

# Older adults' lived experiences of physical rehabilitation for acquired brain injury and their perceptions of well-being: A qualitative phenomenological study

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## Abstract

**Aim:** To explore the experiences of older adults (65+) living with acquired brain injury regarding their sense of well-being during physical rehabilitation within the Greek Healthcare System.

**Background:** With the increasing ageing population and the life-changing effects of acquired brain injury, there is a need to focus on care for older people and their potential to live well. Rehabilitation systems deserve greater attention, especially in improving the well-being of those who are using them.

**Design:** A qualitative study design with a hermeneutic phenomenological approach was used.

**Methods:** Fourteen older adults living with acquired brain injury and undergoing physical rehabilitation in Greece were purposively sampled. Semi-structured interviews were conducted to collect data and were thematically analysed using van Manen's and Clarke and Braun's methods. The COREQ checklist was followed.

**Results:** Four themes emerged from the analysis: (1) Challenges of new life situation, (2) Seeking emotional and practical support through social interaction, (3) Identifying contextual processes of rehabilitation, (4) Realising the new self.

**Conclusions:** The subjective experiences, intersubjective relations and contextual conditions influence the sense of well-being among older adults living with acquired brain injury, thus impacting the realisation of their new self. The study makes the notion of well-being a more tangible concept by relating it to the degree of adaptation to the new situation and the potential for older adults to create a future whilst living with acquired brain injury.

**Relevance for Clinical Practice:** Identifying the factors that impact older adults' sense of well-being during rehabilitation can guide healthcare professionals in enhancing the quality of care offered and providing more dignified and humanising care.

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**Patient or Public Contribution:** Older adults living with acquired brain injury were involved in the study as participants providing the research data.

**KEYWORDS**

acquired brain injury, lived experiences, older people, phenomenology, physical rehabilitation, qualitative research, well-being

## 1 | INTRODUCTION

Acquired brain injury (ABI) is a chronic and debilitating neurological condition that can cause significant life-changing consequences and a potentially high risk of mortality (Oyesanya, 2017). The definition of ABI includes mild or severe damage to the brain caused by an injury that occurs after birth, as opposed to genetic, congenital, hereditary, degenerative disorders or developmental disabilities (Chan et al., 2013; Giustini et al., 2013; Toronto ABI Network, 2022). The aetiology of ABI is complex and multifactorial and discerned according to causation: (a) Traumatic Brain Injuries (TBIs) if caused by exogenous causes and (b) non-Traumatic Brain Injuries (nTBIs) if caused by endogenous factors, such as stroke (Table 1). TBIs and n-TBIs can result in a wide range of functional changes, including physical, cognitive, emotional, and behavioural changes, leading to personal and psychosocial difficulties and maladjustments (Giustini et al., 2013; Jones et al., 2011).

Over the last two decades, international studies have identified a significant surge of ABI (specifically, TBI) incidents in people over 65, especially in high-income countries (Chan et al., 2013; Majdan et al., 2016). Unintentional falls are the leading cause of TBI in older adults (Gardner et al., 2018; Majdan et al., 2016; Peterson & Kegler, 2020). Non-traumatic brain injuries, such as stroke, also significantly affect older adults, with the risk of stroke doubling for every decade of life after 55, irrespective of gender, and approximately 50% of all strokes occur in people over age 75 and 30% over age 85 (Lui & Nguyen, 2018).

## 2 | BACKGROUND

Various studies have investigated stroke individuals' experiences of rehabilitation, focusing either on their experiences about their daily lives and coping mechanisms after their hospital discharge or on their experiences and involvement during their inpatient physical rehabilitation (Brown et al., 2014; Lloyd et al., 2014; Taule et al., 2015). Some studies have also explored TBI's challenges, long-lasting effects and significant impact on individuals' lives, self-perceptions and social integration (Abrahamson et al., 2017; Jones et al., 2022; McPherson et al., 2017). Other literature has examined the negative impact of rehabilitation experiences of these individuals, such as disempowerment, lack of control, ineffective communication, loss of valued roles and activities, stigmatisation and social isolation (Luker et al., 2015; Ritchie et al., 2014; Rosewilliam et al., 2011; Villa et al., 2020).

### What does this paper contribute to the wider global clinical community?

- Well-being in older individuals suffering from an ABI relates to the degree of adaptation to the new situation and the potential to create a future whilst living with ABI.
- Older individuals living with ABI can achieve a sense of well-being if they display a genuine readiness to adapt to the new situation, if there are available supportive familial mechanisms and if the individual has developed positive coping potentials.
- The preconditions for increasing the ABI individual's resilience include a supportive family, a collective positive narrative for the future life and ensuring uninterrupted care and rehabilitation beyond hospitalisation.
- Person-centred care models, adequate staffing levels and accessibility to care services positively impact the well-being of ABI individuals.

However, it is worth noting that most research on TBI experiences tends to have a broad age focus, including mainly younger adults or a mix of young and older individuals. Moreover, some studies demonstrate that the deterioration and disabilities of older people living with ABI are not unavoidable and, possibly more importantly, it is not inevitable that older people living with an ABI will experience sentiments of ill-being (De Bonis et al., 2010; Denti et al., 2008; Lilley et al., 2016; Mak et al., 2012). Somatic rehabilitation and positive psychosocial support can improve the quality of life and increase satisfaction and post-traumatic development (Douglas, 2012; Grace et al., 2015; Muenchberger et al., 2008). Furthermore, the literature asserts that constructive communication, emotional support, family and social support, and a stimulating social environment can facilitate older individuals' adjustment to their new reality following ABI, thus successfully contributing to their rehabilitation, reducing ABI's negative impact and inducing a sense of well-being (Douglas, 2012; Grace et al., 2015; Jones et al., 2011; Lafiatoğlu et al., 2022).

These studies overtly or covertly imply that older people living with ABI did not fatalistically cease their right or possibility for well-being; nevertheless, they found it difficult to formulate a framework or create a rational argumentation in supporting these people to achieve a sense of well-being. In part, the elusiveness of

**TABLE 1** Types of Traumatic and non-Traumatic Brain Injury (adapted from Giustini et al., 2013).

Traumatic (TBI)	Non-traumatic (nTBI)
Electrical shock	Anoxic brain injury
Trauma of head and/or neck (e.g. concussion)	Hypoxic brain injury
Traumatic brain injury with or without skull fracture caused by accidents, falls, assaults etc.	Brain tumours
	Brain injury due to Airway obstruction
	Cerebrovascular Accident (CVA) – also known as stroke
	Vascular disruption
	Vestibular dysfunction
	Brain injury due to Heart attack, arteriovenous malformation
	Brain injury due to Infectious disease
	Meningitis
	Toxic exposure

the term well-being and by extension its multiple facets including psychological, physical, socioeconomic, mental, and philosophical perspectives of well-being, have contributed to limiting the understandings, explanations and linkages of factors that enhance or limit well-being to these individuals (Diener, 2009; Galvin & Todres, 2013).

This study approaches well-being from an existential-phenomenological perspective, drawing upon the humanising framework of care (Galvin & Todres, 2013). While other frameworks, such as Self Development Theory (SDT) and Personality Systems Interaction (PSI), were considered, they were found less fitting since their core emphasis is on psychology or education and not on the caring sector, targeting mainly young individuals with a natural propensity for development rather than older individuals (Koole et al., 2018; Ryan & Deci, 2019). Furthermore, neither SDT nor PSI persuasively account for human agency or accommodate the notion of autonomy in a viable and coherent manner. In contrast, hermeneutic phenomenological frameworks provide a more comprehensive interpretation of human action and meaningful engagement in possibility-laden contexts of everyday practices (Gantt et al., 2022).

Central to the humanising framework of care is that well-being results from the individual's potential to move forward, evolve, and adapt to potentially challenging life changes. From this perspective, well-being extends beyond the mere absence of illness and suffering to include processes of 'dwelling' and 'mobility'. Dwelling implies accepting and adapting to life events, even if challenging, and mobility implies moving on in life and avoiding entrapment in a past life that no longer exists (Galvin & Todres, 2013). Studying how older individuals with ABI accepted and adapted to their current situations (dwelling) and the means and mechanisms they used to move on

from what they previously perceived as normality to the creation of a new one (mobility) is vital in providing explanatory linkages and practical suggestions to support these individuals in achieving a sense of well-being.

### 3 | AIM

This study aimed to acquire an in-depth understanding of the lived experiences of older adults (65+) living with acquired brain injury who undergo or have undergone physical rehabilitation in relation to their sense of well-being during care provision within the Greek Healthcare System.

## 4 | METHOD

### 4.1 | Design

A qualitative study design with a phenomenological-hermeneutic approach is used to understand the lived experiences of older adults living with ABI. Consistent with the hermeneutic phenomenological tradition, the aim is to understand what it is like for older individuals who undergo rehabilitation following an ABI incident and to explore their lived experiences concerning their sense of well-being during this time, with the overall intent of generating a synthesis that explains these sentiments and phenomenon (van Manen, 2014; Zahavi, 2019). Hermeneutic phenomenology's distinctive emphasis on interpreting and depicting individuals' subjective views and experiences as well as their association with their realities (van Manen, 1990, 2014) renders this methodology suitable for the current study. Moreover, the current qualitative phenomenological study's goal is to offer a more comprehensive interpretation of the phenomenon of living with an ABI and produce a deeper knowledge that can be communicated in a coherent and structured manner (Parahoo, 2014; Patton, 2015) and which can be used by healthcare providers to enhance these individuals' senses of well-being.

The qualitative literature explicitly and unashamedly argues that the researcher is the central figure who influences and is influenced by the data, and to suggest otherwise would be insincere (Finlay & Ballinger, 2006; Mantzoukas, 2005). However, qualitative studies, such as the current one, secure their validity by identifying such influences and using reflections and memos throughout the study (Morse, 2015). At the commencement of the study, the researchers completed a reflective analysis of their preconceptions of the topic, maintained reflective memo notes during the data collection and analysis phase, and concluded the study with a final written reflection identifying how they had developed their thinking on the topic. Consistent with qualitative inquiry traditions, we made a great effort to acknowledge our biases and accept that, like all qualitative projects, our research has synthesised and abstracted the views of all involved in the study, including the researchers (Morse, 2015).

## 4.2 | Data collection

Data collection occurred in the region of Epirus in the northwest part of Greece, and specifically within the region's Physical Rehabilitation Unit (PRU). The specific area is rural and one of the poorest regions in Greece, with limited and underdeveloped healthcare service provisions, especially for the older people population (World Bank, 2020). The region also scores high on older people dependency (35%–40%) and has the most aged population within Greece (Eurostat, 2023; OECD, 2020). Understanding the available support system in enabling well-being in older individuals with ABI within this region is pivotal for grasping the unique needs of this population and for developing care models that support well-being.

With regular meetings, the principal researcher (PL) established an open and transparent relationship with the Head of PRU and the Head Nurse, who acted as gatekeepers (Houghton et al., 2017). Also, the study's poster was pinned to the Unit's information board, and information sheets were provided. The study employed a purposive sampling strategy, and individuals who expressed interest in participation were selected according to their specific characteristics and relevant lived experiences.

The study's inclusion criteria included (a) adults aged 65 years or older diagnosed with ABI and residing within the region of Epirus, Greece; (b) capable of effectively communicating with the researcher without presenting any speech difficulties; and (c) being or had been in rehabilitation at least 1 month before the interview. Individuals with severe physical, cognitive or psychosocial difficulties that impeded communication were excluded, as were individuals who had received physical rehabilitation services more than once and for another health reason, as this would alter their initial ABI rehabilitation experiences. A total of 14 eligible participants were included in the study (Table 2).

Data collection occurred between July and December 2021 using semi-structured interviews. The principal researcher conducting all interviews had no prior direct relationship with the participants and ensured that all understood the voluntary nature of their participation, that they were free to withdraw at any point without any consequences, and that they had fully understood all information by providing informed consent. The interviews began with less invasive questions such as 'what' is the interviewee's opinion or 'how' the interviewee performed activities (Price, 2002; Seidman, 2006). The interview then progressed to knowledge questions which relate to more invasive matters, such as 'what do you know?' or 'what do you think?' acquiring details of their experiences and actions and understanding the reasons behind their actions (Price, 2002; Seidman, 2006). Lastly, as the interviewees eased in their role, more in-depth questions were asked concerning their life philosophy and personal values, beliefs, motives and feelings (Price, 2002; Seidman, 2006) (Table 3). The interview script was tested by conducting one pilot interview in early July 2021 and was revised accordingly. The pilot interview was included in the research, as the participant met all the inclusion criteria and the interview worked well.

While the interviews were initially designed to allow participants to decide where they preferred them to be done (either in the rehabilitation unit or their home), during the piloting phase of the study it became apparent that the rehabilitation unit was too noisy and disruptive. Hence, they were conducted in the participants' homes as this provided a quiet place, and participants felt comfortable within a familiar and safe place. The interviews were conducted face-to-face without anyone else present besides the participant. The interviews lasted between 45 and 60 min and were audio-recorded. Immediately after each interview the recordings were transcribed and along with the researcher's reflective memo notes (which included non-verbal cues and emotional expressions) constituted the study's data. The reflective memo notes facilitated the more profound comprehension of the data during the analysis process by enriching the contextual and emotional backdrop of the individuals' responses. The interviews were concluded when no new insights were elicited.

## 4.3 | Ethical considerations

Ethical approval was granted from the Research Ethics and Deontology Committee of the University of Ioannina, the Ethical Scrutiny and Advisory Board of the funding INNOVATEDIGNITY project and the healthcare setting where the participants came from, recognising the requirements for obtaining data safely and securely. Participants provided voluntary and signed informed consent, and privacy and anonymity were ensured by securely storing data and using pseudonyms.

## 4.4 | Data analysis

The data were thematically analysed. The thematic analysis was philosophically informed by van Manen's (1990) work on thematic analysis and, at a practical level, by Clarke and Braun's (2013) steps of the thematic analysis framework. All transcripts were first fully translated into English and were read multiple times to achieve familiarisation. Consequently, each interview transcript was tabularised and divided into separate extracts based on the participants' answers. The tabularised extracts were further divided into three different columns reflecting sequentially the coding steps that were followed: (a) the first column from the left had the transcribed raw text of the interview; (b) the second column represented the first cycle of analysis, where the raw data was filtered according to the salience of the text and condensed into smaller but more meaningful phrases or sentences; and (c) the third column represented the second cycle of analysis, where the condensed meaningful phrases were scrutinised for meaning and where interpretative process occurred (Saldana, 2015). A final extra column was included that contained the researcher's reflective memo notes, further contributing to the interpretation of the second cycle.

TABLE 2 Participants' characteristics.

#	Name	Age	Gender	Place of residence	ABI type	Interview setting	Duration of in-patient rehabilitation	1st diagnosis
1	Part. A	73	Female	City within the Regional Unit of Epirus, Northern Greece	Ischemic stroke	Rehabilitation clinic	1–2 months	2021
2	Part. B	75	Female	City within the Regional Unit of Epirus, Northern Greece	Ischemic stroke	Researcher's office	1–2 months	2014
3	Part. C	73	Male	Village within the Regional Unit of Epirus, Northern Greece	Haemorrhagic stroke	Participant's home	1–2 months	2021
4	Part. D	73	Female	Village within the Regional Unit of Epirus, Northern Greece	Stroke	Participant's home	1–2 months	2011
5	Part. E	67	Male	City within the Regional Unit of Epirus, Northern Greece	Stroke	Participant's home	1–2 months	2019
6	Part. F	72	Male	City within the Regional Unit of Epirus, Northern Greece	Stroke	Participant's home	> 2 months	2019
7	Part. G	79	Male	Village within the Regional Unit of Epirus, Northern Greece	Ischemic Stroke	Participant's home	1–2 months	2010
8	Part. H	75	Male	City within the Regional Unit of Epirus, Northern Greece	Haemorrhagic stroke	Participant's home	> 2 months	2012
9	Part. I	70	Male	City within the Regional Unit of Epirus, Northern Greece	Stroke	Participant's home	> 2 months	2014
10	Part. J	68	Male	Village within the Regional Unit of Epirus, Northern Greece	Haemorrhagic stroke	Researcher's office	1–2 months	2011
11	Part. K	85	Female	Village within the Regional Unit of Epirus, Northern Greece	Stroke	Participant's home	> 2 months	2017
12	Part. L	84	Female	City within the Regional Unit of Epirus, Northern Greece	Stroke	Participant's home	1–2 months	2019
13	Part. M	71	Male	City within the Regional Unit of Epirus, Northern Greece	TBI	Participant's home	1–2 months	2021
14	Part. N	68	Male	City within the Regional Unit of Epirus, Northern Greece	TBI	Participant's home	1–2 months	2020

TABLE 3 Example of the interview script.

Questions	Type of question
1. What do you think has changed the most after you were diagnosed with ABI in terms of your daily routine (during the last year)? • Can you give an example?	General/Descriptive
2. What do you know about ABI and the rehabilitation process? • What kind of information you have been provided with regarding your ABI rehabilitation? • Do you think that you have been actively involved in the planning of your rehabilitation programme? • Is there anything else that you would have liked to know about your rehabilitation or your condition (ABI)?	Knowledge
3. Are you satisfied with the support that you are receiving? • How has the healthcare team supported/ affected you during your rehabilitation? • Are you happy/ satisfied with your life at the moment? • (What else would you like from them? / Is there anything else that you would like from them?)	Knowledge
4. Can you describe how your family is/ has been involved in your rehabilitation programme? <i>If yes:</i> • What do they do for you? • In what ways does this affect your rehabilitation? • (Can you tell me how often you see your loved ones?) <i>If they say that their family are not very involved:</i> • Why do you feel that might be? • In what ways does that affect your rehabilitation?	General/Descriptive
5. Do you know what your family thinks of your current situation/ current condition? • Would you like your family to be more involved or would you like to be less involved in the rehabilitation processes? • What else you think your family can do for you to make you feel better/ feel supported?	Knowledge
6. In general, what family involvement do you feel there should be for people living with ABI? / What are your views about family involvement for people living with ABI?	Personal philosophy
7. Do you think that your current situation has changed you as a person? • If yes, in what ways?	Personal philosophy
8. Have you been making plans for your future? • How does your current situation impact on these plans?	Personal philosophy
9. What do you think/ what are your views about the philosophy that guides the healthcare system? • Do you feel that the rehabilitation setting and its setup can support you further? If so, in what ways?	Personal philosophy

Consequently, all codes were assessed, reviewed and refined by constantly moving back and forth across the list of codes to ensure coherence between their meanings (Creswell, 2009). The codes that addressed the same issue or shared common characteristics were categorised into semantically meaningful clusters (Saldana, 2015). Finally, interpretative themes were identified and produced from these categories. The identified themes correspond to abstract concepts, enclosing meaningful essences that run through the data and reflect the meanings within the participants' lived experiences (Richards & Morse, 2013).

#### 4.5 | The rigour of the study

This study bases its methodological rigour and trustworthiness on the criteria of credibility, transferability, dependability and confirmability (Denzin & Lincoln, 2018). Dependability was achieved by ensuring all participants were interviewed face-to-face by the same researcher. Moreover, the data collection and analysis processes were thoroughly discussed and assessed in regular meetings among the authors to minimise misinterpretations and to allow exposure to alternative interpretations, hence ensuring

agreement on the research design's operationalisation. Credibility and confirmability were attained by transparent and precise record-keeping, including detailed field notes and a personal reflective journal of the researcher. The study's transferability was reinforced by careful sample selection to ensure the participants were as diverse as possible. The authors' commitment to preserving and meticulously following the methodological procedures by clearly documenting the analytical process and engaging in self-reflection contributed to minimising potential research bias, further strengthening the transferability and confirmability of the study. In addition, all authors reviewed the findings to ensure all alternative interpretations had been considered (Denzin & Lincoln, 2018).

Although returning the themes and interpretations to participants for member checking was initially considered, it was deemed as not appropriate for semi-structured interviews (Morse, 2015). In phenomenological-hermeneutic research the findings present an amalgamation of all participants' views (including those of the researchers') and consequently are abstracted and synthesised to such an extent that it becomes difficult to discern which data correspond to specific participant inputs (Morse, 2015; Motulsky, 2021). Furthermore, member checking raises memory

concerns as ABI participants might struggle to recall the details they had provided in the interview. For these reasons, member checking did not occur; however, the research outcomes were communicated and presented to the Physical Rehabilitation Unit, from which participants were recruited to identify if these were recognisable experiences and to receive feedback and stimulate constructive discussions.

This study followed the Consolidated Criteria for Reporting Qualitative Studies (COREQ) guidelines (File S1) (Tong et al., 2007).

## 5 | RESULTS

From the analysis four overarching interpretive themes were identified. These and the categories from which they were constituted are presented in Table 4 and are explored in more detail below.

### 5.1 | Theme 1: Challenges of new life situation

Older adults dealt with various emotional and existential considerations and challenges during their physical rehabilitation about their new way of living. The different emotional and existential concerns expressed by the participants are related to their sense of moving forward and their feelings from physical relocation. They included processing their emotional concerns, sense of moving forward in life and meaning of home.

### 5.2 | Processing of emotional struggles and existential concerns

Several participants struggled to cope with their emotions after their ABI diagnosis, experiencing a mood of depression. This was characterised by a sense of pessimism and meaninglessness concerning their life and recovery prospects, with some even

expressing a desire to die. Feelings of guilt and sadness were also experienced by older individuals who perceived themselves as a burden to their families.

To tell you the truth I'm thinking about dying! I don't want to live anymore ... Well, okay, I see my kids, I see my husband, but if I stay like this, I don't want to ... I suffer and they suffer too. Well, having a sick person at home it's ... He wants to go somewhere; his mind is here. To take care of [his] wife, to make [me] something to eat...

(Participant K)

Well, it makes me a little sad because I trouble the children a lot. [...] I'm sad that I call my son [to help me] and he gets tired. [...] Why God doesn't take me...

(Participant L)

Other participants, however, could harness the negative emotions caused by the life-changing ABI conditions by engaging in a process of self-enhancement and making sense of their new life.

I have confidence in myself. I just reviewed what things ... let's say that some things are futile to do. Let's say my attitude towards the other has probably become better. You don't need, let's say, to quarrel/ argue or anything like that.

(Participant J)

### 5.3 | Temporal distribution of past and future life

Participants also expressed their perceptions about making plans for their future. This related to perceptions of moving forward, progressing to a better state or even to full recovery. The majority of participants expressed a lack of future direction, being unmotivated

TABLE 4 Connection between themes and categories.

CATEGORIES	THEMES
Processing of emotional struggles and existential concerns	Theme 1: Challenges of new life situation
Temporal distribution of past and future life	
Emotional variations on returning home	
Strengthening the sense of belonging through social interactions	Theme 2: Seeking emotional and practical support through social interaction
Emotional support and encouragement by family	
Adopting the role of 'good patient' as a coping mechanism	
Impact of clinical environment on rehabilitation process	Theme 3: Identifying contextual processes of rehabilitation
Identifying structural issues in relation to care provision	
Passivity and sense of dependency	Theme 4: Realising the new self
Self-reliance and involvement as a means for independence	
Making sense of the new self	

to make future plans. Some participants, however, felt a strong sense of moving forward, being interested in the future possibilities of their recovery and new life situation.

Well, what plans can I make for the future. I am not able to do things myself now. I want to but I can't... The kids are settled, that's all.

(Participant F)

I want to go to the shop! But [my family] is afraid that I might fall. [They] still want some time to pass for my condition to be improved and then I will be going down to the shop for a little bit, either to deliver a package with my car in the city or to go and get a package. I was a man who was working all the time. I couldn't sit still... I just couldn't. [...] [I just want] to find my strength again to go easily down to the shop. To be able to go down to the shop, to sit comfortably, or just to go from here there to take a package. Just to get it comfortably without being afraid. How long this will take I do not know...

(Participant C)

## 5.4 | Emotional variations on returning home

Returning home after inpatient rehabilitation also emerged as an important topic during the discussions with older adults. Participants experienced this differently as they strove to make sense of and adapt to their new life at home. The return at home was juxtaposed with the hospital experiences regarding whether this transition was pleasant or unpleasant. When returning to their familiar surroundings, several participants experienced a strong sense of 'feeling at home'. Other participants, however, felt a sense of disappointment or ambivalence upon returning home, considering the hospital a safer environment to support the continuation of their recovery.

Well, you have your family, it's your place. So, I felt much better at home. And what else could I do in the hospital? I did the physiotherapies...

(Participant I)

They told me to come back to the rehabilitation clinic [...], but I did not want to [go] back again; I preferred home and slowly with the help of [my] physiotherapist at home, I slowly walked alone with the cane. I felt really good when I managed to walk on my own, I was getting up and walking. [...] Of course, your home is always your home - oh, my God - I didn't want to [be in] the hospital anymore.

(Participant A)

I remember when I left the hospital... I was afraid that after leaving the hospital, something would happen to me... something... I felt safe over there.

(Participant H)

When I came home, I felt bad. I still wanted to stay [in the hospital], I got used to it and everyone loved me, the doctors and the physiotherapists...

(Participant K)

This interesting finding reveals the non-mutually exclusive association between the perceived sense of 'feeling at home' and returning to your own homeplace. Overall, temporal and spatial movement were associated with positive feelings revealing increased levels of well-being.

## 5.5 | Theme 2: Seeking emotional and practical support through social interaction

Participants expressed a variety of experiences and perceptions regarding the emotional and practical support that they received during their rehabilitation care and how this support had contributed to their overall sense of well-being. Overall, the experiences of older adults living with ABI illustrate that they perceive the process of seeking support as fundamental for increasing the levels of their well-being and for strengthening their rehabilitation progress.

## 5.6 | Strengthening the sense of belonging through social interactions

Participants accentuated the significance of experiencing a sense of human belonging through meaningful interaction during their rehabilitation. The need for social interaction was brought out during most discussions as a transformative factor that can deeply affect the participants' perception of self and self-esteem.

There are other doctors too; I have a physiotherapist; in the past I also had a speech therapist and a neurologist; all of them were very good. When I was hospitalised, we all co-existed very nicely, the neurologist was visiting me; she loved me very much. [...] Our relationship is very good! Always with a smile in their faces. They will welcome me, we will talk, they tell my husband that he is very lucky to have such a woman! I always smile!

(Participant B)

The behaviour of the staff was excellent thanks to [the doctor] [...] He was very polite. He inspired me with confidence. That is, even if I said something stupid,

which I definitely did, he would look at me in a serious manner and would say 'yes', to give you courage.

(Participant J)

In contrast, the lack of active social engagements and meaningful communication produced (or aggravated) feelings of isolation, sadness, and insecurity, thus negatively affecting their self-esteem and their overall sense of well-being. In such cases, participants expressed their sorrow and disappointment when they felt that they had lost contact with their friends or when they were not anymore actively included within social groups.

I have lost many activities and at the same time many friends... This saddens me in a way... I mean, I sit at home and I feel bad...

(Participant H)

### 5.7 | Emotional support and encouragement by family

Family support was also viewed as a fundamental parameter for achieving high levels of well-being. Participants' experiences were appreciative of the emotional and practical help their family provided them by acknowledging the positive effects this had on their emotional state during their rehabilitation. The supportive and intimate environment that family provided to older adults instilled them with confidence, boosted them mentally and encouraged them to carry on with their rehabilitation.

My family gives me love; they cannot offer me help with treatments; they don't know how. Their help is their love. [...]. My husband and children help me, they cook, my son's wife brings me food now and then or she does some simple household chores. My husband assists me a lot; above all else, I've never had a problem of not having someone.

(Participant B)

At the hospital, my husband and my son were helping me, (so) there was also practical help. It was also important to know that someone is always there for you! If you are locked in the golden cage as we say and you are alone it is not the best... I didn't feel that I was in a hospital.

(Participant D)

### 5.8 | Adopting the role of 'good patient' as a coping mechanism

Lastly, participants expressed their views regarding their behaviour and clinical performance during their rehabilitation. Their

perceptions were primarily based on traditional representations and understandings of the "good patient" role, including characteristics such as politeness, patience, and being undemanding and appreciative towards the healthcare staff. However, this traditional understanding of what constitutes appropriate patient behaviour in the clinical setting poses many questions about the actual essence of the well-being that they experience.

I never had any complaints; I never complained about anything. Neither when I was hospitalised, nor about the food, nor about anything. A person who always smiles, bind them on your heart.

(Participant B)

### 5.9 | Theme 3: Identifying contextual processes of rehabilitation

Participants' experiences regarding the impact that the overall hospital environment and their inpatient care had on their rehabilitation and sense of well-being were also examined. The consequences of these contextual factors and organisational processes are evaluated by the participants in different ways according to their lived experiences and felt emotions. These factors included the clinical environment's structural processes.

### 5.10 | Impact of clinical environment on rehabilitation process

The participants either positively or negatively assessed the impact of the hospital environment and provided care, indicating both pleasant and unpleasant experiences. More specifically, most participants felt a sense of place, security and familiarity within the hospital setting, highlighting the positive impact of these contextual factors on their recovery.

[The rehabilitation clinic offered] a familial environment, love, care. I was very satisfied. I had no dissatisfaction. And the food was good... whatever we wanted. And quiet.

(Participant D)

At the rehabilitation clinic, I had excellent impressions from everyone [...] And especially with the girls there [i.e., the nurses]. The girls were something else! With a smile, everything, everything. I'm very pleased.

(Participant N)

In the rehabilitation centre, things were completely different. The bathroom was much better than in the house. With supports. More convenient. [...] I felt

great confidence and love from the doctors. From all the staff, from the nurses to the professor. And that boosted my morale.

(Participant D)

Some participants, however, were more detached and judgmental about the clinical environment displaying a sense of alienation. Still, they express their appreciation for the support and encouragement that they received from the healthcare staff.

It was difficult. I was in the hospital, I didn't understand, I didn't speak well, I didn't walk... nothing. Okay, the nurses and the doctors were of course attending to me, I had no complaints. Of course, I was in a hospital environment which is not the most pleasant thing. Just knowing what would follow, but also my situation, I was very sad.

(Participant A)

Also, the speech therapist... They were all perfect, I'm telling you, they were perfect. I just wanted to leave. I was bored.

(Participant J)

Overall, the felt experiences of most participants regarding their relationship with the medical staff during their inpatient rehabilitation were filled with liveliness, hopefulness and a strong sense of familiarity, leading to a greater sense of well-being.

### 5.11 | Identifying structural issues in relation to care provision

In contrast, the felt experiences of participants about the structural issues they identified throughout the rehabilitation process have unfavourably affected older adults' emotional condition, limiting their capacity for achieving a sense of well-being. Participants highlighted the understaffing issues within the rehabilitation departments and the lack of affordable alternatives in rehabilitation as critical factors that can largely disrupt their rehabilitation experiences as well as the improvement of their well-being.

What has stuck with me is that my wife was seeking help from the staff in there and she says that she didn't get [any] help. [...] She was asking for help. [...] Good thing that my wife was there. But she wanted a little help and she got it a little bit late, [she wanted help] to hold me... [...] my wife asked the nurse for help... [...] And I say, it's a good thing for those patients who have someone with them in the hospital... Those who don't have anyone, what should/can they do?

(Participant C)

When I got back home [at the village], I continued doing rehabilitation, exercises, but after I got up, I stopped for a while because it also cost a lot! Then I have my son who is a fitness instructor and he helps me a lot...

(Participant K)

I wanted to have a carer... but how can I have one? This requires money. I'm getting a low pension now. My expenses are many. Having a woman [i.e. a carer] requires money.

(Participant L)

### 5.12 | Theme 4: Realising the new self

Participants expressed different experiences and feelings with respect to their self-identity and self-awareness following their diagnosis with ABI and during their rehabilitation. The analysis identified a distinction between a sense of dependency and passivity and a sense of self-reliance and involvement that participants experience as inpatients but also after their hospital discharge. In their attempt to adapt to the new reality and the challenging process of their rehabilitation, participants strove to make sense of their new selves, bringing many conflicting emotions and experiences to the surface.

### 5.13 | Passivity and sense of dependency

During their rehabilitation, many participants felt a sense of dependency and passivity as a result of being unable to perform activities or communicate effectively due to their ABI condition. Most participants experienced this as being reliant on others, such as healthcare professionals, carers, or family members. This sense of dependency led to unpleasant feelings and low levels of well-being.

What would I want? To be able to walk a little... to cook, to wash clothes... These things. I wouldn't want anything else! But now I can't... I see that I can't and that makes me sad. Now I have a girl who takes care of me and bathes me, she cooks... I get sad. I would like to do these things myself. I used to do everything myself...

(Participant K)

In some cases, however, participants seem to have acknowledged their passivity as an unavoidable situation. Even though the reliance on their family was not pleasant, it was not necessarily felt as dehumanising:

At first [I couldn't communicate]. My wife was telling me [that] today we were going to do speech therapy or physiotherapy and I was going wherever I was told I was going. I couldn't react.

(Participant H)

Others even valued and embraced their dependency as a coping mechanism during their healthcare and rehabilitation process. The normalisation and acceptance of this situation by some participants concerning how their passiveness can eventually lead to achieving a sense of well-being illuminate the complexity of the human experience when faced with such challenging conditions.

Can I tell you the truth? I was interested about the rehabilitation, and I had put these things in second place. Even if you insulted me, I would smile.

(Participant J)

## 5.14 | Self-reliance and involvement as a means for independence

A felt desire and need to regain their independence and autonomy was noticeable throughout the discussions with all the participants who had experienced a sense of dependency after their ABI diagnosis and during their rehabilitation. Participants reported an increased sense of autonomy when they were able to act independently in their daily lives and take care of themselves without relying on the help of others.

I started walking around the house a little bit as soon as I got there. They told me to come back [to the rehabilitation clinic] after Easter for 2 weeks, but I didn't want to come back again; I preferred home and slowly with the help of the physiotherapist at home I slowly walked alone with the cane. I felt really good when I managed to walk on my own, I was getting up and walking. Of course, I still wanted some help. And I still need some help, but I'm better!

(Participant A)

In addition, participants' desire to be more involved in their recovery program and in goal-setting processes (i.e. obtaining more information about their admission, their state of health and the continuation of their rehabilitation) highlighted their effort to become more autonomous and restore their ability to make their own decisions. Feeling a sense of self-preservation positively affected older individuals' experiences and increased their sense of well-being. Participants felt reinvigorated and more comfortable with themselves, facilitating their adaptation to the new reality.

Yes, I asked for it too! I wanted to be [there], I knew it was fine [there]. I said it too, to continue [there] in the rehabilitation unit and so did my children.

(Participant A)

## 5.15 | Making sense of the new self

Lastly, the analysis emphasised a variety of experiences in the narratives of older adults regarding the process of making meaning of

their new self throughout the challenging stages of their rehabilitation. The physical changes that have occurred due to the ABI have affected many participants emotionally, as they realise the noticeable changes in themselves and the difficulties and struggles they face. For some, this self-awareness intensified their unpleasant feelings, creating a strong sense of disappointment and pessimism that did not allow them to move forward.

I cannot do the things I did before. [...] I feel weaker. [...] I cry more easily; I get sad more easily...

(Participant E)

I'm having a tough time. Not just some challenging time but a lot! I used to go to work, time was passing, then I would return home... Now I can't get down the stairs. I also used to go for walks...

(Participant I)

Some participants, however, developed a more optimistic attitude towards their new life by realising their new self as a horizon full of open possibilities. In this way they manage to put aside any negative emotions and face the new challenges with a sense of excitement and movement towards the future.

I always feel the joy from the infinitesimal to the greatest. First, I am a self-sufficient person. I have no demands, I probably did not and when I was little, I had no special demands on life. Did we have food to eat, did my mother make an egg? I am satisfied with the simple things; I have always been like that. A neighbour asked me last year how can you laugh and I replied why not laugh? If I do not laugh now... [...] I try to laugh at my problems... You are walking and (suddenly) you find yourself bedridden. Thank God I have no pain to say that I suffer.

(Participant D)

## 6 | DISCUSSION

This study aimed to explore older people's experiences during physical rehabilitation for ABI and understand their felt sense of well-being. Most participants expressed uncertainty and anxiety about their present ABI condition and their future self, leading to difficulty adapting to their changed lives. The ABI exacerbated a sense of entrapment in their past more active life that compared unfavourably to their present circumstances, leading to disillusionment with the present (Galvin & Todres, 2013). However, in those cases participants did not mourn the life they lost but instead considered their ABI condition as an unavoidable step towards their future recovery and were able to make future plans, demonstrating greater levels of adaptation and maintaining a strong sense of 'renewal' (Galvin & Todres, 2013). These findings resonate with similar studies carried out in a different context and sample, advocating for guiding

individuals who undergo a transitional phase in their lives towards future potentials and formulating forward-focused goals to suppress maladaptive coping behaviours and facilitate successful transitions (Chua et al., 2015; Johnson et al., 2014).

The study further highlights the importance of family and healthcare professionals in providing motivation and support to individuals living with ABI, helping them to achieve a positive outlook towards the future and constructively use the memory of their past self to develop future plans. In line with the findings of this study, other research has also shown that individuals can redefine their abilities and challenges that chronic illnesses create and, by doing so, find new resources for carrying on, thus energising them to continue living meaningful lives and move towards a hopeful future (Berntzen et al., 2020; Flinterud et al., 2021). Even though some participants managed to achieve a positive future orientation through various means, the fragility and vulnerability that is still evident in all their narratives should serve as a reminder of the precarious balance between achieving a felt sense of well-being and slipping back into a state of suffering (Flinterud et al., 2021).

Concurring with other studies, many participants felt their return home from rehabilitation was a positive experience, providing a sense of independence and protection of privacy and identity (Gillsjö & Schwartz-Barcott, 2011; Silverglow et al., 2020). In these cases, returning home strengthened their sense of well-being, providing a keen sense of 'being and feeling at home' and offering a sense of peacefulness and possibilities for more adventures and journeys (either metaphorically or literally) (Galvin & Todres, 2013). For example, looking at the garden from the window, one participant could feel calmness and a sense of joyousness when playing with her grandchildren. The stillness of the grass was complemented by the spatial movement and energy of playing with her grandchildren on it. This reconnection with her place offered a sense of familiarity and, in agreement with other studies, returning home created the hope of regaining her autonomy and sense of normality (Hestevik et al., 2019; Nordin et al., 2015).

However, this was not always the case; some participants experienced difficulties in continuing their rehabilitation at home. For them, the hospital environment was perceived as safer and more secure than their home, as they were worried about not receiving the same professional support. The study found that hope and (sometimes potentially unrealistic) expectations about returning home can boost emotional well-being and positively affect recovery; nevertheless, this is not always the case for all ABI individuals. Prior to discharging these individuals, healthcare professionals need to consider and understand their perceptions of going back home and the available supportive mechanisms therein.

Such supportive mechanisms include meaningful social ties and the emotional support that their family members provide. The study findings align with previous research that emphasises the importance of family emotional and practical support in the physical and emotional recovery of older individuals with ABI (Bennett et al., 2016; Lawler et al., 2015; Loft et al., 2017). Family members' emotional and practical support creates a sense of 'kinship and belonging' for the participants, fostering a sense of security and togetherness that functions therapeutically. Therefore, it is essential for healthcare

professionals to acknowledge that cultural issues impact familial support and social networking. This viewpoint gains greater significance considering that this study was carried out in Greece where family involvement in care constitutes a distinctive cultural feature of Greek society (Gal, 2010; Naldini, 2016).

Equally crucial is that even if ABI individuals have supportive familial and social environments, this does not automatically guarantee sentiments of well-being as some participants expressed guilt viewing themselves as burdens to their families. This perception elicited unpleasant emotions as well as psychological and existential concerns, such as frustration, depression and a desire to alleviate the perceived care burden on their families by dying, thus making their re-integration into the family environment more challenging (Galvin & Todres, 2013; McPherson et al., 2007; Wilson et al., 2005). Therefore, even if a supportive environment exists, it is useful for healthcare professionals to engage with the individuals and their family members to create or reinforce positive interactions based on mutual reminiscence and life review and assist in developing a positive narrative for their shared future (Allen, 2009; Senden et al., 2015).

The current study also identified a correlation between the positive (or not) transition of ABI individuals to their home environment and their relationships with staff during the rehabilitation phase. Some participants adopted a 'good patient' persona to either ensure a better treatment experience, express appreciation for the received treatment, or fulfil their need for interpersonal belonging. The adoption of this role is usually a result of the hierarchical structure of the clinical environment (Löfmark & Hammarström, 2005). Irrespective of participants' motives, such a persona can lead to ABI individuals suppressing their actual needs and concerns, objectifying themselves or even fearing to express themselves freely. Hence, healthcare professionals need to consider whether individuals' adaptation to their new life conditions reflects a genuine sense of well-being or is merely a facade influenced by existential concerns and the need for interpersonal fulfilment.

Previous studies have emphasised the importance of the environmental surroundings and organisational culture of the clinical setting for the well-being of patients and their attitudes towards rehabilitation care, with positive workplace cultures linked to better patient outcomes (Braithwaite et al., 2017; Douglas & Douglas, 2004). A felt sense of place within the hospital or rehabilitation environment, including the comfort, familiarity, and accessibility to healthcare staff, fosters pleasant feelings and aids in coping with the negative experiences of their condition (Galvin & Todres, 2013).

In this study, participants perceived the setting of their inpatient rehabilitation unit as a supportive and friendly environment, but at the same time they felt a sense of 'dislocation' and a sense of strangeness. These sentiments were further exacerbated by the nursing staff shortages observed in the Greek health system. The literature acknowledges that the lack of adequate healthcare staff constitutes a global issue that has reached a critical point for healthcare services (Marć et al., 2018; Oulton, 2006; WHO, 2022) and has real consequences that result in substandard patient care, compromise of patient safety and hindering collaboration between healthcare professionals (Buerhaus et al., 2007). Similarly,

participants in this study perceived the lack of adequate healthcare staff in the Physical Rehabilitation Unit as a disruptive factor that impacted their recovery progress. This situation intensified their sense of suffering as the unmet needs or expectations cultivated feelings of unsafeness, helplessness, and dissatisfaction. This form of suffering emphasises a sense of 'agitation', characterised by irritation and disturbance that things are going wrong (Galvin & Todres, 2013).

Another indirect but pertinent issue to staff shortages is that some ABI individuals complemented or supplemented their home rehabilitation with privately paid professionals or by attending private rehabilitation centres. The literature acknowledges that the limitation of accessibility to rehabilitation services, the uneven distribution of nurses and the shortages of healthcare staff direct individuals to the private sector (Economou et al., 2017; Ziomas et al., 2018). The private sector provides rehabilitation and physiotherapy services for profit, thereby imposing socioeconomic criteria on rehabilitation options and provisions (Economou et al., 2017; Zikos et al., 2019). This led the less financially well-off participants to feel further frustrated and a sense of suffering and, in some cases, forced them to discontinue their rehabilitation program, causing a further burden on their families.

Finally, the current study's findings highlight the ABI's physical, cognitive and emotional impact on the individual's sense identity, marking a transition from a previously held identity to the emergence of a renewed self-identity. The findings demonstrate that the medicalised structure of the rehabilitation process limited the ABI individuals' autonomy and reinforced high levels of passivity. The literature asserts that passivity and docility during hospitalisation can inhibit well-being sentiments, increase feelings of suffering and create a sense of inability to make meaningful changes or adaptations (Galvin & Todres, 2013). However, in a few instances, what we perceived as passivity was actually a conscious coping mechanism to navigate the challenges posed by ABI and to create a new routine they felt safe with. This resonates with the continuity model of ageing, suggesting that individuals can adjust to disruptive changes in their health and surroundings by building upon pre-existing coping and personality patterns; some individuals may indeed use passivity as one such coping method (Lange & Grossman, 2006).

It is thus important for healthcare professionals to recognise and discern the causative factors of such passivity. Regardless of its origins, ABI individuals' passivity must be addressed by striving to implement person-centred models of care that promote more positive-oriented coping mechanisms. By shifting one's focus from looking at their vulnerabilities to identifying their strengths it is possible to transition from passive to resilient coping mechanisms, which in turn can provide the means for a better quality of life, reduced distress levels, better adaptability to changes, and an increased sense of well-being (Neils-Strunjas et al., 2017; Pollack et al., 2016; Vaghela et al., 2021).

## 7 | STUDY LIMITATIONS

This study presents some limitations. The fact that most of the selected participants were diagnosed with stroke (a nTBI) may have

affected the balance of the sample and limited the opportunity to include a comprehensive sample of older individuals' experiences living with TBI. In addition, the specific geographical region where all participants resided may have further affected the representativeness of the findings. However, as this study adopts a qualitative approach, the focus rests on the in-depth analysis, resonance and transferability of the findings rather than on the sample's representativeness. Finally, the lockdown restrictions due to the COVID-19 pandemic impacted access to potential participants as movement was significantly limited, especially in healthcare units. This posed a considerable challenge in recruitment and required considerably greater efforts to secure participant interviews and data collection.

## 8 | CONCLUSION

This study concludes that older ABI individuals' well-being is adversely impacted by difficulties in adapting to and moving forward with their new situation due to intrinsic and extrinsic factors. The intrinsic impediments include nostalgia for a previous self that no longer exists, entrapment in the past rather than making plans for the future, a sense of guilt for the self-perceived burden to the family, and the innate individual characteristics of passivity and pessimism. The extrinsic impediments include insufficient familial support, cultural influences concerning family and social roles, the hierarchical and medicalised structure of formal care services, the lack of adequate staffing and access to health services, and healthcare privatisation. Hence, when designing and implementing care for ABI individuals, healthcare professionals would benefit from taking into consideration the readiness of the individuals and their families to return home from inpatient rehabilitation. This involves assessing individuals' focus on their strengths versus their weaknesses, whether individuals and their family have developed a positive relationship centred on positive shared reminiscences and future narratives, and whether individuals have the financial capability to continue their care and rehabilitation. ABI individuals can achieve a heightened sense of well-being when the transition from inpatient rehabilitation to home leads to the successful integration into their family and social structures and the creation of a new normality, with as much as possible greater levels of autonomy and a positive life narrative that incorporates the past, but significantly moves away from it towards a new presence and future.

## 9 | RELEVANCE TO CLINICAL PRACTICE

This research study offers significant theoretical and practical implications for clinical practice. The study makes the notion of well-being in older individuals suffering from ABI a more tangible concept by relating it to the degree of adaptation to the new situation and the potential to create future plans whilst living with ABI. The greater the adaptation to the new ABI condition and the more realistic the future life plans are, the greater the levels of

well-being can be. To achieve this, healthcare professionals ought to assess the genuineness of older individuals' potential for adaptation, their readiness to return home from inpatient care, the available support structures within their family and their coping potentials. Furthermore, healthcare professionals ought to create the preconditions for increasing resilience in ABI individuals and for developing a collective positive narrative for future prospects involving both the individuals and their family, while also guaranteeing the provisions for uninterrupted care and rehabilitation at home. Finally, healthcare professionals should strive to deliver care within person-centred care models, with adequate time devoted to each individual, and relay their concerns to policymakers regarding the impact that financial and accessibility issues may have on the well-being of ABI individuals.

### AUTHOR CONTRIBUTIONS

Panagiota Lafiatoğlu independently developed the study's design, carried out the interviews and conducted the coding and analysis of the data as well as the interpretation of findings. Panagiota Lafiatoğlu, Caroline Ellis-Hill and Stefanos Mantzoukas reviewed the drafting of the manuscript and revised it critically for important intellectual content. All authors gave final approval of the version to be published.

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### CONFLICT OF INTEREST STATEMENT

We have no known conflict of interest to disclose.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are publicly available through the UK Data Service ReShare repository at <https://reshare.ukdataservice.ac.uk/856656/>. The data are available for download to users registered with the UK Data Service.

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## SUPPORTING INFORMATION

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