its nature, even led to the patient’s hospitalization and the involvement of social services.

In a “more refined” interview analysis aiming at addressing the most peculiar aspects concerning each raised question (as a whole or divided into five themes), some differences but, obviously, many points in common were also found. A first group of questions focused on the patient’s current situation. As a possible synthesis, various elements emerged relating to body functioning (the organic dimension) which were focused on the dysfunctional aspect: fatigue, difficulties in performing tasks, various changes (motor, sensitive, sensory ...). The importance and presence of pain was referred to and emphasized by patients. As said by informer 5 (I<sub>5</sub>), here resumed, **“He feels he is getting better, but life has changed a lot... balance is still not good; ...he fell twice. He has difficulty starting to walk now; ...shoulder pain”**.

The second group of questions aimed at understanding the patients’ perception of their quality of life. As a synthesis, we realized the multidimensionality of the concept involved but also its peculiar understanding by patients; some functional arguments were recurrent, but the same was also true for arguments concerning the family, the dimensions of work/ profession, the discriminatory social environment, and the importance of a social and economic network. A patient (I<sub>3</sub>) was enlightening and referred to the **“High impact; it changed things completely. A radical change, for the worse. The view of people and the society, the poor fellow...”**

Lastly, the rhetoric question made by another patient (I<sub>12</sub>) when thinking about this issue and which we could apply to some other situations and patients: **“quality of life?”**

In the third group of questions, we cautiously asked for a judgment on the health care received. In summary, because an informal “assessment”

[unrecorded] of a path or process was allowed, in general, we observed a positive view of paths/processes, which prevailed over the less positive (or negative) aspects. As an example, one patient (I<sub>2</sub>) said **“I was very well taken care of; I know a lot of people and that also helps!”**, and another one (I<sub>12</sub>) mentioned: **“the health care professional should «be professional»”**.

However, a feeling of reluctance was also perceived from patients who could easily make such an assessment. As a negative aspect, we underline the excessive/ unnecessary bureaucracy and disorganization which was mentioned by some patients. Aspects such as inter-service and inter-institution communication (when needed by the clinical and therapeutic process) were highlighted (I<sub>8</sub>), but also aspects such as organized transportation and schedules (I<sub>5</sub>) to access rehabilitation centres (for treatment, in later stages of the same process).

In the fourth group of questions, we asked patients to remember and refer to their period of hospitalization. The interviewees answered every question, while describing the feelings and emotions they had experienced, some fear about the near future, the possibility of relapse and, once again, the functional, family and social aspects; **“I was very anxious, nervous, worried. I didn’t know how things would evolve and I had very severe examples in my family”** (I<sub>1</sub>). Almost all patients found that they had been hospitalized for the necessary period of time [**“It was normal”** (I<sub>1</sub>)], which indicates a positive outlook of the institution and the health care provided.

In the fifth and final group of questions, patients were asked about their discharge, their leaving the hospital (discharge-leaving process) and the post-discharge referral, which was something less “tangible” or understandable for them. (I<sub>9</sub>: **“happy and glad”**), but, on the other hand (as a natural result of specific individual circumstances), it also induced concern and fear. There was a clear awareness of the difficulties brought about by the stroke episode. The hospital was also perceived as a safe place, where one could and should be, where recovery took place, and the post-discharge referral was organized. The importance of the family, its crucial presence, and its (greater or lesser) collaboration in the transition from the hospital to the community were also perceived (I<sub>7</sub>: **“I was even**

*happier because I was moving closer to my daughter."*)

We sought to identify the "units of meaning" (Bardin, 2013, p.131) assigned by patients, in their answers to the various questions raised and structured into five different themes. We understand many of their hesitations and reservations, but, above all, we appreciate their sincere and, almost always, brief testimonies.

### Discussion

As Olofsson, Andersson and Carlberg (2005) pointed out, the patients' genuine awareness of their condition as stroke victims and of the real impact of its consequences occur when they go home; "*when the individual takes control again of his or her life*" (idem, 2005, p.433). Our study was developed mainly in a "home environment" and, therefore, we shared and observed some of the difficulties reported by these authors. The interviewed group was already in control of their lives or was in the process of regaining control over their lives, i.e. over the specific difficulties that each inherited from the cerebrovascular process of which they were the leading actors.

We could question and discuss multiple aspects, but we focused on those which we considered to be the most representative and significant, in accordance with Almborg, Ulander, Thulin *et al* (2010), related to the perception of quality of life, the valuation of what happened to them and the path taken, pain and its impact, functionality, i.e., we aimed at providing a frame for this matter based on the objectives initially set out. As expected, we encountered a reality in which stroke mainly affects the elderly, increasingly the very old, also called the great-elderly. This results from an objective reading of data, namely the mean age and its standard deviation. We saw diversity in sequels and length of hospital stay, which are naturally interdependent (Chang, Tseng, Weng *et al*, 2002). The length of hospital stay ranged between 9 and 61 days, which is significantly less than the reported by Hakim & Bakheit (1998) for stroke episodes. Considering that some periods of hospitalization stay were too long, and although this was not an objective of this work, it seems that extending hospital stay does not bear such negative economic repercussions. At least, that is according to the conclusions and the context of the study of Taheri, Butz & Greenfield (2000).

With regard to pain, which was referred to in abstract terms but in the dependence (or sequence) of the stroke process, it was mentioned and emphasized by patients as a precursor of discomfort and increased difficulties in their daily lives. This is in line with Gaspar & Antunes (2010), who identified its frequent devaluation and its actual contribution to depression mechanisms and post-stroke loss of quality of life. Pain was mentioned several times, thus reflecting its negative impact on patients and their lives in general. The multidimensionality of the quality of life concept (Canavarró & Serra, 2010) was evident in this small sample, and patients mostly mentioned arguments relating to their greater ability or disability, particularly in functional terms. It seems, however, that satisfaction was low when the questions (about current situation, pain and quality of life) were directly formulated.

The analysis of the answers given to the fourth and fifth groups of questions allowed us to withdraw an element of hope and trust in both the system and the professionals. Given the inherent health care complexity, this consistent - if not surprising - positive overview of the received care should be emphasized, with favorable references to the therapeutic process that they had undergone and the perception of the hospital as a safe place, where recovery takes place and the post-discharge referral is organized. The family was never forgotten by the interviewees. Their key contribution to therapeutic success or mitigating effect of the enormous difficulties and suffering resulting from stroke should be noted, as was also highlighted by Cramm, Strating & Nieboer (2012).

As Carvalhais & Sousa (2007, p.616) refer to in the conclusion of their study, "*for the very elderly, as well as for most people of any age, the nurses' behaviors in the provision of care are as important as the treatment itself*". Obviously, this does not apply only to nurses, but this less "technological" and interventive dimension as mediator of well-being and comfort for patients ought to be highlighted. Hospital stay, while translating a rupture that is particularly experienced in terms of its time/duration and nature, seems to bring with it mainly a perspective of hope and a focus of energy on the process of recovery, which is differently valued through the dependence of the clinical evolution

regarding the individual's initial state. It is from this particular perspective that quality of life and well-being seem to be more conditioned, always taking into consideration the current difficulties experienced and the undesired changes induced.

This approach to patients' situation after a stroke (while underlining their good functional recovery) showed frequent expressions of pain, discomfort, depressive mood and low satisfaction with several aspects of their day-to-day life. Small changes in their personal, family and social routines were significantly valued. Despite some critical views concerning the care process as a whole - and in which they were protagonists and receivers - they assessed it in a positive way. Hospitalization, i.e., hospital stay was understood as virtuous, and discharge, though desired, was anticipated with concern and fear.

### Limitations

This study shows some limitations, but also strengths. The group under study was a small-sized non-probabilistic sub-sample which only allowed for an explanatory perspective on the group. The initial inclusion criteria were encompassing, which was then translated in heterogeneous groups regarding the clinical and therapeutic process. We point out the data collection method as a strength; we visited, listened to and spent time with the patients, giving them their well-earned importance. The fact that the interviews took place significantly after the ischemic event enabled the desired psychological distancing from the event (despite the participants' potential memory difficulties).

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