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“A proof of life” through transition from hospital to home after a stroke in a Portuguese setting - a multi-perspective, longitudinal qualitative study

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ABSTRACT

Purpose: The impact of a stroke is particularly evident during the transition home, with reported unmet needs. However, little is known about post-stroke adaptation in Portugal. This study aimed to understand how Portuguese people with stroke and their informal carers/family adapt over time, and how health professionals support their adaptation.

Methods: A multi-perspective, longitudinal qualitative study was conducted using in-depth semi-structured interviews one and six months after inpatient discharge. A purposive sample of 24 participants (8 triads) participated. Thematic and narrative analysis strategies were used.

Results: Three themes were identified: *Managing change over time*; *Balancing support over time*; *Changing priorities*. These suggest the importance of time and gradual adjustment of health professionals’ approach throughout the rehabilitation process tailored to people with stroke’ and carers’ needs. Both valued positive thoughts and support from others to adjust life goals and find a balance between a mutual/bidirectional support and time for themselves.

Conclusions: Findings show that the manner in which changes after a stroke are approached may be positively transformed to provide strength. As a result of the deeper understanding gained from this study, health professionals may be better placed to acknowledge the needs of people with stroke and carers and find effective ways of supporting them.

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Stroke; caregivers;
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1. Introduction

Stroke is a worldwide leading cause of death and one of the most common reasons for long-term and complex disability among adults. In 2019, stroke was the second leading cause of disability-adjusted life-years (DALYs) in people over 50 years (Abbafati et al., 2020). In Portugal specifically, stroke affects around 15,200 people every year and it is the leading cause of death (OECD/European Observatory on Health Systems and Policies, 2017; Stevens et al., 2017). Stroke remains in the top three causes of DAYLS (GBD 2016 Stroke Collaborators, 2019; OECD/European Observatory on Health Systems and Policies, 2019) with these disabilities leading to sudden changes in the lives of both Portuguese people with stroke and their families.

The impact of a stroke is particularly evident during transition from hospital to home, which is marked by uncertainty, fears and loss of autonomy experienced by both people with stroke and their informal carers/family (Chen et al., 2021; Lou et al., 2017; Pringle et al., 2013; Theadom et al., 2018). The first six months at home seem crucial for people with stroke and carers to build their capability to maximize recovery, adjust to their

changed life and learn how to manage health challenges at home (Chen et al., 2021). In particular, the increased emphasis on early discharge schemes over recent years highlights the importance of co-ordinated discharge plans and the engagement of both people with stroke and carers to guarantee a successful transition to the community (Chen et al., 2021; Langhorne et al., 2017).

Previous research has shown that it is important for both people with stroke and carers to play an active role in managing their condition throughout rehabilitation and the recovery process (Sadler et al., 2017; Satink et al., 2013; Siegert & Levack, 2018). Trustful relationships and open dialogues between them and health professionals appear to be important to promote a partnership approach and ensure people are involved in decision-making during the rehabilitation process (Dineen-Griffin et al., 2019; McCarthy et al., 2020; Pereira et al., 2021). However, although health professionals tend to emphasize their patient-centred values and desire for a more participatory approach, some obstacles seem to perpetuate a power imbalance (Norris & Kilbride, 2014; Pereira et al., 2021). Barriers to a partnership approach throughout the

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rehabilitation process include the readiness of people with stroke and carers to participate, as well as the lack of organizational support for health professionals and mismatched care goals between health professionals and people with stroke and carers (Chen et al., 2021; Kable et al., 2019; Laver et al., 2010). Longitudinal studies suggest that the divergence in priorities and rehabilitation goals between health professionals and people with stroke and carers may result in unmet care needs and a negative impact on the development of self-management capacities for long-term stroke management at home (Bendz, 2003; Kable et al., 2019; Pereira et al., 2021). As a consequence, people with stroke and their carers often seem ill-prepared for the transition from rehabilitation services (Pindus et al., 2018), which highlights the importance of greater understanding about the adaptation process and how to collaborate to bridge these gaps.

A previous overview of qualitative systematic reviews has shown that people with stroke and their carers share many experiences, concerns and emotional responses, and are involved in the rehabilitation process together (Lou et al., 2017). In Portugal, there has been an historical reliance on the family as the first line of informal care for dependent people, with a high percentage of co-residential carers aged 50+ (Barbosa et al., 2020). Supporting a spouse with stroke or a close relative seems to be taken for granted, with Portuguese families feeling more compelled to interrupt their usual daily activities or cancel planned activities in order to provide care. Previous studies have shown that in Portugal home-caregiving and stroke-related consequences were more disruptive among Portuguese carers, compared with other countries of Northern Europe (Lurbe-Puerto et al., 2012; Pereira et al., 2021). In the same way, mutuality in the couple, which includes the affective relationship involving shared activities, have been highlighted to contribute to a fulfilling adjustment after stroke (Lurbe-Puerto et al., 2012; Pereira et al., 2021). However, there is a lack of understanding about how both Portuguese people with stroke and carers make sense of adapting to life after stroke and strategies to deal with the challenges they face during reintegration in the community. An enhanced understanding of adaptation is crucial to align health professionals' approaches to their needs and tailor strategies to collaborate and bridge the previously identified gaps (Simões & Hernández-Quevedo, 2017; WHO, 2018).

In the Portuguese culture, health is associated with someone who does not need health care services or medication and a healthy body is related to longevity (Gonçalves & Domingos, 2004). Longevity is considered a matter of family genetics, meaning the notion of possessing a strong body. In contrast, illness is

commonly associated with sadness and isolation (Gonçalves & Domingos, 2004), and disability involves physical and social barriers, and individual blame (Loja et al., 2011). Living and believing in fate, has been considered by some Portuguese sociologists as a cultural characteristic of Portuguese people, who alternates between demonstrations of sorrow and joy, pessimism and hope (Nielsen et al., 2009; Sobral, 2012). Understanding how people with stroke and carers perceive their experience and adapt over time may also offer insight into cultural influences and health beliefs after stroke.

Additionally, despite the improvements over the last two decades in the Portuguese stroke pathway and specialized services implemented (e.g., the "Stroke Priority Lane" and referrals to the National Network of Long-Term Care), there has been little practical impact on individuals' empowerment and person-centred care (DGS, 2019; Simões & Hernández-Quevedo, 2017; WHO, 2018). The National Health Plan emphasizes the importance and need for patient-centred care and self-management support, with more attention starting to be given to participatory approaches (WHO, 2018). However, the literature is also limited in understanding the role of the health professionals in facilitating the adaptation process after a stroke.

This study aimed to deepen the understanding of strategies used by Portuguese people with stroke and their carers, as well the health professionals' perspectives about their role in facilitating adaptation during rehabilitation and transition to home. This paper builds on previous published work which focused on the collaboration within the triad during the rehabilitation process and uses the same data set (Pereira et al., 2021).

2. Methods

2.1. Study design

A multi-perspective, longitudinal qualitative study was adopted, following a constructivist-interpretivist paradigm (Denzin & Lincoln, 2018). A reflexive thematic analysis approach was used through in-depth semi-structured interviews (Braun & Clarke, 2006, 2021). Interviews were used as a means for exploring and gathering the meaning of the recovery process and how people with stroke and carers, as dyads, manage the challenges imposed by the consequences of the stroke and rehabilitation, as well as for exploring the health professionals' experiences, thoughts, and practical knowledge about how they can contribute to the adaptation process after stroke. The standards for reporting qualitative research (SRQR) were followed for this paper (O'Brien et al., 2014).

Interviews were conducted one and six months after discharge from inpatient hospital or the rehabilitation unit. Discharge home involves the process of taking back responsibility, moving from an environment prepared to minimize the limitations and with professional support to their previous context, where previous habits and routines may no longer apply (Chen et al., 2021). For that reason, both interviews took place at home one and six months after discharge, following changing, adapting and developing strategies used by participants to cope with their new life situation.

A pilot study was conducted, including four people with stroke, four carers and two health professionals in order to develop appropriate interview skills and to ensure the adequacy of the questions for each group and interview format (Malmqvist et al., 2019). These interviews helped to understand important issues to manage in the subsequent interviews, including the importance of giving time and letting participants speak freely and being sensitive to emotional reactions of participants due to the emotional topic in discussion. Pilot interviews were not included in the final analysis. Ethical approval was obtained from the Centro Hospitalar de Setúbal (N.019) and from the National Commission of Data Protection (N.15727). An information sheet was given to each participant and details about the purpose, nature and procedures of the study were explained. Additionally, the longitudinal approach of the study was emphasized. Confidentiality and anonymity of the participants were guaranteed. Once all questions had been answered, participants who agreed to take part in the study gave written consent. Participants were assigned a pseudonym, which was used during transcripts, and all the other data that could lead to a possible identification were kept confidential.

2.2. Participants

Participants were recruited in triads from health institutions in the region of Lisbon in Portugal, through a purposive sampling and according to the nature of care provided to the participants with stroke. Each triad included the following participants: the person with stroke, carer and a health professional. A stepwise approach was used, starting with the face-to-face identification of the person with stroke, by the ward clinicians responsible for the patient's discharge plan; then recruiting the carer, and finally the health professional. This recruitment process was based on the inclusion criteria (Table 1), ability and willingness to take part. The person with stroke nominated a carer and a health professional. They were able to include more than one carer or professional if they wished.

Since people with communication difficulties represent an under-studied subset of the stroke population (Stinear et al., 2020), they were purposefully included in this study. A speech and language therapist gave advice about ways to optimize communication in the interviews for people with aphasia based on words understood and comprehensibility, that is, the ability to understand communication which occurs through speech, gestures, facial expressions, writing, drawing, picture pointing and other augmentative and alternative means. Short breaks were also included if participants was losing attention or showing other signs of fatigue (Dalemans et al., 2009).

The carer was identified by the participant with stroke as the person who they considered would offer support following discharge. In this study, carers or primary caregivers were stated as the person who provides the most care to the person with stroke at home, without payment for that service (da República, 2020). Secondary carers, defined as other people who may sometimes provide informal care to the person

Table 1. Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Participants (total)	<ul style="list-style-type: none"> – 18 years old or over; – able to provide their informed consent. 	
People with stroke	<ul style="list-style-type: none"> – diagnosis of stroke from clinical observation or brain imaging; – be undergoing stroke rehabilitation or had received rehabilitation services for at least five sessions; – discharged from hospital or rehabilitation unit during the last month. 	<ul style="list-style-type: none"> – diagnosis of cognitive disorders; – discharge to a residential care facility; – no Portuguese nationality.
Carers	<ul style="list-style-type: none"> – support the participant in their own or the participant's home; – participated or attended at least to one rehabilitation session 	<ul style="list-style-type: none"> – formal carers; – no Portuguese nationality.
Health professionals	<ul style="list-style-type: none"> – worked with the person with stroke in the rehabilitation process for a minimum of sessions (five) to be able to talk about the person's recovery, expectations, rehabilitation goals and adaptation process, as well as about their role as health professionals in the person's and/or family's adaptation after stroke. 	

(da República, 2020), were also interviewed with the primary carer, if the person with stroke and/or the primary carer wished.

In the recruitment process of the study, sufficient participants were required at the last time point to ensure data saturation, particularly if any new themes became apparent at this point (Calman et al., 2013). In order to undertake more in-depth and long-term analysis, a total of 10 triads were initially invited to participate in the research. Two potential participants who with stroke declined to participate. Both declined when approached by the researcher to explain the aims and procedures of the research, declaring no interest or desire to talk about their illness and adaptation process after stroke.

2.3. Ethical considerations

Ethical approval was obtained from the Centro Hospitalar de Setúbal (N.019) and from the National Commission of Data Protection (N.15727). An information sheet was given to each participant and details about the purpose, nature and procedures of the study were explained. Additionally, the longitudinal approach of the study was emphasized. Confidentiality and anonymity of the participants were guaranteed. Once all questions had been answered, participants who agreed to take part of the study gave written consent. Participants were assigned a pseudonym name, which was used during transcripts, and all the other data that could lead to a possible identification were kept confidential.

2.4. Data collection

Eligible participants were invited to take part before discharge from hospital or rehabilitation unit, with the setting for interviews chosen by participants. Separate interviews were carried out to allow an exploration of individual coping strategies, how these were constructed and maintained (Kendall et al., 2010; Sakellariou et al., 2013). When preferred by both the person with stroke and carer, interviews were conducted together. These interviews were conducted in Portuguese were undertaken by CP in the participants' home or health institution (hospital or private clinic). No repeat interviews were carried out.

All interviews included introductory questions (e.g., "What happened? Can you describe what has been most meaningful for you?" And for health professionals: "In your perspective, how have the person and family been dealing with what happened?"), followed by questions related to strategies used during the adaptation process and rehabilitation challenges (e.g., "How have you been dealing with the fact that you had suffered a stroke? How is life for you now?

What are your expectations in future? What kind of support has been helpful for you?"; and for health professionals: "From your perspective, what have been the position and actions of the person with stroke and carer during rehabilitation?"; "What is your perceived role for a better adaptation of the person after a stroke and carer?"). Prior to the second interview, experienced researchers went over transcripts of participants' earlier interviews to ensure follow-up of any specific issues raised by individual participants.

Interviews were audio recorded (duration: min- 24 minutes; max- 143 minutes, with a total of 34 hours of recorded data), which allowed preservation of the raw data for review at a later date. It has been shown that using video-tape can be intimidating (Dalemans et al., 2009), therefore additional notes were taken during interviews with people with communication problems. Interview notes about the interviewing process, feelings and/or non-verbal communication were written in a reflexive diary by the research-interviewer (CP).

2.5. Data analysis

Multiple analysis methods were used to avoid reporting descriptions of each time point rather than focusing on the changes between time points. Accordingly, both thematic and narrative strategies were used (Braun & Clarke, 2006; Calman et al., 2013; Holland, 2007; Murray et al., 2009).

Verbatim transcript of on-going interviews was carried out within a week. Colloquialisms were kept in the written transcript for authenticity. All individual interviews with people with stroke, their carers, and health professionals were coded separately and then further analysed as: (1) a grouped "people with stroke set", "carers set" and "health professionals set"; (2) serial interviews for each participant, considered as a longitudinal single unit; (3) integrated interview triad sets, including across triads and time points.

An initial inductive analysis took place alongside continuing data generation through subsequent interviews. The analysis process was iterative allowing emerging themes to be further explored in later interviews, carried out six months after discharge from hospital or rehabilitation unit. The method of thematic analysis offered the flexibility required to adopt an initial line-by-line approach in identifying general themes, whilst retaining individual contributions of participants from different groups (Braun & Clarke, 2006). Each transcript was coded line by line, firstly from the interview of the person with stroke of the triad 1, with further codes deriving from data sequentially from other people with stroke's first interviews. These initial steps of coding interviews from the group set "people with stroke" were followed by

the development of sub-themes and themes. The same steps were conducted within the other groups: “carers set” and “health professionals set”, followed by the second interviews for all group sets, providing an initial indication of differences over time and divergence of perspectives (Table 2).

This was followed by a longitudinal approach with each interview analysed individually and compared with earlier interviews to determine how coping strategies changed, and how participants managed change over time. During this stage, the focus was to explore the processes and changes, both backwards and forwards in time, using a narrative strategy (Holland, 2007; Saldana, 2003). This approach helped to understand how individual’s thoughts, strategies and challenges changed through time and interpret their explanations of changes occurring during their adaptation process. Firstly, a description was written about what kind of changes occurred, in whom (e.g., in the person with stroke or carer) or what (e.g., what situations), at a specific time and in a specific context through time. These descriptions provided a body of data for the next stage: analysing how and the changes might have occurred. This analytic process was guided by framing questions as described by Saldana (2003) in order to facilitate engagement in deeper levels of analysis and interpretation. The following questions were used: (i) what contextual and intervening conditions appear to influence and affect participant changes through time?; (ii) what increases or emerges through time?, and (iii) which changes interrelate through time?. A thematic horizontal analysis was used in order to explore longitudinal trends in the data, which was enriched by a narrative vertical analysis, that is, a temporal analysis of serial interviews for each participant, considered as a longitudinal single unit (Calman et al., 2013).

2.6. Researcher characteristics and reflexivity

CP, who is a female Portuguese citizen and a PhD researcher, was the interviewer on this study, with background in Physiotherapy and experience of research in the field of stroke rehabilitation. Throughout the research, the rationale and practice

of reflexivity was anchored in the research questions, avoiding shift attention from the phenomena being studied. It was carried out to acknowledge the impact of position and presence of the researcher and not as an aim in itself (Berger, 2015). A balance was important in order to capture the viewpoint of people who lived the experience, let them speak for themselves and maintain an ongoing self-awareness of the understandings from the perspective of the researcher (Berger, 2015; Calman et al., 2013). There was no previous contact or relationship between the interviewer and the participants of the study. The reasons for undertaking the study were explored during the explanation of the study aims and procedures before participants consent for participating in the study. The importance of reflexivity in this research was not only of relevance for the researchers, but also for participants by providing them time to reflect and re-evaluate their experiences (Calman et al., 2013). By undertaking a longitudinal study, reflexive opportunities were created for the triad participants.

In order to increase the credibility of the findings, the translation of interviews from triad 1 was carried out to promote cross-checking of data between Portuguese (CP) and British researchers (FJ, NG), both female researchers in the area of Psychology and Rehabilitation, with experience in qualitative research in the field of stroke rehabilitation. After this initial analysis, members-checking and peer review was carried out with frequent debriefing sessions between the researchers. The transcripts were not returned to the participants for comment and/or correction. However, an advisory group was carried out aiming to ask participants’ views on the value of the findings and their thoughts about the implications of the study.

3. Results

A total of 24 participants were included in the study. Eight were people who had experienced a stroke, ten were carers and six were health professionals (Table 3). The majority of the stroke participants had a first stroke, were retired and were living in their own home at the time of both interviews. The time between

Table 2. Example of codes and sub-theme generated in the “people with stroke set”.

Data extract (example)	Codes	Sub-theme
PwS 3 1st: We must be as upbeat as possible ... It isn't easy to deal with the situation, but we have to look forward (p.7)	Importance of not giving up Thinking positively	Being optimistic
PwS 4 1 st : <i>It's a proof of life for me, and I will overcome it</i> (p. 13)	Looking at situations challenges, not as problems	
PwS 8 1 st : <i>My-y-y positive mind ... I go, I go</i> (p.11)		
PwS 1 2 nd : <i>Having a positive outlook is already a start</i> (p. 13)		

Legend: People with Stroke (PwS); 1st- first interview; 2nd – second interview.

Table 3. Participant socio-demographic and clinical/professional characteristics.

People with stroke (8)	Age (mean; SD; min- max)	66; 12.5; 43–79	
	Gender (female)	2	
	Time after stroke (months- Mean; SD)	4.5; 2.82	
	Discharge from: (n)	Hospital- 5 Rehabilitation unit- 3	
	Professional status (n)	Retired- 5 Unemployed- 1 Sickness absence/leave- 2	
	Severity of stroke: Barthel score (Mean; SD)	81.25 (28.09)	
	Speech difficulties (n)	4 (3 with aphasia, 1 with apraxia of discourse)	
	Rehabilitation service (n)	Physiotherapy- 4 Occupational Therapy- 1 Speech and Language Therapy- 3	
	Carers	Age (mean; SD; min- max)	58; 15.2; 37–77
		Gender (female)	8
Relationship with the person with stroke (n)		Partner- 7 (primary carers) Adult children- 3 (secondary carers)	
Living with the person with stroke (yes- n)		8	
Previous experience of caring (yes- n)		2	
Health Professionals	Age (mean; SD; min- max)	46; 10.1; 28–58	
	Gender (female)	6	
	Profession (n)	Physiotherapist- 4 Occupational Therapist- 1 Speech and Language Therapist- 1	
	Professional setting (n)	Hospital- 3 Private clinic-2 Non-profit rehabilitation institution- 1	

Legend: N- number; SD- Standard Deviation.

Table 4. Themes and sub-themes.

Themes	Sub-themes
1. Managing change over time	1.1 Being optimistic
	1.2 Finding their own strategies
	1.3 Understanding what happened
2. Balancing support over time	2.1 Balancing mutual support
	2.2 Finding motivation through different sources of support
	3.1 Learning how to enjoy life after stroke

stroke onset and the first interview varied due to the time spent in hospital and/or rehabilitation unit, with five participants having an average length of a hospital stay of one month, and three with an average length in a rehabilitation unit stay of seven months. Carers (10) were predominantly female, living with their partner and had no previous experience of caring. In two triads there were two carers included, with both the wife (primary carer) and daughter (secondary carer) interviewed. Health professionals who participated were all female, including four physiotherapists, one occupational therapist and one speech and language therapist. At the time of the second interview, one family member, from triad 8, dropped out due to personal reasons unrelated to the study.

Three major themes were derived from the data analysis: i) *managing change over time*, ii) *balancing support over time*, and iii) *managing priorities over time*, which represented the importance of time throughout the accounts of different strategies by both people with stroke and carers in order to find their own way to respond to the challenges imposed by the stroke.

Each of the three major themes were connected to sub-themes, as detailed in Table 4 and described below

in further detail. Quotes are included with the identification of the participant's group (e.g., carer) followed by the identification of the triad (e.g., triad 1) and time point of the interview (e.g., 1st interview). Names included in quotes were anonymized using a pseudonym.

In the theme "managing change over time" three key issues were presented, namely, the importance of maintaining optimism and looking forward, the meaning of finding personal strategies, with no *right* or *wrong* ways of managing the situation, and the significance of a gradual understanding about the situation. Time was needed for both people with stroke and carers to understand the impact of stroke on their lives and how to deal with its consequences, as well as to adjust to new roles and a reality of uncertainty. Although health professionals' advice was reported as important, both experience and time were also needed to understand it. Moreover, by exploring the triads' perspectives, differences were highlighted in the way each seemed to develop knowledge, according to what was relevant to them in each period.

The theme "balancing support over time" highlights the differences in people with stroke and carers' needs and sources of support over time. A shift seems to occur from an initial period when a shared journey between the person with stroke and the carer was emphasized to a broader support, involving other family members over time.

Through this process, people with stroke and carers' priorities changed over time, with the theme "changing priorities" suggesting the importance of understanding these differences and adjusting the

professional approach in order to work for a main and common purpose.

3.1. Managing change over time

3.1.1. Being optimistic

After returning home from hospital or rehabilitation unit, both people with stroke and carers reported frustration, anger and despair over their losses, uncertainties about the situation or difficulties in managing their new roles. The unexpected, sudden and overwhelming nature of the stroke seemed to challenge their ability to manage the situation and resultant changes in their lives, with some triads reporting how important it was to respond to these changes with an optimistic perspective. Despite struggling with their losses and recognizing enormous changes in both their lives, most participants emphasized the importance of not giving up and thinking positively as a way of moving forward. Having an optimistic approach facilitated both people with stroke and carers to look at situations as challenges and not as problems by positively re-appraising changes and their own abilities. This also helped carers to deal with the burden.

*“From an emotional point of view this is a challenge that I thought I wouldn’t be able to handle it OK (...)
For me it’s good to understand that I can do things at home that I couldn’t ever imagine doing (Carer, triad 7, 2nd interview)
It’s a proof of life for me, and I will overcome it (Person with stroke, triad 4, 1st interview)*

Although some health professionals highlighted the importance of maintaining an optimistic outlook, they appeared to perceive it as related to person’s and carer’s personality, not emphasizing the role they could have to facilitate it. Only one health professional described her role in helping to find alternative and positive perspectives to challenges.

He reported the difficulty that some people still have and they just stare (...) and then we joke, and I talk about other patients... (Speech and Language Therapist, triad 4, 1st interview)

The optimistic outlook seemed to relate to not only their innate qualities or tendency towards positive thinking, but also to strategies developed by participants through their experiences. Moreover, even for people who described themselves as positive and being focused on challenging themselves, like the person with stroke from triad 4, others having an optimistic outlook was also important. Both his carer and health professional’s positive thoughts were acknowledged as important when he was feeling down.

During the sessions I help him looking at the good things we have, it’s not all bad things. I talk about the possibility for them to go to the beach. Then they go

and he comes back talking about how it was. It’s important to focus, not on what he has, what had happened, but on the good things or positive aspects of what has changed (Speech and Language Therapist, triad 4, 1st interview).

This sub-theme illustrates how an optimistic outlook gradually helped participants in managing the situation. Looking at the difficulties as challenges and not as problems was emphasized as an important approach to recovery, which may also be built or reinforced by positive thoughts and support from others. However, health professionals appeared to generally overlook their role and contribution to it.

3.1.2. Finding their personal strategies

Triads reported finding their own strategies as important in order to manage their new, challenging situation. These strategies were perceived as having different meanings for each participant, which supports the idea of no “right” and “wrong” ways to manage. Some participants, both people with stroke and carers, highlighted the importance of accepting what happened, others reported finding strategies supported by their religious belief or perceiving humour and willpower as important strategies.

We have to accept what life gives us; the future belongs to God (Carer, triad 8, 1st interview)

*It’s the life that no one expects ... This is it; it was meant for us. Little by little I’ll have to accept it (...)
But I have faith that my husband will be able to walk and drive. We have faith and faith is the last thing to die (Carer, triad 1, 2nd interview)*

Being able to work and to do what I did, it’s basically that what I want. Now let’s see, the destiny belongs to God, as we say (Person with stroke, triad 3, 1st interview)

Initially, faith seemed also to be related to a sense of fatalism or a focus on former lives, with people feeling little or no control over their future and waiting to get back to previous lives. For instance, by the time of the second interview the faith of the couple from triad 1, appeared to be transferred more towards the need of acceptance.

I have patience and faith, yes; I have faith that things will get back to normal (...). The day this started came without notice too, right? The day when I get well will also come, when I get well, and it won’t take very long (Person with stroke, triad 1, 1st interview)

We don’t do prospects for the future; we live one day at a time. We have to accept what life gives us (Carer, triad 1, 2nd interview)

However, although both people with stroke and carers talked about the importance of faith in coping with the difficulties provoked by the stroke, health professionals did not mention the role played by

religious beliefs, their potential value or disadvantages in dealing with the situation.

Other strategies perceived as useful to manage their new challenging situation, both by people with stroke and carers, included humour. Whether after discharge, or six months later, humour was described as helpful to deal with difficult circumstances.

I enjoy good humour (...) I believe that humour helps the person to overcome some moments. Not all day, but in certain moments; it's what happens with her (Carer, triad 5, 1st interview)

I continue ... when she is in a good mood she laughs. But when she is in a bad mood, she looks at me seriously and I tell her "you don't even give a smile", I see that in fact the humour has influence on this (Carer, triad 5, 2nd interview)

Health professionals reported the value of people with stroke and carers' motivation for treatment but did not mention humour or its importance in sessions.

In addition, some people with stroke described approaching their new life situation with willpower, which appeared to be related to three main concerns: their desire not to depend on others, their perception of burden of care and desire for controlling their own life.

I'm dying to get well, walking instead of having to wait for my daughter who is working, she can't come... That way I could go wherever I 'd like and by my own foot, I wouldn't need to wait for anyone (Person with stroke, triad 2, 1st interview)

I want to have a normal life, not depending on others, or depending as little as possible on family, especially the children, that's all I want. I don't want to be a burden (Person with stroke, triad 6, 1st interview)

Over time, it seemed easier to find and perceive strategies as helpful, or not, to minimize stress and manage problems. Moreover, this increased awareness appeared to lead to a transformation or adjustment of strategies used in order to be perceived as helpful by each participant.

3.1.3. Understanding what happened

From the triads' perspective, searching for advice from health professionals and finding information on the internet or books were significant strategies to help both people with stroke and their carers find ways to deal with the sudden changes in both lives, as well as to manage the anxiety related to the absence of immediate rehab gains. Although not everyone in each triad emphasized it, there was always at least one person, often the person with stroke or the carer, who was most active in finding answers for their doubts. The importance of understanding the situation was also reported by participants who expressed frustration and anger due to their own and others' assumptions about the meaning of having a stroke and why they had it.

I have some friends that asked: "Did you have a stroke?" (expressing surprise). Unfortunately, people relate stroke to old people. "You? You did sports", they said ... I also thought everything was normal. They are shocked, so am I (Person with stroke, triad 4, 1st interview)

I wasn't prepared but I understood a few things; I have an encyclopaedia (...) There it explained how to care for the person and talk to her (Carer, triad 5, 1st interview)

Over time the type of doubts seemed to change from an initial need for understanding what had happened to a later need of finding out what might help in the longer term. Additionally, the recommendations and advice initially given by health professionals were added to people with stroke and carers' own experiences, who seemed to find their own ways of understanding what had happened. This understanding was built over time, which helped them to manage perceived slow progress and the uncertainty of outcomes, as emphasized by the person with stroke and his carer from triad 3 in each time point,

Dr Luis said that he's recovering and he's progressing, but that is not recognised on a daily basis. And it's true, he comes to physiotherapy and it seems that we don't see advances (Carer, triad 3, 1st interview)

It's what the doctor says: "it takes time, no one can't predict, with a broken leg we know that we recover in a month". But here, there is no chance of knowing (Person with stroke, triad 3, 1st interview)

The neurologist and the physician warned me: "be careful; from now on things will be different", but we never really realise. Only with time, with things happening we realise that in fact they're right (Person with stroke, triad 3, 2nd interview)

3.2. Balancing support over time

3.2.1. Balancing mutual support

From the triads' perspective, both the person with stroke and the carer benefited from mutual support over time, which seemed to help in their often labile emotions. When one was feeling down, they could support the other. Both seemed to value the mutual tenderness, love and support, which were also perceived as giving motivation for managing rehabilitation. In some triads, the person with stroke identified how important it was to feel needed, maintaining previous roles and familiar interactions. For some carers, it seemed to be important to feel the mutual support between each other when facing shared losses. From the health professionals' perspective, the mutual support and close relationship between the person with stroke and carer(s) was also perceived as positive in the recovery process, resulting in a higher motivation and collaboration in treatment. This mutuality was highlighted, for example, in the triad 1.

He is always saying "I don't want you to get upset" and then he holds me tight, he kisses me all the time (...) My husband was always someone who really cared about me ... we have always been a united couple, we are always together (...) I think that my role next to him, I think that he feels protected and that there is someone there who worries about what he's doing (Carer, triad 1, 1st interview)

It's what keeps me happy, being close to my family. Day by day being always happy with them (...) it's good for me and for them, for my wife, it's better like this (Person with stroke, triad 1, 1st interview)

This stroke has affected not only Mr Silva, the husband, but also his wife and he also supports her (Physiotherapist, triad 1, 1st interview)

However, over time the close relationship between the person with stroke and the carer were not always perceived as positive by health professionals or other family members. Managing emotions was perceived as difficult for both and their closeness did not always represent support for each other. Furthermore, over time, some carers emphasized both the importance of emotional support and time for themselves. Six months later, a balance between mutuality and time away seemed to increase in importance.

We also travel because of me. I'm with her 24 hours and as you can imagine these 24 hours are not always easy. Travelling is good for me and for her. At João's home (his brother) he or his wife cooks for us ... I go to the cafe and things like that. When we arrive home, I already have my brain fresh and ready to start again (Carer, triad 7, 2nd interview)

Sometimes we say (to the carer): "you can sit, you can be watching, let it be, don't worry", to see if we also can reduce some of his wife's anxiety (...) I think she is assisted by a psychologist (...) often I treat the patient, not the carer, but I guide the carer to other alternative sources so she can also solve her problem. Because these situations of extreme dependency are also difficult for the carer (Physiotherapist, triad 1, 2nd interview)

Additionally, in some triads, carers also reported starting to withdraw some of the support they used to give to the person with stroke as a way of encouraging independence. If at the beginning both physical and emotional support was needed, gradually this seemed to be given by the carer less frequently and with different purpose. In some situations, the support was more motivational and affectional, as stated in later interviews by the following carers.

She only wants to feel a touch. It's like getting out of bed: she's already getting out alone, but she's always asking for help (...) and she doesn't put and lock the car seat belt because she knows I'm there ... if I'm not, she puts it (Carer, triad 7, 2nd interview)

Sometimes, when he was more unmotivated and lazier ... me and my mother, we used to make things easier to him, things like hygiene in the bathroom. But now, I often don't do it, but I know that when he is alone with my mother, sometimes, she ends up by doing... it's also her way of helping him (Secondary carer, triad 1, 2nd interview)

This sub-theme represents the value given by each triad to the mutual support. Although this reciprocal and bidirectional assistance appeared to change with time, it remained important as a source of motivation and support for each other. Over time, a balance between their mutual support and individual time seemed to be important, particularly for carers as a way of finding emotional stability and time for themselves.

3.2.2. Finding motivation through different sources of support

The involvement of the whole rehabilitation team, was, from the triads' perspective, an important strategy to deal with the difficulties and challenges in the transition process to home. For most participants, their perception of the team included the person with stroke, the carer and health professionals with each seeming to have a specific role. All parties involved highlighted the engagement, willpower and motivation of the person with stroke as central to the rehabilitation process. Both carers and health professionals emphasized the person's motivation, as well as their own role to increase his/her motivation and engagement. Carers, in particular, appeared to perceive themselves as collaborators during rehabilitation as well as an important support to increase the person's confidence in his/her capabilities. Additionally, both the people with stroke and their carers seemed to see health professionals as important partners guiding, motivating and also encouraging them. For instance, in triad 3, participants, interviewed separately, highlighted their individual efforts and how both the carer and the occupational therapist became involved, helped and challenged the person with stroke.

At lunch, when we are at home, sometimes I leave the cork and say: "put the cork inside the bottle"... Sometimes he doesn't remember and I ask him again. Stirring the coffee too; at the beginning he had no control in the spoon. And I: "see if you can, try it, do it like this" and he said "no, I can't". I insist and now slowly he can do it, he starts thinking about it and then stirs the coffee well (Carer, triad 3, 1st interview)

I have been increasing the difficulty's level, but at the same time I show him that I'm there to help him. It's normal him to think: "I don't know if I'll be able to do this by myself" (Occupational therapist, triad 3, 1st interview)

Sometimes it appeared they (health professionals) wanted more and the person is limited, can't do it, but it was in a good way. On the following day, we realized it's worth having that pressure and it's important. They insist, it's their role and it's important (Person with stroke, triad 3, 2nd interview)

From the triads' perspective, the people with stroke's ambition, hard work and always doing more than expected were perceived as important for a successful recovery. However, this involvement and motivation was not reported equally in different triads and over time. Although both the carer and health professionals appeared to have an important role in the recovery process of people with stroke, in some triads maintaining motivation was difficult. In these situations, both the carers and secondary carers' role in supporting and encouraging their relative was emphasized by everyone.

With time, strategies found within the family, such as, changing cyclically who was the main carer and finding solutions together to increase the person with stroke's independence appeared to help in their motivation. Involving other family members, such as, grandchildren was also reported, as stated below.

We suggested that her [granddaughter] to play puzzle games with her grandfather and she likes to play, like before. She used to play with him (...) Now, when they have the opportunity, they play (Physiotherapist, triad 1, 1st interview)

This sub-theme evidenced the importance participants gave to working together. All parties recognized the importance of the involvement of all parties including the person with stroke, the carer and health professionals. Over time, involving also other family members seemed to be important to maintain the motivation in the rehabilitation process.

3.3. Changing priorities over time

In the initial stage of adaptation, one month after discharge from hospital, participants in each triad seemed to be focused on the challenges of gaining as much functional independence as possible. Later on, the major goal moved from expecting to recapture their former lives to regaining control in their new life post stroke and it seemed to be important for both the person with stroke and the carer to understand what was best for them. As time went on, *learning how to enjoy life after a stroke* represented the value of changing their priorities.

3.3.1. Learning how to enjoy life after a stroke

By the second interview, there was a notable shift in how making plans and adjusting to stroke was seen in as a positive life transformation. From some triads' perspectives, changing lifestyles or making new

plans for the future due to the consequences of the stroke was recognized as a positive life change. For instance, the person with stroke from triad 3, 54 years old, was retired due to his stroke and, at the time of the second interview, he and his wife were planning to move to the countryside as a result of the change in his professional situation. This was emphasized by all as a positive change.

There are things that make sense for a person to think about a little more... I keep myself entertained there in the garden; I have chickens, a vegetable garden (...) is also good for stress. Now with retirement, the year is 13 (relating to Catholic religion belief), but it may give luck anyway... Possibly we'll go to the countryside (Person with stroke, triad 3, 2nd interview)

In his case, I think it is beneficial because he gets more time to do different things. He says he is also dedicated to gardening and that he does things there in the garden, so I see that he keeps busy and I believe that it is important (...) it would be problematic to stagnate at his age (Physiotherapist, triad 3, 2nd interview)

However, for some participants, it was still difficult to adapt their future plans, relating it to difficulties dealing with the continued uncertainty, as mentioned by a carer (triad 5),

In fact, I really wasn't expecting something like this. She always had worked ... she did so much for people, and everyone loved her... And, now, after retirement we were going to enjoy life (...) My dream was ... we would get to know the North of Portugal together ... We would now recover from the years of work. But this happened. I have family in [anonymised- city in the South of Portugal] and [anonymised- city in the South of Spain], but she is afraid of making the trip... and I say: "listen, we'll go slowly, instead of making the entire trip at once we can do it in stages", but she says that it's too many hours and she is afraid of not feeling well and I don't insist (Carer, triad 5, 2nd interview)

Other participants demonstrated difficulties in adapting in order to enjoy life. Although strategies to find new meaningful activities and future plans were discussed within some families, during the follow-up interviews some participants were still avoiding contact with others outside the family, perhaps highlighting feeling unprepared to meet their previous social network. For them, adapting represented abandoning hope for a full recovery as well as showing their fragility to others. For instance, in triad 1, even though the person with stroke and his carer had spoken about their isolation from everyone, they still wanted to hide away from most people. On the contrary, their daughter (secondary carer) was worried about her parents' future, trying to find new activities as a way of integrating the consequences of her father's stroke in their lives.

With most people, I stopped having contact with them. I don't have the means to go to certain places where I used to go (...) I'm not prepared to go to the fish auction with my husband in a wheelchair ... no, I can't, people come and ask (Carer, triad 1, 2nd interview)

They will have to continue living (...) I'm trying to give them their own life (Secondary carer, triad 1, 2nd interview)

These situations seemed to be also difficult for health professionals, who were sometimes worried about future recovery and had difficulties in communicating and managing people with stroke' and carers' expectations.

Currently he is a bit more realistic, he realizes that probably he'll not get back to the life he had (...) I think the main goal right now is to go with his daughter during weekends, helping her or just being there. I think he already has his feet on the ground, he no longer talks about returning to driving (Physiotherapist, triad 6, 2nd interview)

I know that many of his plans probably will not be possible to carry out, isn't that right? It's like driving, which is something he loved, but probably he'll never be able to drive. I searched for a rental car on the Internet the other day with my husband. Just to motivate him... hire a car with automatic transmission just for him to feel that he might be able to do it. We still didn't do it because I'm afraid to. But he got very excited about the idea... on one hand it's good to see him so motivated, to see if he engages (Secondary carer, triad 6, 2nd interview)

As presented in this last theme, managing and learning how to live with the consequences of the stroke, as well as maintaining optimism about the future, even about a different future from what was previously expected, seemed to represent a challenge, as well as a goal for both people with stroke and carers. Discussing it within the families seemed to be important to help them finding new meaningful activities and avoid communication difficulties within the family members and with health professionals.

4. Discussion

By collecting data from different time periods and perspectives, this study contributes to a better understanding of the adaptation to stroke over the first six months at home in a Portuguese context. From an initial difficulty in managing the new situation, there seemed to be a shift in their understanding and integration of the consequences of stroke in daily life. Time was emphasized as helpful to understand the impact of stroke on their lives and adjust to new roles and a reality of uncertainty. These findings are consistent with previous findings suggesting that adapting involves an ongoing and cyclical process with landmarks, transitions and changing demands

(Brennan, 2001; Lou et al., 2017; Taylor et al., 2011). In this process individuals evaluate their post-stroke coping responses and modify them over time, in a non-linear and dynamic process, with each phase being unique and requiring different strengths, attitudes or changes from the family (Lou et al., 2017).

However, the constructions of time varied between participants and triads, with various coping strategies being used, but not all perceived as helpful to everyone, which was also reported by Donnellan et al. (2006) and argued by Taylor et al. (2011). The type of support (e.g., physical assistance or emotional support) varied, as well as varied their needs for education (Quinn et al., 2014). Likewise, it varied not only over time, but also from carer to carer; it was not directly determined by the severity of the stroke, but in particular to its perceived impact in their lives. For both people with stroke and carers, finding their way and time for managing change after stroke across the care continuum was important, which emphasizes the importance for health professionals to develop a deeper understanding of both people with stroke and carers' needs and provide timely and tailored support, instead of focusing on the assumption of rigid time window for recovery (Lou et al., 2017).

The multi-perspective results obtained also suggest that over time Portuguese participants were moving from a positive perspective focused on the past, based on the hope of regaining their former lives, to a positive perspective centred on their present situation. This shift in perspective was recognized as important to adjust life goals and priorities in their new life situation. Similar findings were reported by carers in a review (Mackenzie & Greenwood, 2012) who were able to identify more positive elements of caregiving throughout time. In other Portuguese studies, caring for a relative was found as positively valued, rewarding, and related to inherent Portuguese family' principles (Antunes & Marques, 2017; Capelo et al., 2022). Additionally, findings from systematic reviews on people post stroke's experiences and perspectives suggest that the positive outlook may be a desire to think more positively about a situation (Sarre et al., 2014) and an important element in maintaining hope (Bright et al., 2011). Focusing on positives and a high positive affect have been associated with a better psychological adjustment to a chronic illness (Anderson et al., 2017). Coping strategies such as the use of humour has been positively associated with the emotional management after a stroke (Gallacher et al., 2013; Mackenzie & Greenwood, 2012). Additionally, participants' positive coping strategies can be explained by a dialectic nature of the Portuguese culture, as described by some authors (Gil, 2007; Loja et al., 2011; Nielsen et al., 2009; Sobral,). From their point of view, the Portuguese identity, captures the

dialectic between fatalism and perseverance, two considerably different attitudes. For some participants, both people post stroke and carers, the focus was on the resolution of looking forward, indicating an underlying strength and resilience to overcome the situation (Nielsen et al., 2009). For others, the fatalistic view, also related to their Catholic beliefs, may suggest that their actions are futile. However, this was mainly emphasized during the first interviews. With time, although faith remained important, it seemed not to promote a passive role or a sense of fatalism. Instead, it was described as a source of willpower to look forward and find a meaning for what happened in their lives, as also found in other studies (Gibbs et al., 2020; Kes & Aydin Yildirim, 2020). In Portugal, a predominantly Roman Catholic country with a close-knit family ethic, a previous study undertaken in the area of palliative care also revealed the importance of the family and religious beliefs to provide strength and spiritual support (Rego et al., 2020). Religious belief may influence the ability to cope after a stroke, acting as a possible protective factor against emotional distress (Giaquinto et al., 2007) and helping to accept the uncertain situation and maintain hope (Bright et al., 2011; Carlsson et al., 2009; Davis & Grant, 1994; Greenwood et al., 2009). These findings reveal that the way changes after a stroke are approached may be positively transformed in a helpful way. Our study help gaining a deeper understanding of the coping strategies used by both people with stroke and carers, providing to health professionals a better understand their needs and find effective ways of supporting them. This understanding may be also useful for other people with stroke and carers, who may find these helpful in creating their personal efficacy (Hole et al., 2014; Pindus et al., 2018).

Furthermore, by undertaking a triad-based and longitudinal design, this study has contributed towards a deeper understanding of the role of bidirectional support in managing the situation after stroke within a Portuguese context. The mutuality emerged from this study appeared to promote a shared redefinition of changed roles within the family, which may avoid carers "suffering in silence", as reported previously (Quinn et al., 2014); to loneliness or involve changes in their relationships, which could move from a partnership to a caregiver relationship (López-Espuela et al., 2018).

The mutuality in receiving and giving support allowed participants to find emotional stability within the unexpected situation that affected both, which has not been explored before in the literature. The main findings from earlier studies were focused on the importance of the family and social support (Greenwood et al., 2009; Pringle et al., 2013; Sarre

et al., 2014) with a unidirectional focus, looking at the resources available as supportive and helpful to the person post stroke and not on how they support each other in a relationship of mutuality.

By combining perspectives, the bidirectional support and the importance of achieving a new balance in the relationship was highlighted, with both appearing to be settling into new patterns of giving and reciprocating. Other studies, involving dyadic interactions reported that relationships may become closer, others become more distant, not being always clear how relationships were readjusted over time (Sarre et al., 2014). By analysing the different perspectives longitudinally, this study has provided insights into the need to tailor support and how people with stroke and their carers may require either collective and/or individual support. Not every kind of support is necessarily useful for all and not all significant others are able to provide the support that person found helpful. Moreover, although the balance between mutuality and time for themselves described, particularly, in later interviews it was not reported as time exclusively for carers and away from the person post-stroke, as found by other authors (Quinn et al., 2014). Commonly, carers wanted to be with the person post-stroke, which may be related to the desire to maintain common routines in a close relationship (Greenwood & Mackenzie, 2010; Van Dongen et al., 2014), and, as found in other Portuguese studies to the devotion of providing care to the dependent relative (Pereira & Rebelo Botelho, 2011). Informal care within the Portuguese family is assumed as natural, showing a strong commitment to the family, being culturally justified and socially accepted. Other findings also show the difficulty in leaving their relative with others, justified by Portuguese participants as related to their belief that others will not care equally or to avoid social disapproval (Hespanha, 1993; Teixeira et al., 2020).

The support from others, such as neighbours or close friends, was underlined by few Portuguese people post stroke and carers. Their social contacts appeared to be restricted to their family and a few close friends, which was similar to the results from other results on stroke survivors' experiences, reporting loss of friendships (Salter et al., 2008; Sarre et al., 2014). However, different findings resulted from reviews on the carers' experiences, with benefits from long-term friendships being reported (Hesamzadeh et al., 2015; Quinn et al., 2014). Both Portuguese people post stroke and carers, who avoided contact with friends, described disappointment and avoiding others' comments about their life situation after stroke. Opting to not make contact with people from their previous social network due to others' reactions and comments may be associated with the pressure to

appear as socially expected (Hespanha, 1993; Teixeira et al., 2020). Moreover, as argued by Murray Parkes (1971), people still need to feel a “degree of mastery” over their environment. However, Parkes (1988) also asserts that these defences may prevent anxiety, but they are also likely to delay the relearning process. In fact, the participants from the Portuguese sample, who initially avoided contact with others outside their trusted circle, were still avoiding them later on and felt their life was on-hold, which may indicate the importance of understanding better the influence of others’ support during the adaptation process.

4.1. Limitations, application and future research

An issue, commonly reported in qualitative research, concerns the generalizability or transferability of the study findings to a broader context. The research was undertaken in the context of transition to home, during six months, in a specific Portuguese stroke setting. Attempts were made to enable the reader the possibility of transferability to other Portuguese and international contexts. However, regional and cultural differences should be borne in mind.

In terms of study participants’ level of disability, the findings may have practical implications for carers and people with very mild and moderate stroke, as well as to people with communication difficulties. However, findings may not be immediately generalizable to all those with severe stroke and their carers. Those with significant memory and cognitive deficits could not be included due to the design and methods of this study. Transferability to other conditions may only be considered for participants with similar clinical and social characteristics. Moreover, it would be important to consider the onset and impact of the clinical condition. These study findings may be generalized to conditions with sudden, unexpected and life-altering event, which represent a life change to both the person and close people/family and with unpredictable outcomes.

Although flexibility for the timing between interviews was not previously outlined, in practice due to numerous factors, such as care transitions, timing of clinic visits, illness trajectories or participants’ preferences, the second interview was carried out within a two-week window. Considering the challenges of longitudinal research, a flexible approach was preferred in order to maximize data collection opportunities at a time when participants can be vulnerable (Murray et al., 2009).

5. Conclusion and practical implications

This study has showed the complexity of the process of adaptation after stroke. Multi-perspective findings suggest the importance of reciprocal support between the person post stroke and carer(s), balanced with individual time and other sources of support. Through gaining a dyadic perspective, health professionals may be able to understand better patients’ and carers’ needs in their specific contexts, which can help them to inform their practice. Supporting people with stroke and carers to find their own personal strategies to provide strength and resilience, to look positively at situations and find the balance between mutuality and time for themselves, may be helpful to cope with what had happened and support each other. By adopting a relational approach rather than an individually focused one, health professionals may contribute to a positive transformation on how problems are perceived within the family.

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