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Exploring the lifeworld of elderly individuals undergoing physical rehabilitation and their perceptions of well-being within formalised care systems

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Panagiota Lafiatoglou
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Η συλλογή και η επεξεργασία των δεδομένων προσωπικού χαρακτήρα που υποβάλλονται πραγματοποιείται σύμφωνα με τα οριζόμενα στις διατάξεις του Ν.4624/19 και του Κανονισμού (ΕΕ)2016/2019. Το Πανεπιστήμιο Ιωαννίνων συλλέγει και επεξεργάζεται τα δεδομένα προσωπικού χαρακτήρα αποκλειστικά στο πλαίσιο της υλοποίησης του σκοπού της παρούσας διαδικασίας. Για το χρονικό διάστημα που τα προσωπικά δεδομένα θα παραμείνουν στη διάθεση του Πανεπιστημίου Ιωαννίνων το υποκείμενο έχει τη δυνατότητα να ασκήσει τα δικαιώματά του σύμφωνα με τους όρους του Γενικού Κανονισμού Προστασίας Δεδομένων Προσωπικού Χαρακτήρα 2016/679 (Ε.Ε.) και τα οριζόμενα στα άρθρα 34 και 35 Ν. 4624/2019. Υπεύθυνη Προσωπικών Δεδομένων του Ιδρύματος είναι η κα. Σταυρούλα Σταθαρά (email: dpo@uoi.gr).

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Abstract

Background: The increasing ageing population and the profound life-changing consequences of ABI make it critical to reorient the focus of care and rehabilitation for older adults towards promoting their potential for a fulfilling and prosperous life. Consequently, there is a growing need to investigate well-being qualitatively, especially in the context of enhancing rehabilitation systems. This necessitates current research to give more attention to older adults' experiences of well-being and satisfaction levels concerning their care during ABI rehabilitation.

Aim: To acquire an in-depth understanding of the lived experiences of older individuals (+65) living with acquired brain injury when undergoing physical rehabilitation in relation to their sense of well-being during care provision within the Greek Healthcare System. To provide an interpretive exposition illustrating the impact that Greece's healthcare and rehabilitation system has on older individuals' felt sense of well-being.

Design: A qualitative study design with a hermeneutic phenomenological approach was developed to provide a comprehensive exploration and interpretation of the well-being subjective experiences of older individuals living with acquired brain injury, undergoing physical rehabilitation.

Method: A total of 14 semi-structured interviews with older individuals living with acquired brain injury were purposively conducted. A thematic analysis of the interviews' transcriptions was carried out within the perspective of a hermeneutic phenomenological paradigm, following van Manen's and Clarke and Braun's methods.

Findings: 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) The felt sense of self in the aftermath of ABI. The different subjective experiences, intersubjective relations and contextual clinical conditions influence and determine older individuals' sense of well-being and by extension the realisation of the new changes in their life, leading to various well-being or suffering possibilities.

Conclusions: The exploration of the interrelation between these dimensions is crucial to understand further older individuals' needs regarding their rehabilitation as well as for the enhancement of their mental and physical state. A deep and comprehensive knowledge of the factors impacting older individuals' felt sense of well-being during rehabilitation can contribute to the provision of more dignified and humanising health care.

Keywords: acquired brain injury, well-being, older individuals, physical rehabilitation, phenomenology, humanising care, qualitative research.

Abstract in Greek

Υπόβαθρο: Δεδομένης της επικείμενης αύξησης του ηλικιωμένου πληθυσμού και των σημαντικών αλλαγών που μπορούν να προκαλέσουν οι επίκτητες εγκεφαλικές βλάβες στη ζωή του ατόμου, η περίθαλψη και η φροντίδα για τα ηλικιωμένα άτομα που έχουν υποστεί επίκτητη εγκεφαλική βλάβη πρέπει να επικεντρωθεί περισσότερο στη βελτίωση της ευεξίας τους, δηλαδή στις δυνατότητες αυτών των ανθρώπων να ζουν καλά και με αξιοπρέπεια. Υπό τις επικρατούσες συνθήκες, η ποιοτική διερεύνηση της ευεξίας κατά τη φυσική αποκατάσταση καθίσταται ιδιαίτερα σημαντική και χρήζει μεγαλύτερης προσοχής, ειδικά για τη βελτίωση και ενίσχυση των εν λόγω προγραμμάτων αποκατάστασης. Κατά συνέπεια, παρίσταται η ανάγκη να διερευνηθούν εις βάθος οι προσωπικές εμπειρίες των ηλικιωμένων που ζουν με επίκτητη εγκεφαλική βλάβη σχετικά με την περίθαλψή τους και την αίσθηση ευεξίας τους κατά τη διάρκεια της φυσικής αποκατάστασής τους.

Σκοπός: Η παρούσα έρευνα επιχειρεί να αναπτύξει μία εις βάθος κατανόηση του βιόκοσμου των ηλικιωμένων ατόμων (+65 ετών) που χρήζουν φυσικής αποκατάστασης μετά από επίκτητη εγκεφαλική βλάβη με σκοπό να παράσχει μια ερμηνεία που θα απεικονίζει τον αντίκτυπο που έχει το σύστημα υγείας και οι υπηρεσίες αποκατάστασης της Ελλάδας στην αίσθηση ευεξίας και γενικότερα στις εμπειρίες αποκατάστασης των ηλικιωμένων ατόμων.

Σχεδιασμός: Αναπτύχθηκε ένας σχεδιασμός ποιοτικής μελέτης με φαινομενολογική-ερμηνευτική προσέγγιση για την ολοκληρωμένη διερεύνηση και ερμηνεία της υποκειμενικής εμπειρίας των ηλικιωμένων ατόμων που ζουν με επίκτητη εγκεφαλική βλάβη, αναφορικά με την αίσθηση ευεξίας τους όταν υποβάλλονται σε φυσική αποκατάσταση.

Μέθοδος: Διενεργήθηκαν συνολικά 14 ημι-δομημένες συνεντεύξεις με ηλικιωμένα άτομα που ζουν με επίκτητη εγκεφαλική βλάβη. Πραγματοποιήθηκε θεματική ανάλυση των απομαγνητοφωνημένων συνεντεύξεων στο πλαίσιο ενός ερμηνευτικού φαινομενολογικού παραδείγματος, ακολουθώντας τις μεθόδους των van Manen και Clarke και Braun.

Ευρήματα: Τέσσερα θέματα προέκυψαν από την ανάλυση των δεδομένων: 1) Προκλήσεις της νέας πραγματικότητας μετά την ΕΕΒ· 2) Αναζητώντας συναισθηματική και πρακτική υποστήριξη μέσω της κοινωνικής αλληλεπίδρασης· 3) Προσδιορίζοντας το ευρύτερο πλαίσιο των διαδικασιών αποκατάστασης· 4) Η αίσθηση του εαυτού μετά την ΕΕΒ. Η ευεξία των ηλικιωμένων ατόμων καθώς και η διαδικασία συνειδητοποίησης των αλλαγών στη ζωή τους καθορίζονται και βιώνονται ως μια αλληλοσυσχέτιση διαφορετικών υποκειμενικών εμπειριών, διυποκειμενικών σχέσεων και περικειμενικών συνθηκών, προκαλώντας ποικίλες ενδείξεις ευφορίας ή δυσθυμίας.

Συμπεράσματα: Η διερεύνηση της αλληλοσυσχέτισης αυτών των διαστάσεων είναι ζωτικής σημασίας για την περαιτέρω κατανόηση των αναγκών των ηλικιωμένων ατόμων σχετικά με τη διαδικασία αποκατάστασή τους, καθώς και για τη βελτίωση της ψυχικής και σωματικής τους κατάστασης. Η ολοκληρωμένη και εις βάθος γνώση των παραγόντων που επηρεάζουν την αίσθηση ευεξίας των ηλικιωμένων ατόμων με επίκτητη εγκεφαλική βλάβη κατά τη διάρκεια της αποκατάστασης μπορεί να συνεισφέρει στην παροχή πιο αξιοπρεπούς και εξανθρωπισμένης υγειονομικής φροντίδας.

Λέξεις-κλειδιά: επίκτητη εγκεφαλική βλάβη, ευεξία, ηλικιωμένα άτομα, φυσική αποκατάσταση, φαινομενολογία, εξανθρωπισμένη φροντίδα, ποιοτική έρευνα.

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List of abbreviations and acronyms

ABI	Acquired Brain Injury
CASP	Critical Appraisal Skills Programme
CCU	Coronary Care Unit
EE	Enriched Environment
GDPR	European Union’s General Data Protection Regulation 2016/679
HDU	High Dependency Unit
ICU	Intensive Care Unit
nTBI	Nontraumatic Brain Injury
PAC	Post-Acute
PEOT	Population, Exposure, Outcome and Type of studies
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCTs	Randomised Control Trials
TBI	Traumatic Brain Injury

Publications/ Conference Presentations

Publications

1. **Mantzoukas, S., Lafiatoglou, P. and Zygouri, I. (2022) 'Interventions of Formal and Informal Caregivers in People with Acquired Brain Injuries for Achieving a Sense of Well-Being'**, in A. Ploumis (ed.), *Physical Medicine and Rehabilitation Issues with Clinical Scenarios and Interventional Method*. NEON Publications, pp. 609-619 (in Greek).
2. **Lafiatoglou, P., Ellis-Hill, C., Gouva, M., Ploumis, A., and Mantzoukas, S. (2022) 'A systematic review of the qualitative literature on older individuals' experiences of care and well-being during physical rehabilitation for acquired brain injury'.** *Journal of Advanced Nursing,* 78(2), pp. 377–394. doi: https://doi.org/10.1111/jan.15016
3. **Lafiatoglou P. et al. The felt sense of well-being of older people living with acquired brain injuries and undergoing physical rehabilitation**, *Nursing* (in Greek) [under review]

Oral Presentations

1. **Lafiatoglou, P. (2023) 'The felt sense of well-being of older adults living with brain injuries and undergoing rehabilitation in Greek Healthcare System'** [Presentation], *50th Panhellenic Congress of the Hellenic Nurses Association*, Syros, Greece, 3 - 6 May 2023 (in Greek).
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3. **Lafiatoglou, P. (2021) 'A systematic literature review of older individuals' experiences of care and well-being during Acquired Brain Injury (ABI)**

physical rehabilitation’ [Presentation], *RCN International Nursing Research Conference 2021*, Virtual event - Hopin, 7 - 9 September 2021.

CHAPTER 1: INTRODUCTION

1.1 Introduction to the Chapter

In this thesis I present a qualitative phenomenological study of the lived experiences of older individuals living with Acquired Brain Injuries (ABI), who have received physical rehabilitation within the context of formalised care in Greece, regarding their felt sense of well-being. This introductory chapter commences with the researcher's pre-understandings and reflections on her personal background to set out the justification of pursuing this research topic. The chapter continues by providing background information on ABI and rehabilitation; this is followed by the research problem and rationale for studying the well-being experiences of older individuals with ABI during rehabilitation. The first chapter concludes with the outline of the thesis by briefly describing each chapter.

1.2 Author's reflections and pre-understandings about care and well-being

The way I perceive, comprehend and conceptualise healthcare research and related issues has been influenced and informed by my own personal beliefs and professional experience as a nurse.

During my undergraduate studies in Nursing, I worked as a practice nurse in the cardiology ward of a Greek hospital for six months. I was responsible for the patients' medication administration and for conducting their daily health checks, i.e., checking blood pressure, body temperature, their care treatment schedule etc. Due to the austerity measures implemented at the time in Greece, the hospital was short-staffed so I had to perform my duties in a fast pace in order to be able to assist with other tasks as well. One day, I was administering the medication to a 70-year-old woman who was suffering from chronic heart failure and had also signs of Alzheimer's disease. On that morning, the patient was refusing to take her medication. She was asking exactly what this was and why she had to take pills all the time. She was also claiming that she was feeling all right and she did not need any medication. I was trying to explain her - always in a polite and professional manner -that it was really important to adhere to her medication schedule as this would help control and relieve her health condition. Eventually, she did take the medication but she was still a bit confused.

I felt that this was a reflective incident; my initial thought was that I followed the proper procedure by convincing the patient to take the medicine. However, I felt that I dismissed the patient's queries and concerns quite quickly due to my heavy workload. After I walked out of the room, I sympathised with the patient's situation and I felt bad as she looked quite confused and distressed. Later that day, I spoke to the charge nurse about the incident. She suggested that I should stay and discuss further with the patient to ensure that she felt comfortable to take her medication. In the meantime, she acknowledged the heavy workload due to the understaffing and how this had affected me.

The incident was extremely challenging for me. I regret that in the first instance I did not stay with the patient to give comfort to her and make her feel settled. However, I did return to her room to see how she was feeling. I listened to her concerns with my full attention. Through our discussion I managed to understand and learn more about her feelings and thoughts. The incident made me aware of how crucial it is to follow a more humanising approach in healthcare delivery. It taught me to be more alert when it came to preserving patients' well-being - no matter the challenges and difficulties we may be going through in the working environment. Also, to always dedicate time to patients in order to comprehend their feelings and needs as human beings. Finally, I learned how significant it is to revise care, support and treatment practice by relying on what matters the most to the patients and their families.

Looking back on that moment, I can now see that I should have acted differently. Through the years, I have gained further work experience as a registered nurse in the UK and I have learned how the safeguarding of patients' well-being can actually lead to positive outcomes when it comes to healthcare provision.

In my point of view, I believe that the Greek National Health system needs structural changes in order to deal with the current healthcare challenges, especially for the older population whose numbers have risen significantly. Through my research, I explored the needs, feelings and thoughts of patients and how these should be appreciated more during healthcare provision. The current project also looked at how patients' experiences can be effectively utilised in order to develop a coherent healthcare approach that will be based on more humanising care practices for older individuals.

1.3 Background Information on Acquired Brain Injury

1.3.1 Defining Acquired Brain Injury

Acquired Brain Injury is one of the most common neurological diseases, afflicting around 939 per 100,000 individuals worldwide (Dewan *et al.*, 2019) with the age groups most affected being young children (0–4 years), young adults (15–29 years) and older people (65 years and above) (Yates *et al.*, 2006; Jones *et al.*, 2011). ABI is a chronic condition that can entail serious life-changing ramifications and a potential high probability of mortality (Corrigan and Hammond, 2013; Oyesanya, 2017). As a result of an ABI mild, moderate, or severe (temporary or permanent) impairments and functional changes in one or more areas may occur – ranging from physical to cognitive, emotional, and behavioural changes such as headaches, memory loss, depression and aggression – which can lead to personal and psychosocial difficulties and maladjustments for individuals (Jones *et al.*, 2011; Giustini, Pistarini and Pisoni, 2013).

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, Pistarini and Pisoni, 2013; Toronto ABI Network, 2022). The literature usually uses the term ABI as an umbrella term, that encompasses different moderate-to-severe brain damages with different aetiologies. These are differentiated into two types, namely, traumatic brain injury (TBI) and nontraumatic brain injury (nTBI) (Table 1.1).

Table 1.1 *Types of traumatic and nontraumatic brain injury (adapted from Giustini, Pistarini and Pisoni, 2013)*

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

DSM-5 defines TBI as “a brain trauma” caused by “an impact to the head or other mechanisms of rapid movement or displacement of the brain within the skull”, with one or more of the following phenomena serving as evidence of force-induced disruption or alteration of brain function:

- Loss of Consciousness
- Posttraumatic Amnesia
- Disorientation and Confusion, and
- Neurological Signs (e.g., positive neuroimaging demonstrating injury; a new onset of seisures; a marked worsening of a pre-existing seisure disorder; visual field cuts; anosmia [loss of smell]; hemiparesis).

(Black and Grant, 2014, p. 378)

Likewise, the American Association of Neurological Surgeons defines traumatic brain injury (TBI) as:

> “a disruption in the normal function of the brain that can be caused by a blow, bump or jolt to the head, the head suddenly and violently hitting an object or when an object pierces the skull and enters brain tissue.”
>
> (American Association of Neurological Surgeons, 2020, para. 1)

TBIs can be further distinguished into *closed or non-penetrating* head injuries (e.g. blunt trauma, acceleration/ deceleration injury, and blast injury) and *open or penetrating* head injuries (e.g., gunshot wound, other penetrating injuries). Both types of TBIs often occur as a result of vehicular and sports related accidents or other incidents/ accidents (e.g. falls, assaults).

On the other hand, nTBIs include injuries to the brain that are not caused by an external physical force to the head (Giustini, Pistarini and Pisoni, 2013). They can be the result of brain hypoxia after cardiac or respiratory arrest, metabolic disorders, subarachnoid haemorrhage, ischemic or haemorrhagic stroke. Other nonviolent circumstances, such as tumours and lead poisoning, can also damage the brain (Greenwald, Burnett and Miller, 2003). From this point of view, nTBI is defined by exclusion, i.e., all other injuries that are not caused externally induced head trauma or impact.

Essentially, the main difference between TBI and nTBI concerns the cause of the brain damage and the site where it occurs or derives from. In short, the former refers to brain damage caused by an external force whereas the latter refers to damage caused to the brain by internal factors (BIAA, 2020). Mentioning the internally induced nature of nTBI adds another dimension regarding its aetiologies. As it stands, there is not a precise definition of nTBI mainly due to the heterogeneity and diversity of the conditions.

Studies of the last two decades identify an increase in ABI (and more specifically TBI) incidents in people over 65 years old worldwide especially in high-income countries (Chan *et al.*, 2013; Majdan *et al.*, 2016), with unintentional falls being the leading cause of TBI in older individuals (Grigorakos *et al.*, 2016; Gardner *et al.*, 2018; Peterson and Kegler, 2020). According to the literature, there are various reasons why this increase has occurred. First, the absolute incidence of TBIs among older individuals is largely due to the increased life expectancy and their greater autonomy (Roozenbeek, Maas and

Menon, 2013). At the same time, it is associated with a reduction in the incidence of TBI caused by road accidents, which mainly affects younger individuals due to improved road safety measures (Faul *et al.*, 2010). In addition, nTBI, such as stroke, also appear to greatly affect older individuals. Specifically, the risk of having a stroke doubles for every decade of life after 55, regardless of gender, with approximately 50% of all strokes occurring in people over age 75 and 30% over age 85 (Lui and Nguyen, 2018).

1.3.2 Physical rehabilitation for Acquired Brain Injury

Moderately to severely injured individuals may receive specialised rehabilitation care, including treatments and services such as physical therapy, occupational therapy, speech/ language therapy, physiatry, neurology, psychology, psychiatry, and social work Giustini, Pistarini and Pisoni, 2013). This needs a coordinated delivery of discipline-specific as well as multidisciplinary expertise healthcare services. The overall goal of rehabilitation after a brain injury is to improve the individual's ability to function independently at home and in society in the face of the residual effects of the injury, which may be quite complex (Giustini, Pistarini and Pisoni, 2013). The rehabilitation treatments of people with brain injury can include:

- acute rehabilitation programs
- subacute rehabilitation programs
- long-term rehabilitation programs
- transitional living programs
- behaviour management programs
- day treatment programs
- home rehabilitation and independent living programs

(Maas *et al.*, 2004; Gordon *et al.*, 2006; Giustini, Pistarini and Pisoni, 2013; Goranson, Wong and Fung, 2020)

As Giustini, Pistarini and Pisoni (2013) note the establishment of a comprehensive continuum of medical and rehabilitative care, as well as the coordination of services across health disciplines, is of primary concern when dealing with persons with varying degrees of brain injury, since these processes can positively affect the patient's care quality. According to Wells *et al.* (2003) and Jónsson *et al.* (2003), the most effective rehabilitation programmes are those which: promote interdisciplinary teamwork, are patient-centred, provide comprehensive evaluations and intensive rehabilitation services. Most importantly, the personal needs of individuals undergoing physical rehabilitation need to be recognised and taken into consideration for more specialised and patient-targeted care to be provided. Physical rehabilitation is thus of great importance, as it can enable individuals living with ABI to achieve the optimal level of physical, mental and psychosocial health and well-being (Atwal *et al.*, 2007).

1.3.3 Physical and psychological impact of ABI on older individuals

On average, older people with ABI (stroke and TBIs) experience higher morbidity and mortality as well as slower recovery rates than younger people (Lui and Nguyen, 2018; Peters and Gardner, 2018; Furlan *et al.*, 2021). At the same time, they may have worse functional, cognitive and psychosocial consequences (months or even years after their injury) as well as more severe disabilities after hospitalisation, thus being less independent compared to younger individuals (Thompson, McCormick and Kagan, 2006; Gardner *et al.*, 2018).

In addition, the financial costs associated with the physical rehabilitation and treatment of older individuals living with stroke or TBIs are usually significantly higher than those reported in younger patients, due to the longer rehabilitation period that is usually required for older populations (Thompson, McCormick and Kagan, 2006; Chen *et al.*, 2012; Khan *et al.*, 2021; Lee *et al.*, 2021). Even after their hospital discharge several older individuals may face higher costs for the continuation of their rehabilitation in comparison with their in-patient treatment (Vasiliadis and Zikić, 2014).

According to previous research old age together with the severity of TBI and nTBI had long been recognised as independent predictive indicators of negative outcomes related to the progress of individuals' rehabilitation, their functional recovery and their levels of well-being (Hukkelhoven *et al.*, 2003; Coronado *et al.*, 2005; Flanagan, Hibbard and Gordon, 2005; Teasdale and Engberg, 2005; Thompson, McCormick and Kagan, 2006;

D’Amore *et al.*, 2013; Yoo *et al.*, 2020). However, research has shown that a subset of older individuals living with TBI or stroke can improve their recovery through rehabilitation and even achieve similar rehabilitation results regardless of the severity of the injury compared to younger patients (Denti *et al.*, 2008; De Bonis *et al.*, 2010; Mak *et al.*, 2012; Lilley *et al.*, 2016). Hence, age and severity are insufficient indicators of accurate ABI prognosis especially concerning long-term rehabilitation outcomes (Denti *et al.*, 2008; Alawieh, Zhao and Feng, 2018; Peters and Gardner, 2018). At the same time, increased positive psychosocial outcomes may occur in individuals with ABI, even when the brain damage is severe, such as improved quality of life, increased satisfaction, and post-traumatic development (Muenchberger, Kendall and Neal, 2008; Wood, 2008; Douglas, 2012; Grace *et al.*, 2015).

Furthermore, as Jones *et al.* (2011) conclude, changes in the well-being of individuals after ABI are greatly affected by personal and social changes that may occur due to the injury. These have to do with the different perceptions that sufferers may have of themselves after the injury, as well as the changes they may experience in their social relationships. Boosting self-confidence as well as gaining more support from relatives or the wider social environment can also play a crucial role in reducing the injury's negative impact (Jones *et al.*, 2011; Douglas, 2012; Grace *et al.*, 2015).

1.4 Statement of the Research Problem

Various qualitative and quantitative studies have investigated the experiences of individulas living with ABI. In relation to nTBIs, many studies have focused on stroke individuals’ experiences of rehabilitation, looking either at their experiences in their daily lives after their discharge from the hospital or on their physical rehabilitation experiences during their hospitalisation and their involvement in their inpatient rehabilitation goal setting (Wressle, Öberg and Henriksson, 1999; Almborg *et al.*, 2010; Barbour and Mead, 2012; Brown *et al.*, 2014; Lloyd, Roberts and Freeman, 2014; Taule *et al.*, 2015; Lou *et al.*, 2017). Studies dealing with adults’ TBI experiences have also been conducted, exploring the challenges and long-lasting effects of traumatic brain injuries on individuals' lives, self-perceptions, and social integration (Abrahamson *et al.*, 2016; McPherson *et al.*, 2017; Jones *et al.*, 2022).

Beyond empirical research studies, there are literature reviews exploring stroke individuals' inpatient physical rehabilitation experiences. Luker *et al.* (2015) carried out a systematic review of thirty-one studies from ten different countries with all of them reporting negative experiences of rehabilitation including disempowerment, boredom and frustration, lack of control, lack of understanding, and lack of effective communication. Rosewilliam, Roskell and Pandyan (2011) carried out a systematic review and synthesis of quantitative and qualitative studies, indicating negative experiences and various barriers that hinder the adoption and application of a patient-centred goal-setting model in stroke rehabilitation practice. Lastly, the review of Neils-Strunjas *et al.* (2017) explored the construct of resilience in rehabilitating adults with ABI concluding that resilience has a vital role in the recovery and rehabilitation process, by amplifying individuals' adaptation and emotional adjustment following ABI.

Focusing on the subjective experiences of adults with TBI, Villa, Causer and Riley (2021) highlight in their review the negative impact of TBI on individuals' sense of self and ability to engage in meaningful relationships and daily activities. The review primarily reveals some significant TBI consequences such as loss of autonomy, gaps in memory, loss of valued roles and activities, social rejection and stigma (Villa, Causer and Riley, 2021). Furthermore, Ritchie *et al.* (2014) point out the reduced community integration, social isolation, and decreased participation in activities that occur after TBI, which affects older individuals more than their younger counterparts. It should be pointed out, however, that most studies and reviews on TBI experiences tend to have a broad age focus, including mainly younger adults or a mix of young and older individuals.

Still, there seems to be a scarcity of studies in the literature that identify links between the subjective experiences of older individuals living with ABI and their sense of well-being during rehabilitation. Moreover, participants in relevant studies usually consist of individuals under 65 years old or include both younger and older individuals. On top of this, qualitative studies dealing with this subject area are quite limited, as most of the recent literature adopts quantitative methods.

Given the impending increase in ageing populations (United Nations, 2020) and the fact that ABI is often a condition that people have to live with and need to adapt to, caring and rehabilitation for older people diagnosed with ABI needs to focus more on these people' potential to live well. In other words, it is important to consider the ways that older individuals and especially those who are living with ABI can acquire and maintain a sense of well-being.

Under the prevailing conditions, the concept of well-being during the physical rehabilitation of older individuals with ABI becomes quite salient and deserves greater consideration especially when improving ABI treatment programs (Jones *et al.*, 2011). This requires current researchers to pay more attention to the levels of satisfaction of older individuals with ABI, by shifting the focus towards their subjective conceptualisations of well-being when they undergo physical rehabilitation (Mantzoukas, Lafiatoglou and Zygouri, 2022).

There are different approaches related to well-being in the literature, including psychological, physical, socio-economical, mental and philosophical (Diener, 2009; Galvin and Todres, 2013). In general terms, the term well-being is associated with the presence and experience of positive feelings by individuals which can lead to a pleasant, fulfilling and happy life (Ruggeri *et al.*, 2020). Among the various well-being approaches, the current study considers well-being from an existential philosophical perspective using the dwelling-mobility matrix of well-being, as developed by Galvin and Todres (2013). Their definition captures the subjective, experiential and dynamic nature of well-being, emphasising its positive and strength-based potential of enabling and empowering individuals to move forward, evolve and adapt to any potentially difficult life changes. From this perspective, well-being can be considered a multifaceted and intricate phenomenon that encompasses much more than simply the absence of illness and suffering. In particular, well-being is viewed as an experiential process that consists of the processes of dwelling and mobility. Dwelling implies the adaptation to a condition and can be translated as a sense of peacefulness, and mobility implies the moving on with this condition, hence opening the path to explore new places, things and possibilities (Galvin and Todres, 2013). The unity of dwelling and mobility creates a sense of adventure horizons that offer a new place of promise (Galvin and Todres, 2013). The investigation of this complex nexus of qualities can shed light to the ways that older individuals can experience and achieve a strong sense of well-being during the process of their ABI rehabilitation.

The lack of scholarship on the subjective experiences of older individuals who live with ABI regarding their well-being during their rehabilitation, reflects an important research problem that the current study addresses by conducting a qualitative phenomenological research study that focuses on the felt sense of well-being as experienced by older individuals. The emphasis on the lived experiences of older individuals, and more specifically on their own perceptions of their well-being, can provide a deeper understanding of how physical rehabilitation processes take place while further providing the basis for assessing and improving the quality of rehabilitation services.

1.5 Structure of the thesis

In Chapter 2, I provide a systematic literature review on the experiences that older individuals who live with ABI have regarding their rehabilitation and their overall sense of their well-being. The intention of this review is to identify the available evidence and any key factors relating to these issues as well as to consider any existing gaps in the research literature. The chapter concludes with the presentation of the research question, aim and objectives of this study.

In Chapter 3, I present the theoretical framework underpinning the current study. Considering the purpose of this study and the results of the systematic literature review, the dwelling-mobility matrix of well-being proposed by Galvin and Todres (2013) was used for the identification and interpretation of the lived experiences. This framework is theoretically informed by a phenomenological lifeworld approach and pertains to an existential understanding of well-being and suffering.

In Chapter 4, I deal with the philosophical assumptions that shape and inform the current study while also detailing the qualitative phenomenological methodology that was employed for conducting the research. I also describe in detail the data collection process by justifying the sampling method and the recruitment strategy. Consequently, I present the interview process and the analytical approach that was used for the analysis of the data. Lastly, I discuss the issues of rigour concerning this qualitative research.

In Chapter 5, I present and interpret the findings of the analysis of the interviews. The analysis of the data is phenomenologically guided, focusing on the interpretation of the subjective experiences, conceptions and assumptions of the participants in relation to the topics under investigation. The analysis of the findings is further linked with the objectives of the study by highlighting how their interpretation contributes to their achievement.

In Chapter 6, I generate a tentative framework for exploring the impact of ABI rehabilitation on older individuals' experiences and sense of well-being. The framework is based on the various links and patterns between the themes and categories, as these arose through the analysis of the data.

In Chapter 7, I discuss and clarify the key issues that stem from the findings in relation to the existing literature and the well-being matrix of Galvin and Todres (2013) that was used in this study.

In Chapter 8, I conclude the thesis by providing a summary of the study's key findings. I also discuss the main limitations of this study, the recommendations for future research possibilities as well as the study's implications for clinical practice and policy influence. Lastly, I provide my personal reflections following the completion of the study, indicating how this research project influenced me but also how I may have influenced the research process.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The current chapter presents a systematic qualitative review of the literature on the experiences that older individuals who live with ABI have regarding their rehabilitation and their overall sense of their well-being. The intention of this review is to explore how the issues at hand have been covered in the relevant literature, identify the available evidence and any key factors relating to these issues and lastly to consider any existing gaps in the research literature concerning the topic the current study. The chapter concludes with the presentation of the research question, aim and objectives of this study.

2.2 Aim and Objectives of the Literature Review

The purpose of this review is to acquire an in-depth understanding of the available literature on how older individuals diagnosed with ABI conceptualise and experience their sense of well-being as well as their care when undergoing physical rehabilitation.

Emerging from this aim, the following study question guided the current systematic literature review process: *What are the experiences of older individuals diagnosed with Acquired Brain Injury (ABI) when undergoing physical rehabilitation?*

To answer the above question, a set of objectives were developed which the review sought to address in a sequential manner:

i. To search published articles referring to the process of physical rehabilitation of older individuals diagnosed with ABI.

ii. To search for published articles referring to the experiences of older individuals diagnosed with ABI and their well-being when undergoing physical rehabilitation.

iii. To collect, organise and synthesise the results/ outcomes from the selected published articles that pertain to older individuals' experiences of ABI physical rehabilitation and their sense of well-being.

iv. To discuss and compare the findings of this review with the broader relevant literature.

v. To identify any potential research gaps in the literature on ABI diagnosed older individuals' rehabilitation care and sense of well-being and develop a research question for further research on the topic.

2.3 Search Method and Strategy

The current review focuses on the systematic investigation of qualitative research studies. The main reason for conducting a qualitative systematic literature review pertains to the particular view adopted in this study regarding the nature of well-being. The notion of well-being is understood as an experiential phenomenon and by extension as a primarily qualitative and cultural concept that signalises 'evaluation and appreciation of how well people live' (Thin, 2018, p. 123). Such an interpretation de-emphasises the quantitative enquiry of well-being by shifting the focus towards a more qualitative exploration of the notion, that aims to understand well-being from the point of view of the individuals who experience it. Put it simply, a qualitative understanding of well-being seeks to know the internal contemplation of people about how well they believe their lives go and how they think about and pursue well-being (Thin, 2012; Engelke, 2016; Walker and Kavedžija, 2016), instead of 'how long they live or how 'high' they would rate their temporary feelings or self-evaluations' (Thin, 2018, p. 123). Qualitative enquiries thus seem to be more comprehensive and valid in contrast to the useful but endlessly debatable measurements and quantifications of the phenomenon (Thin, 2018). In addition, qualitative methods have proved to be uniquely suited for exploring people's experiences, perspectives, and expectations on health-related phenomena, and for providing more comprehensive explanations about the effectiveness of certain interventions, i.e., why, how, and for whom certain interventions are effective (Thomas and Harden, 2008; Atkins, Colville and John, 2012; Spann and Stewart, 2018). Due to the above, the current review is focused on qualitative well-being research that aims to explore and understand how older individuals diagnosed with ABI experience and conceptualise their well-being during their rehabilitation.

Following the guidelines suggested by (Bettany-Saltikov and McSherry, 2012), this literature review has adopted the PEOT (Population, Exposure, Outcome and Type of studies) question format for identifying and clarifying its component parts as it has been designed and used mainly for qualitative review questions (Khan *et al.*, 2003). The PEOT question for the current systematic literature review emerging from the aforementioned guiding question is as follows:

- P = individuals aged over 65 years diagnosed with acquired brain injury (ABI);
- E = undergoing physical rehabilitation following an ABI;
- O = sense of well-being of older individuals;
- T = qualitative studies.

Based on the above, specific keywords along with key synonyms were identified and developed for each component of the PEOT question. Truncations, as well as abbreviations of the keywords, were also used. In general, truncations assist our search by identifying any possible variations of each keyword; these are usually indicated by adding the asterisk symbol (*) at the end of each word (Watson, 2020). The abbreviations *ABI* and *TBI* are identified for the keywords *Acquired Brain Injury* and *Traumatic Brain Injury*, respectively, as these are commonly used within the relevant literature. It should be noted that it was decided to include the keyword *stroke* based on the fact that stroke as presented in the relevant literature constitutes one of the most common ABIs occurring in older populations (Lui and Nguyen, 2018). All the keywords, synonyms, truncated words and abbreviations were then combined during the electronic search of the databases using specific Boolean operators, in order to obtain as many relevant articles as possible and also to optimise the sensitivity and specificity of the search (Watson, 2020). More specifically, all the synonyms under each of the four components were combined with the Boolean operator “OR”, and then all the results were combined with the Boolean term “AND”. In Table 2.1, I specify the search terms and keywords used to conduct the electronic literature search in each database. The first column lists the PEOT components and the second column presents all the keywords, synonyms, truncations and abbreviations that we identified - with each row indicating the keywords and phrases that correspond to each PEOT element.

Table 2.1 *Search terms and keywords*

PEOT	Keywords and phrases
Population/ condition	older individual* *OR* older people *OR* older adult* *OR* elderly *OR* aged *AND* acquired brain injur* *OR* traumatic brain injur* *OR* brain injur* *OR* TBI *OR* ABI *OR* stroke *AND*
Exposure	physical rehabilitation *OR* physical therapy *OR* geriatric rehabilitation *OR* hospital rehabilitation *OR* community rehabilitation *OR* elderly care *AND*
Outcomes	experience* of well-being *OR* perception* of well-being *OR* sense of well-being *AND*
Type of studies	qualitative research *OR* qualitative stud*

A comprehensive search was conducted from April to May 2020, using the electronic databases of PubMed, CINAHL, APA PsycInfo, ASSIA and Scopus. These databases were selected due to their relevance with the academic subject of the literature search – as they cover a wide range of health-related disciplines, such as nursing, medicine, psychology, sociology, health and social care (Aveyard, 2014; Bettany-Saltikov and McSherry, 2012). In accordance with similar qualitative literature reviews (Piccenna *et al.*, 2016), the current systematic literature review also searched the Google Scholar database with the first 100 records being selected for screening (Bettany-Saltikov and McSherry, 2012). The quota of 100 results was applied because the retrieved results after this number usually lack relevance to the search prompt. This is in part due to the variable retrieval of content that occurs when searching Google Scholar, which means that different rankings (and possibly different search results) can be produced for the same search string, based on the algorithms that regularly altered by Google and the individual's search history and location (Atkinson and Cipriani, 2018). Concerning the search strategy used in Google Scholar, it differs from the one used in the other databases. While in Google Scholar basic Boolean terms can be applied within a single search string, there is no option to combine multiple search terms by using simultaneously the "OR" and "AND" operators. For this reason, I decided to translate the search strategy into a search string similar to the guiding review question mentioned above. More specifically, the search prompt that was used in Google was *"Well-being in older individuals diagnosed with Acquired Brain Injury (ABI) when receiving rehabilitation care"*. Lastly, it should be noted that truncations are used only in two databases (i.e., PubMed and APA PsycInfo). In CINAHL, ASSIA and Scopus I decided to rely on the standardised search terms and subject headings suggested by each database, since this proved to be more effective by generating more relevant results than with using truncated words. The search strategies and strings used in each database are presented in Appendix A.

A search for grey literature was also undertaken (specifically, conference abstracts and PhD dissertations that were available in electronic format) drawing on the Open Grey and Grey Literature Report databases. For this search the review employed the same search string that was used for Google Scholar database. Nevertheless, the search did not produce any relevant records. A possible reason for that is that the search was restricted only to English language literature and also to publications that were produced from 2005 onwards.

The reference lists of the selected studies (after the full-text screening) as well as the lists from previous relevant literature reviews (retrieved from the databases' search) were further scanned for additional references on the topic. The hand search relied on the same PEOT question used for the database searches. It should be noted that this search took place during the second, full-text screening of the databases' search results.

Overall, the literature search in the databases was filtered by the language (English), the age of informants (65 years and older) and the period of publication (2005-2020). The particular date period was selected since the literature explored during a systematic review is usually required to be as up to date as possible. This steered the review towards the most recently published materials which are normally the most relevant ones (Watson, 2020). In short, it was decided to limit the search to a 15-year time period (from 2005 until 2020), as the data and research evidence prior to that period might prove outdated and thus insufficient to use for investigating research on the overall process of ABI rehabilitation and the experiences of older individuals during that time.

2.4 Eligibility criteria

The current review developed specific inclusion and exclusion criteria to guide the overall screening process and selection of studies. Developing inclusion and exclusion criteria is an important stage, as they can 'provide clear information about the remit of our review' (Aveyard, 2014, p. 78), thus helping literature reviewers to identify the appropriate research studies that address the review question and exclude any irrelevant ones (Bettany-Saltikov and McSherry, 2012). As Torgerson (2003) points out, both the inclusion and exclusion criteria should be explicit and applied stringently during the literature screening. The criteria developed for our review are guided by the wording of the review question and the PEOT components developed above. In particular, the criteria used for the selection of studies in this review are specified as follows:

- The study participants are individuals aged over 65 years (or mean age over 65 years) diagnosed with ABI (e.g. moderate-to-severe traumatic and nontraumatic brain injury such as stroke and aneurysm).
- The study participants are older individuals who are undergoing/ underwent physical rehabilitation that takes place in a formalised care setting (e.g., hospital rehabilitation and/ or community rehabilitation), or at home (discharge from hospital, home rehabilitation).
- Studies that examine individuals' experiences of physical rehabilitation and their perceptions of well-being since the aim of this review is to gain an in-depth understanding of individuals' conceptualisations of well-being during their rehabilitation.
- Primary qualitative studies were the main type of study included in this review. Secondary qualitative studies that have used meta-synthesis were also included. These refer to studies that have taken data and themes from primary qualitative studies and re-analysed them to develop new interpretations. The aim was to scan the meta-syntheses to assess their conclusions and identify any new themes and interpretations that they might have elucidated, as well as to identify further relevant references.

The criteria for excluding studies from the review are described below:

- Studies that include people who received rehabilitation care more than once, and for another reason apart from ABI, were not included as the individuals' experiences and conceptualisations of well-being might be different – e.g., drawing on the overall rehabilitation care they had received.

- Studies that look at people who have been diagnosed with brain injury but are part of a drug trial or intervention study.
- Studies that include only family members, carers or health professionals were also excluded as our review explicitly focused on the experiences of ABI diagnosed individuals.
- Studies that refer to rehabilitation in hospital intensive care unit (ICU), coronary care unit (CCU) or high dependency unit (HDU) are excluded since the aim of these units is to provide intensive care (treatment and monitoring) to people who are critically unwell (NHS, 2019).

Based on the above, Table 2.2 provides a summary of the inclusion and exclusion criteria that we used for the literature screening.

Table 2.2 *Inclusion and Exclusion criteria*

PEOT	**Inclusion criteria**	**Exclusion criteria**
Population	Individuals aged over 65 years, diagnosed with Acquired Brain Injury (ABI). or Mean age of participants ≥ 65 years	People who received rehabilitation care previously and for another reason apart from ABI. People diagnosed with brain injury but are part of a drug trial, no studies that include only family members, carers, health professionals.
Exposure	Undergoing/ underwent physical rehabilitation in hospitals, community settings or at home.	No hospital intensive care unit (ICU), coronary care unit (CCU), high dependency unit (HDU).
Outcome	Experiences of physical rehabilitation, conceptualisations of well-being, perceptions of well-being.	
Type of studies	Primary qualitative studies, secondary qualitative studies, in the form of meta-synthesis.	

2.5 Search Results

In total, 2846 records were retrieved from the initial search of the databases. All results were subsequently imported into the literature management software *Zotero* (Taubman Health Sciences Library, 2019) to detect and delete any duplicates as well as to organise them into folders – with each folder corresponding to each database used. The number of the results was adjusted to 2564 as a result of removing the duplicates (Table 2.3).

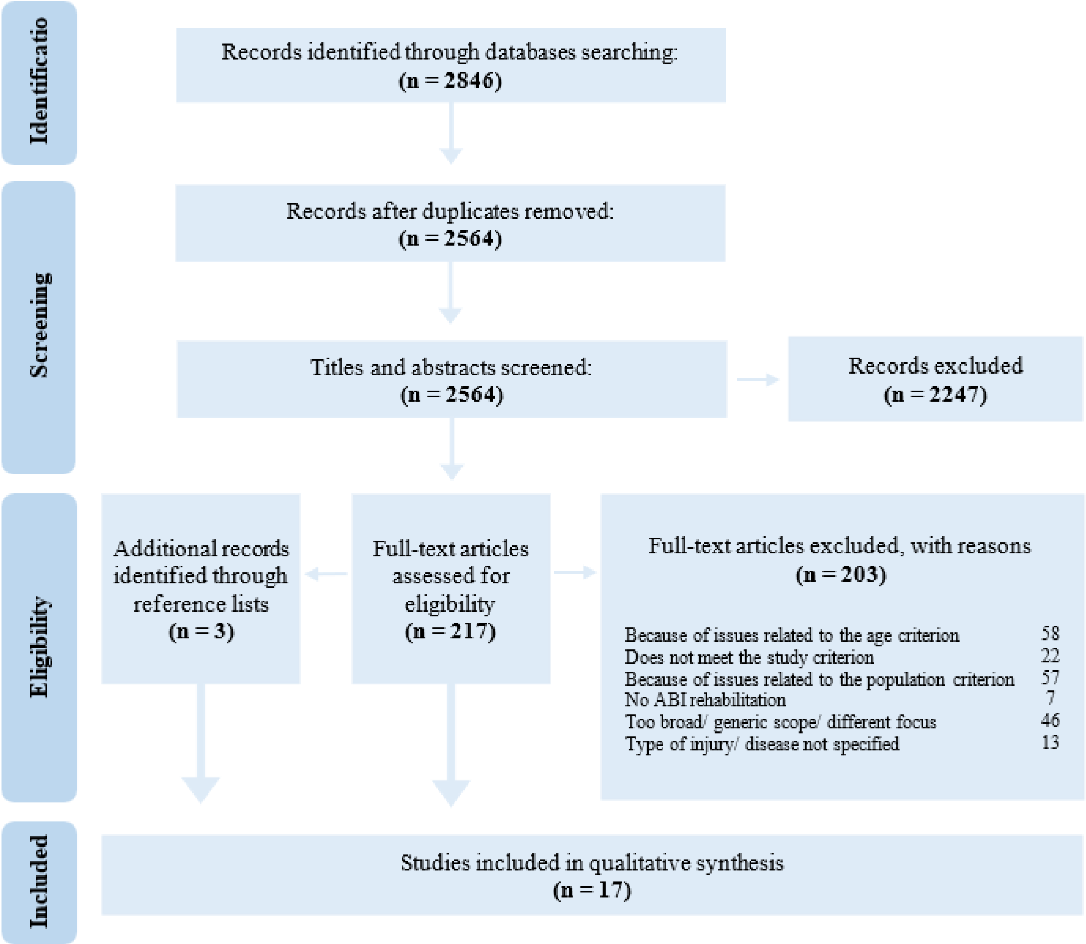
Table 2.3 *Results from the databases' search*

Database	**Search Results (filters applied)**	**Results after duplicates were removed**
	Filters: Language: **English** Date range: **2005 - 2020** Age of informants: **65+ years**	
PubMed/ MEDLINE	218	216
CINAHL Plus	389	330
APA PsycInfo	253	93
ASSIA	1062	1024
SCOPUS	824	801
GOOGLE Scholar	100	100
Total results	**2846**	**2564**

The inclusion/exclusion criteria were then applied by screening the title and abstract of each of the remaining studies. This reduced the number of results to 217. A second screening was followed by carefully reading the full text of each of the 217 studies to assess which ones fully meet the inclusion criteria. Ultimately, 14 studies from the databases' search were found to fully meet the inclusion criteria. The reference lists of these 14 studies as well as the lists of previous relevant literature reviews were hand searched (pearled) thoroughly with the aim to discover any potentially valuable resources that may have been missed in the systematic search. This yielded 3 additional studies meeting the inclusion criteria fully. In total, 17 studies were selected as being eligible for the systematic literature review of this research project.

The PRISMA protocol (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) has been used by the researcher for displaying the selection process of the identified records and for reporting the findings (Moher *et al.*, 2009). Overall, the PRISMA flow diagram helps to structure and formalise the reporting of our systematic review by visualising how information moves through the different steps of the systematic review. Specifically, it outlines the number of sources that were identified, included and excluded, while also providing the reasons for exclusions (Moher *et al.*, 2009). Most importantly though, the PRISMA flow diagram can help reviewers to reduce the risk of poor reporting of systematic reviews by improving the clarity and transparency in the way that their review methods and findings are reported (Liberati *et al.*, 2009). The PRISMA flow diagram describing the selection process and the findings is shown in Figure 2.1.

Figure 2.1 *PRISMA flow diagram*



2.6 Quality appraisal of selected studies

To strengthen the internal validity of the review, the seventeen included studies were assessed for their methodological quality (trustworthiness), by applying the Critical Appraisal Skills Programme (CASP) tool for appraising qualitative research (Critical Appraisal Skills Programme, 2018). This is a reliable and easy tool which has been widely used in various syntheses of qualitative studies for assessing a large number of studies and determining their validity and quality (Dixon, Thornton and Young, 2007).

The CASP checklist consists of a series of 10 questions/ criteria designed to help researchers critically appraise issues such as the study design, the selection of participants, ethical considerations, the methods of data collection and analysis, the value and contribution of the research and the comprehensive and explicit reporting of the findings (Critical Appraisal Skills Programme, 2018; Majid and Vanstone, 2018). Most of the questions are closed-ended allowing for a “yes”, “no” or “can’t tell” answer with a possibility of justification of answers. In this review, each study was given a score of either low, moderate, or high methodological quality, defined as meeting ≤ 5, 6–8 and 9–10 of the CASP checklist criteria, respectively (Horntvedt *et al.*, 2018).

Nevertheless, as with all appraisal tools, CASP comes with some limitations as well. One basic shortcoming is that it places more importance on evaluating how qualitative research studies are reported in their journal articles rather than on issues such as the analytic rigour, originality, or scholarly contribution of the study (Majid and Vanstone, 2018). Furthermore, the checklist does not address any philosophical or theoretical issues with regards to the study (Majid and Vanstone, 2018).

The quality appraisal produced no studies of insufficient quality. Therefore, all seventeen studies were included in the synthesis. In fact, all articles were scored with high methodological quality: seven (7) studies met all ten criteria of the CASP checklist, while the remaining ten (10) studies met nine out of ten criteria, as they did not explicitly examine or reflect on the researchers’ potential biases and/or influences during the data collection (including sample recruitment and choice of location). The lack of reporting of this specific item in some studies did not impact on the quality of the articles ergo no further consideration was given on this during the discussion of those studies. The findings as well as the methodological quality score of each study are presented in Table 2.4.

Table 2.4 *Quality assessment based on the CASP Qualitative Research Checklist (adapted from Horntvedt et al., 2018)*

Selected studies	CASP checklist criteria										Assessment
	1	2	3	4	5	6	7	8	9	10	
Andersson and Hansebo (2009)	Y	Y	Y	Y	Y	N	Y	Y	Y	(Y)	High
Bennett *et al.* (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	(Y)	High
Ellis-Hill *et al.* (2009)	Y	Y	Y	Y	Y	N	Y	Y	Y	(Y)	High
Gallacher *et al.* (2018)	Y	Y	Y	Y	Y	N	Y	Y	Y	(Y)	High
Krishnan *et al.* (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	(Y)	High
Löfmark and Hammarström (2005)	Y	Y	Y	Y	Y	N	Y	Y	Y	(Y)	High
Loft *et al.* (2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	(Y)	High
Mangset *et al.* (2008)	Y	Y	Y	Y	Y	N	Y	Y	Y	(Y)	High
Morris *et al.* (2015)	Y	Y	Y	Y	Y	Y	Y	Y	Y	(Y)	High
Morris, Payne and Lambert (2007)	Y	Y	Y	Y	Y	U	Y	Y	Y	(Y)	High
Nimrod and Hutchinson (2010)	Y	Y	Y	Y	Y	Y	Y	Y	Y	(Y)	High
Galvin, Cusack and Stokes (2009)	Y	Y	Y	Y	Y	Y	Y	Y	Y	(Y)	High
Olofsson, Andersson and Carlberg (2005)	Y	Y	Y	Y	Y	N	Y	Y	Y	(Y)	High
Poltawski *et al.* (2015)	Y	Y	Y	Y	Y	U	Y	Y	Y	(Y)	High
Tholin and Forsberg (2014)	Y	Y	Y	Y	Y	N	Y	Y	Y	(Y)	High
White *et al.* (2015)	Y	Y	Y	Y	Y	N	Y	Y	Y	(Y)	High
Wray, Clarke and Forster (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	(Y)	High

CASP criteria for qualitative studies:

1. Was there a clear statement of the aims of the research?
2. Was a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been considered?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of the findings?
10. (How valuable is the research?) *This is an open-ended question

(Y=Yes, N=No, U=Unclear/Can't tell)

2.7 Data extraction

Consequently, data extraction was performed to capture the necessary information about the key characteristics and results of the individual studies (Centre for Reviews and Dissemination, 2009). Data extraction is a process that facilitates the thorough analysis and comparison of the studies. In accordance with Spann and Stewart (2018), the main purpose of data extraction in this review is to ensure that the context of the studies is taken into consideration during the synthesis of the qualitative evidence that these studies provide. In line with Noyes and Lewin (2011), the extraction requirements for this review were informed by the review question and aim, and consequently tailored to the PEOT features identified above. As a result, a unique format was created solely for the purposes of this review, which included information on (a) the author(s), year of publication and study location; (b) the study design/ methodological approach; (c) the research aims; (d) the setting where fieldwork was conducted; (e) population characteristics (e.g. sample size, age, sex, type of disease); (f) the data collection methods & data analysis techniques used in the study; and (g) the study outcomes/ findings relevant to the topic.

The extraction table is displayed in Appendix B. Studies were published between 2005 and 2019 with eight of them published after 2010. The majority of studies (n = 13) were conducted within Northern Europe, with six being carried out in the United Kingdom, four in Sweden, one in Norway, one in Ireland and one in Denmark. As for the remaining four, two were carried out in Australia, one in Canada and one in the Unites States. All projects had a qualitative study design, which was one of the eligibility criteria for selection.

All studies focused on ABI rehabilitation and included stroke survivors, except from one study which contained groups of individuals diagnosed with other chronic health conditions as well. Moreover, four studies included as participants both health professionals/ caregivers and stroke survivors, one study included both stroke survivors and their accompanying partners and one study included artists together with older individuals. With regards to the age of participants, only three studies focused exclusively on older individuals aged > 65 years old, while in the remainders the age of the stroke survivors' sample had a mean of > 65 years old. In 14 studies, semi structured and in-depth interviews were undertaken for the collection the data, whereas one used only focus groups and two used both individual interviews and focus groups. As for the research setting, most of the studies (n = 9) conducted the fieldwork at the individuals' place of residence, five in a health care facility and four both in health facilities and at individuals' home. The included studies provide an ample amount of qualitative data contributed by 221 stroke survivors in 8 different countries.

2.8 Method of Synthesis

The findings and outcomes of the selected qualitative studies were synthesised using the so-called "thematic synthesis method", as developed by Thomas and Harden (2008). This method combines and adapts methods of primary qualitative research with traditional systematic reviews approaches. It was developed with the aim to provide insight into the need, appropriateness, acceptability and effectiveness of health interventions and treatments by thoroughly exploring individuals' perceptions and experiences (Barnett-Page and Thomas, 2009; Spann and Stewart, 2018).

One aspect of this method is the use of computer software to facilitate and systematise the management of the results of included studies – a technique adapted from methods used in primary qualitative research (Barnett-Page and Thomas, 2009; Creswell, 2009). The aim of this synthesis is to collate, review and discuss thoroughly the outcomes and results from all the selected studies. Therefore, the text from the *Findings*, *Discussion* and/or *Conclusion* sections of each study were imported into the NVivo 12 software. The sections where the outcomes were presented varied across the studies: in some articles the outcomes were discussed under the Findings or Discussion section, whereas others presented their results in the Conclusion. At this point it should be clarified that no primary/original qualitative data from the studies were inserted in NVivo, nor these were taken into consideration (or reinterpreted) in the discussion that ensued. Furthermore, results and outcomes that referred to contributions made by participants other than older stroke survivors, such as health professionals or groups of individuals diagnosed with other diseases, were excluded from the analysis. Subsequently, the 17 selected studies were read multiple times to become familiar with their context and content. Following Thomas and Harden's (2008) approach, the synthesis of the findings was then carried out, by taking the form of three stages:

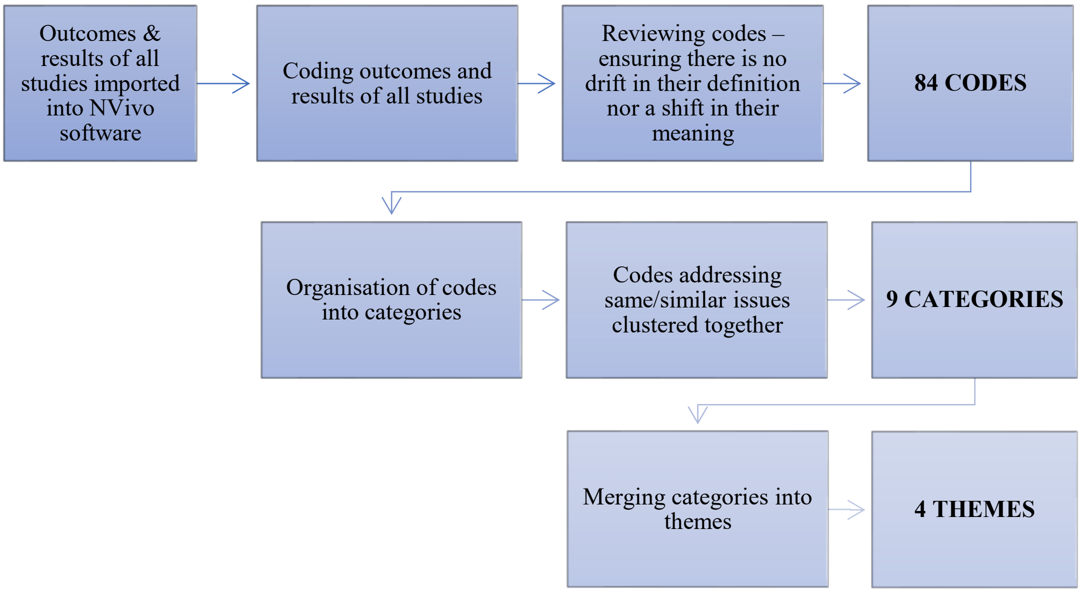
1. The outcomes and results of all studies were coded by assigning codes to textual units, varying from small parts (e.g., words and phrases) to larger sections (e.g. paragraphs). The individual codes were assessed and reviewed to ensure that there is not any drift in their definition nor any shift in their meaning (Creswell, 2009). This invoked a recursive process of moving constantly back and forth across studies to 'translate' and compare data with codes, by editing, adding or deleting

codes where necessary. Overall, 84 preliminary codes were developed, reflecting the findings, outcomes and key concepts identified in the preliminary studies (see Appendix C).

2. Codes were then categorised according to similarities and differences. Essentially, codes that addressed the same issue or were related to one another were united into semantically meaningful clusters, forming 9 descriptive categories.
3. From these categories 4 overarching themes were identified.

In short, each theme contains categories which in turn encompass codes that were retrieved from the primary findings. An overview of the thematic breakdown of the synthesised literature – with all the codes, categories and themes developed – is presented in Appendix D. The process of organising and synthesising the findings of the included studies is presented in Figure 2.2.

Figure 2.2 *The process of synthesis of studies' outcomes and results*



As a final note, it should be clarified that the above method and stages comprise an adapted version of the Thomas and Harden's method, since some of the terms and processes they describe in their article have been altered or modified in this review. For example, while Thomas and Harden use the terms *'descriptive' themes* (with respect to the second stage) and *'analytical' themes* (with respect to the third stage), in this review the terms *categories* and *themes* are preferred instead. With regards to the term *categories*, this is used here the same as Thomas and Harden use *'descriptive themes'*. Nevertheless, in the third stage Thomas and Harden (2008) talk about 'analytical themes' which enable the researcher to 'go beyond' the content of findings of the original studies and potentially offer additional, novel interpretations. In this review the way themes are developed and deployed does not correspond to the stage of developing 'analytical themes' or 'third order interpretations' as found in Thomas and Harden's approach. Instead, *themes* are generated here with the aim to aggregate and identify similar patterns among the categories and provide a broader summary and explication of the original findings. In Table 2.5 below the original version is juxtaposed with the modified version that was adopted in this review, indicating the differences (and similarities) between the two versions.

Table 2.5 *The stages of the synthesis method used in this review juxtaposed with Thomas and Harden's (2008) original version*

SYNTHESIS METHOD	
Original version	**Modified version used in this review**
STAGE 1 **Coding of studies**	**STAGE 1** Coding of the findings of the studies
STAGE 2 **Organisation of codes into "descriptive themes"**	**STAGE 2** Organisation of codes into categories
STAGE 3 **Developing "analytical themes"** ↓ **'third order interpretations': going beyond the original articles**	**STAGE 3** Merging categories into themes ↓ aggregation and identification of patterns among categories

2.9 Findings of the Review

In the review I identified four overarching themes generated from the findings and discussions of the selected studies, namely: (i) Rehabilitation processes and their impact on older individuals' well-being; (ii) Identity and embodiment concerns of older individuals during rehabilitation; (iii) Institutional factors affecting older individuals' experiences of care and well-being; and (iv) Older individuals' participation in creative activities as part of rehabilitation (Lafiatoglou *et al.*, 2022). Each theme is thoroughly examined by expanding and reviewing in-depth its categories, to address the question and the aim of the current literature review.

2.9.1 Theme 1: Rehabilitation processes and their impact on older individuals' well-being

This theme focuses on identifying how older individuals with ABI experience and internalise the processes and tasks involved in their rehabilitation, and by extension how rehabilitation processes impact on their sense of well-being. From the total of seventeen reviewed articles, ten studies inform this theme (Table 2.6). Two categories constitute the current theme, namely a) *Experiences of inpatient rehabilitation and physiotherapy for older individuals with ABI*; and b) *Hospital discharge experiences of older individuals with ABI*. Each category is examined below with reference to the relevant results and discussions.

Table 2.6 *Studies informing theme 1*

Studies informing theme 1: **Rehabilitation processes and their impact on older individuals' well-being**	
Category 1: **Experiences of inpatient rehabilitation and physiotherapy for older individuals with ABI**	**Category 2:** **Hospital discharge experiences of older individuals with ABI**
Tholin and Forsberg (2014) *Satisfaction with care and rehabilitation among people with stroke, from hospital to community care*	
Bennett *et al.* (2016) *Stroke survivors' perspectives on two novel models of inpatient rehabilitation: seven-day a week individual therapy or five-day a week circuit class therapy*	**Ellis-Hill *et al.* (2009)** *Going home to get on with life: patients and carers experiences of being discharged from hospital following a stroke*
Galvin, Cusack and Stokes (2009) *Physiotherapy after stroke in Ireland: a qualitative insight into the patients' and physiotherapists' experience*	**Krishnan *et al.* (2019)** *Stroke Survivors' Perspectives on Post-Acute Rehabilitation Options, Goals, Satisfaction, and Transition to Home*
Loft *et al.* (2017) *Call for human contact and support: an interview study exploring patients' experiences with inpatient stroke rehabilitation and their perception of nurses' and nurse assistants' roles and functions*	**Morris *et al.* (2007)** *Patient, carer and staff experience of a hospital-based stroke service*
Poltawski *et al.* (2015) *Motivators for uptake and maintenance of exercise: perceptions of long-term stroke survivors and implications for design of exercise programmes*	**Olofsson, Andersson and Carlberg (2005)** *'If only I manage to get home, I'll get better'- Interviews with stroke patients after emergency stay in hospital on their experiences and needs*
	Wray, Clarke and Forster (2019) *How do stroke survivors with communication difficulties manage life after stroke in the first year? A qualitative study*

2.9.1.1 Experiences of inpatient rehabilitation and physiotherapy for older individuals with ABI

Five studies in this category focus on the experiences of older stroke survivors around their inpatient rehabilitation across five different countries, with some studies looking specifically at the physiotherapy process: Bennett *et al.* (2016) conducted their research in Australia; Poltawski *et al.* (2015) in the UK; Galvin, Cusack and Stokes (2009) in Ireland; Loft *et al.* (2017) in Denmark; and Tholin and Forsberg (2014) in Sweden. All studies identified a wide range of beliefs and perspectives among older individuals with stroke about the process of inpatient physiotherapy and how its quality could be improved – although many of their experiences were quite positive.

The findings from both Bennett *et al.* (2016) and Galvin, Cusack and Stokes (2009) report that the majority of older individuals focused on the duration of therapy, whereby some of the older individuals argued for greater levels of support needed than routinely provided to them. In Galvin, Cusack and Stokes (2009), nine out of the ten older individuals with stroke thought that additional inpatient physiotherapy could be more beneficial in terms of contributing to the progress of their recovery. In a similar vein, most participants in Tholin and Forsberg (2014), reported that they preferred a more intense, individualised and varied inpatient rehabilitation programme that would be provided by knowledgeable and encouraging professional staff.

Moreover, some argued not merely for more inpatient physiotherapy, but also for physiotherapy that included fewer interruption. Bennett *et al.* (2016) indicate that several participants are in favour of more physiotherapy time in their schedule with some of them preferring to receive physiotherapy seven days per week instead of five. Loft *et al.* (2017), also indicate that during their hospital stay, older individuals were experiencing long waits, which caused a lack of productive time. While some participants in Bennett *et al.*'s (2016) study considered that the amount of therapy received should not be excessive within any one week allowing for breaks within therapy sessions to rest. Nonetheless, the overarching complaint is that breaks between the therapy sessions and waiting for staff assistance between exercises made them feel inactive, further limiting their perceived rehabilitation progress (Bennett *et al.*, 2016).

Another issue where views among older individuals varied is the format of physiotherapy received. Some participants approved the group format and sharing staff with other participants while others supported the need for individualised physiotherapy sessions, as they thought that their individual needs were not satisfactorily covered by the group format (Bennett *et al.*, 2016). Thus, according to participants' views a tailored therapy relative to their own needs and circumstances would be much more beneficial to them

(Bennett *et al.*, 2016). Similarly, Poltawski *et al.* (2015) found that while participants valued the social support offered by group classes in sustaining their commitment and motivation to physical exercise, some were not very keen to participate in group sessions (for various personal reasons), thus indicating their preference for individualised training and guidance.

Even in cases of individualised physiotherapy the inclusion of family was felt to help the rehabilitation process. Overall, older individuals value the positive role that family participation has in their rehabilitation experiences. As Loft *et al.* (2017) mention, older individuals appreciated the opportunity to have their relatives participate in their care and rehabilitation. According to Loft *et al.* (2017), the importance of family participation in older individuals' rehabilitation stems from two key aspects. These are: older individuals' need and concern to discuss their rehabilitation with their families; the difficulty that older individuals have due to their condition to remember and keep track of all the information regarding their care and rehabilitation. According to the participants in Galvin, Cusack and Stokes (2009), their families are eager to participate in the physiotherapy, and their involvement can be advantageous both physically and emotionally. Nevertheless, the majority of older individuals felt that their families were not included as much as the participants would have liked it in the physiotherapy sessions, even though the invitation and participation of families were allowed (Galvin, Cusack and Stokes, 2009).

In a similar vein, most participants in Tholin and Forsberg (2018) mentioned that the support received from people around them was sufficient and invaluable. The social interactions that they had with their friends, colleagues and neighbours along with the practical and psychological support provided by their family members (especially by their children for older informants) made them feel that they were not alone in this situation and that they were cared by others (Tholin and Forsberg, 2018). However, some participants preferred to manage the situation on their own that, feeling that the responsibility for their own care belonged to them and not to their closed ones. Moreover, in cases where the next of kin was a husband or wife, some informants felt that there was a lack of support and information about their condition (Tholin and Forsberg, 2018).

In Poltawski *et al.*'s (2015) study on-going support, especially from family, was viewed by participants as an important external stimulus for generating and maintaining commitment to exercise. In particular, according to older individuals, family members were contributing to their exercise and rehabilitation programme through practical and emotional ways, e.g. by assisting older individuals with particular exercises, accompanying them to classes, helping them with transportation and inspiring them to continue with their physical exercise (Poltawski *et al.*, 2015).

Many older individuals expressed positive experiences during their therapy. Many reported positive personal achievements and success during rehabilitation (Bennett *et al.*, 2016). They also valued the opportunity and importance of observing the progress of others which motivated them with their recovery (Bennett *et al.*, 2016). Many participants also reported being satisfied with the overall hospital stroke care and the rehabilitation they received, appreciating especially the programmes that were intensive, specific, and professional (Tholin and Forsberg, 2018). As such, the high intensity of rehabilitation along with the professionalism and encouragement displayed by the staff were mentioned as important factors by the participants for successfully carrying on with their rehabilitation (Tholin and Forsberg, 2018).

In Poltawski *et al.*'s (2015) study participants emphasised the important role of physical exercise in strengthening their recovery prospects. For older individuals a de-medicalised approach to physical exercise and an emphasis on lifestyle modifications, were perceived as important motivators for engaging in the rehabilitation process and for promoting a sense of well-being (Poltawski *et al.*, 2015). In particular, informants were more interested and engaged in exercise when they viewed it as a healthy and enjoyable leisure activity - rather than as a form of treatment that takes place in a clinical setting and which further alludes to a sense of illness - while also indicating their preference for staff who have a deep knowledge and awareness of stroke (Poltawski *et al.*, 2015).

Overall, this category describes the different and varied experiences and feelings that older individuals with ABI (especially stroke) have during their inpatient rehabilitation. As reported in the reviewed articles there were mixed feelings regarding the duration, the format and family presence of the rehabilitation process. Pleasant experiences were expressed by the participants with regards to the participation of their families in the care and rehabilitation, the progress of their recovery, and their overall stay in the hospital. In particular, participants viewed family support, rehabilitation staff's encouragement and professionalism as well as the provision of personalised and intense, yet enjoyable, physical exercise as important motivators for committing to their rehabilitation programme. At the same time, however, there were many uneasy experiences and feelings targeting similar issues, namely, the lack of additional physiotherapy, the long waiting times, the lack of individualised and intense exercise regimes and inadequate participation of families in older individuals’ rehabilitation.

2.9.1.2 Hospital discharge experiences of older individuals with ABI

Six studies in this category focused on older individuals’ experiences and perceptions of the discharge process after inpatient rehabilitation. Krishnan *et al.* (2019) conducted their study in the United States; Olofsson, Andersson and Carlberg (2005) and Tholin and Forsberg (2018) in Sweden; while Morris, Payne and Lambert (2007), Wray, Clarke and Forster (2019) and Ellis-Hill *et al.* (2009) in the UK. All studies identified a wide range of beliefs and perspectives among older individuals with stroke regarding the mixed feelings they have about discharge.

Olofsson, Andersson and Carlberg (2005) interviewed older individuals with stroke at the Stroke Centre of the University Hospital of Northern Sweden, in Umeå, Sweden, to explore their experiences about falling ill, their stay in the hospital, discharge and coming home. As Olofsson, Andersson and Carlberg (2005) report, older individuals associate discharge with ‘coming home’, which incites positive experiences and feelings such as relief and joy. According to the study, coming home is perceived by older individuals as a confirmation of being in control of their life again and of being a person (Olofsson, Andersson and Carlberg, 2005). The return to their social environment provides older individuals with new insights about their state, which proves to be important for their recovery and rehabilitation (Olofsson, Andersson and Carlberg, 2005). In short, Olofsson, Andersson and Carlberg (2005) highlight the positive experiences that returning home gives to older individuals, as it can re-establish their self-esteem and increase their understanding of their illness and its consequences. Focusing on older individuals who experience post-stroke communication difficulties, Wray, Clarke and Forster (2019) mention that the discharge from hospital and the expectation of returning home created feelings of joy, happiness and relief to older individuals.

Nevertheless, this initial sense of joy for coming home is short lived or even an illusion as they quickly realise that they are no longer the same person. When returning home, older individuals experience a significant change with regards to their self; they feel that they are not the same people as before, since now they perceive themselves as ABI (stroke) survivors which makes them anxious about becoming ill again (Olofsson, Andersson and Carlberg, 2005).

Similarly, Wray, Clarke and Forster (2019) indicate that despite the significant work undertaken by both older individuals and their family to manage and adapt to the new situation, many participants experienced difficulties during their transition from hospital to home, requiring much greater physical and emotional effort to cope with their rehabilitation (Wray, Clarke and Forster, 2019). In particular, older individuals felt powerless and unconfident about their capabilities, while also expressing a felt abandonment and lack of support from community services during their discharge (Wray, Clarke and Forster, 2019).

A reason for their disillusionment when coming home is the fact that they felt as if they did not have adequate information. Thus, in the other three studies it is observed that older individuals focused on two issues that negatively affect their discharge experience: (i) whether the information they had about rehabilitation after discharge was adequate; and (ii) whether the discharge was successful or not and for what reasons (Ellis-Hill e*t al.*, 2009; Morris, Payne and Lambert, 2007; Krishnan *et al.*, 2019). The majority of participants wanted more advice, support and individualised information about their state of health after discharge. Morris, Payne and Lambert's (2007) study, which was conducted in Scotland, UK reinforces this point further when they suggest that the lack of information produced anxiety in the participants and problems with adjustment post-discharge.

Krishnan *et al.* (2019) conducted research in Texas, USA exploring older stroke survivors' experiences regarding the discharge advice they receive as well as their perspectives on their involvement in selecting a post-acute (PAC) provider after leaving acute care. Post-acute care providers refer to settings where individuals continue to receive care and rehabilitation after their discharge from acute care settings. According to their findings, participants revealed the need for more specialised information regarding the rehabilitation services and what to expect following discharge from the healthcare setting (Krishnan *et al.*, 2019). Furthermore, with regards to processes and services following discharge, they wanted to know more about what to expect following discharge, namely the medical interventions post-discharge (such as Botox for spasticity, medications etc.), their health insurance coverage, the availability of additional rehabilitation resources (e.g., support groups) and the various psychological changes poststroke (Krishnan *et al.*, 2019). Similarly, in their study (carried out in England, UK), Ellis-Hill *et al.* (2009) emphasise the importance that older people attach to getting support and being informed about the process of their rehabilitation to characterise their discharge as successful. When participants felt that they were not supported, nor informed about their recovery, the discharge felt quite difficult (Ellis-Hill *et al.*, 2009).

In the case of people not going home and having to go to another setting, an additional issue that can contribute to their disillusionment is that they may have no choice to where they go post-acute. As reported in Krishnan *et al.* (2019), older individuals are not involved in selecting their post-acute care setting - with others making the selection for them (mainly doctors but also family members). Although few participants did mention some involvement, the level and extent of their participation was still not indicative of shared decision-making (Krishnan *et al.*, 2019). Similarly, in Tholin and Forsberg's (2018) research participants also reported that their opinions about the planning and continuation of their rehabilitation were not taken into consideration at the time of their hospital discharge.

Overall, this category describes the mixed feelings that older individuals have when they return home after discharge. Coming home is associated with pleasant thoughts as they take back control of their life and reorganise themselves, but these feelings are short lived, when feelings of anxiety and uncertainty about the future emerge (as older individuals experience major changes in their life). The studies reviewed focused on issues such as maintaining or losing momentum in older individuals' therapy, the non-involvement of older individuals with stroke in selecting their post-acute care setting and the lack of support and information about their discharge, with the latter creating feelings of anxiety to older individuals and adjustment problems post-discharge. Older individuals wanted to know more about what follows after they leave hospital/ acute settings, e.g., about future medical interventions, the availability of additional care support and resources, possible psychological changes.

2.9.2.3 Summary of the Theme

Theme one provides an account of older individuals' experiences regarding their rehabilitation processes, their perceptions of well-being and their sense adaption to the new circumstances caused by their health condition. As reported in the articles reviewed there are both pleasant and uneasy experiences expressed by older individuals about the duration and content of their physiotherapy while others highlight the long waiting times along with the lack of more intense and individualised physiotherapy. At the same time, however, there were many uneasy experiences and feelings targeting similar issues, namely, the long waiting times, the lack of additional, individualised and intense physical exercise regimes and the inadequate participation of families in older individuals' rehabilitation. Nevertheless, older individuals emphasise the positive effect of involving their families in stroke rehabilitation, as well as the significance of having knowledgeable and professional rehabilitation staff and having access to more specialised, intense but also enjoyable exercise regimes. Older individuals' reports about their hospital discharge and their life afterwards are also reviewed, revealing the complex emotions and concerns that they experience. Returning home after the discharge creates mixed feelings for older individuals as it brings, on the one hand, a sense of relief and on the other hand, feelings of anxiety and uncertainty about the future. This initial sense of joy and relief for returning home is only short lived or even an illusion as they quickly realise that they are no more the same person.

2.9.2 Theme 2: Identity and embodiment concerns of older individuals during rehabilitation

This theme focuses on the existential concerns of older individuals with ABI during rehabilitation and the way these concerns affect older individuals' recovery. The articles reviewed display older individuals' perceptions of their personality, social identity and the gender roles before and after their diagnosis that impact upon their embodied lived experiences of rehabilitation. From the total of seventeen articles reviewed, nine studies fitted in this theme (Table 2.7). Two descriptive categories inform the current theme, namely a) *The felt need for autonomy, dignity, humanity of older individuals with ABI*; and b) *Gender influences on older individuals' conceptualisation of ABI condition and* *rehabilitation process*. Each of the categories is examined below with reference to the relevant results and discussions.

Table 2.7 *Studies informing theme 2*

<table>
<tr><th colspan="2">Studies informing theme 2:
Identity and embodiment concerns of older individuals during rehabilitation</th></tr>
<tr><th>Category 1:
The felt need for autonomy, dignity, humanity of older individuals with ABI</th><th>Category 2:
Gender influences on older individuals’ conceptualisation of ABI condition and rehabilitation process</th></tr>
<tr><td colspan="2">Andersson and Hansebo (2009)
<i>Elderly peoples' experience of nursing care after a stroke: from a gender perspective</i></td></tr>
<tr><td colspan="2">Löfmark and Hammarström (2005)
<i>Older stroke patients' negotiations within the hierarchic medical context</i></td></tr>
<tr><td>Ellis-Hill <i>et al.</i> (2009)
<i>Going home to get on with life: patients and carers experiences of being discharged from hospital following a stroke</i></td><td rowspan="7"></td></tr>
<tr><td>Krishnan <i>et al.</i> (2019)
<i>Stroke Survivors' Perspectives on Post-Acute Rehabilitation Options, Goals, Satisfaction, and Transition to Home</i></td></tr>
<tr><td>Loft <i>et al.</i> (2017)
<i>Call for human contact and support: an interview study exploring patients' experiences with inpatient stroke rehabilitation and their perception of nurses' and nurse assistants' roles and functions</i></td></tr>
<tr><td>Mangset <i>et al.</i> (2008)
<i>'We're just sick people, nothing else': ... factors contributing to elderly stroke patients' satisfaction with rehabilitation</i></td></tr>
<tr><td>Olofsson, Andersson and Carlberg (2005)
<i>‘If only I manage to get home, I’ll get better’- Interviews with stroke patients after emergency stay in hospital on their experiences and needs</i></td></tr>
<tr><td>Tholin and Forsberg (2014)
<i>Satisfaction with care and rehabilitation among people with stroke, from hospital to community care</i></td></tr>
<tr><td>Wray, Clarke and Forster (2019)
<i>How do stroke survivors with communication difficulties manage life after stroke in the first year? A qualitative study</i></td></tr>
</table>

2.9.2.1 The felt need for autonomy, dignity, humanity of older individuals with ABI

Five studies in this review focus on older individuals' felt need for greater autonomy during their stroke rehabilitation as well as for greater levels of dignity and humanity during their treatment. All studies underline the significance that older individuals assign to preserve the values of independence and humanising care. There is also mention of the internal existential thoughts that older individuals develop during their rehabilitation, which can lead to negative experiences about their condition, their hospitalisation, and their future lives after their discharge.

According to Mangset *et al.* (2008), who carried out their research in Norway, the sense of well-being for the participants was directly linked to their perception of the quality of their rehabilitation and heavily affected by whether they are treated with respect, dignity and humanity. Participants' descriptions and reflections on daily care experiences indicate the basic needs and the expectations that older individuals have during their rehabilitation, namely: (i) being treated with humanity; (ii) being acknowledged as individuals; (iii) having their autonomy respected; (iv) having confidence and trust in professionals; (v) more dialogue and exchange of information (Mangset *et al.*, 2008). The researchers argue that older individuals' need for autonomy, dignified care and respect derives from the vulnerability and dependence that many of them feel as a result of the diagnosis (Mangset *et al.*, 2008).

Wray, Clarke and Forster (2019) report that older individuals' desire and need to preserve (or regain) a sense of autonomy and independence while accepting that additional support from healthcare professionals, friends or family members was sometimes necessary during their rehabilitation. This empowered many participants to move forwards and cope with their rehabilitation, hence maintaining hope about the progression of their recovery. Several participants, however, expressed their concerns about how their independence was restricted due to the mobility and speech difficulties they had in their post-stroke lives but also due to their reliance on others (Wray, Clarke and Forster, 2019). For some participants, the support and care that they were receiving was not desirable since it was also perceived as a burden placed on their close ones (Wray, Clarke and Forster, 2019).

In their study conducted in Denmark, Loft *et al.* (2017) highlight the mixed feelings and thoughts that older individuals have about suffering a stroke and regarding their inpatient rehabilitation. As the study reports, the new conditions and limitations that stroke poses on older individuals leads them to developing existential concerns (Loft *et al.*, 2017). Their experiences are ambivalent as they find themselves in a strange stage of their recovery. On the one hand they have positive and pleasant feelings and thoughts, such as gratitude, hope and joy that they were alive and that they had recovered relatively fast from their physical impairment. On the other hand, they experience uneasy feelings and thoughts (Loft *et al.*, 2017).

As Loft *et al.* (2017) mention, older individuals are shocked at the way stroke has altered their understanding of their bodies and self-awareness, while also indicating the difficulty and challenges they face on keeping up with the fast-progressing recovery. Older individuals also felt detached from the outside, real-life and that inpatient rehabilitation was restricting their life - and by extension their sense of independence. These experiences and perceptions made older individuals feel bored and trapped during their hospitalisation – further highlighting older individuals' concerns about losing their independence (Loft *et al.*, 2017). Similarly, in Tholin and Forsberg's (2014) study many participants expressed having experienced loss of autonomy during their inpatient rehabilitation and hospitalisation in a clinical setting, especially when their everyday lives were influenced by the institutional rules of the clinical setting.

Loft *et al.*'s (2017) study further focused on the substantial concerns that older individuals had about their future lives, especially how they would manage to reorganise themselves and how they would cope with this new life-changing event. As they point out, these concerns were not related to their physical condition (which they did not think as a permanent issue) but mainly to the impact the stroke would have on their future social relationships and mental health (Loft *et al.*, 2017). Feeling comfortable with themselves again and managing their future were hence the factors that affected the sense of well-being for these individuals.

The two elements above exist because of the model of care upon which rehabilitation is based. As reported in Olofsson, Andersson and Carlberg (2005) and Löfmark and Hammarström (2005), both conducted in Sweden, many older individuals have been striving for recovering their personality/ identity and their autonomy, since they have felt passive, subordinate and dependent on healthcare services without being able to take part in the care and rehabilitation. For example, Löfmark and Hammarström (2005) indicate the subordination and adjustment of older individuals, and the power relations that exist within the hierarchic medical model. This was shown by participants' willingness and wish to build alliances with the staff and to abide by the rules. However, as the study indicates, older individuals also tried to perform resistant negotiations to increase their power and autonomy and to reduce staff's control. They did this by attempting to cope with their challenges independently, refusing personal assistance from the staff even during times of acute illness, and expressing critical remarks regarding treatment and care (Löfmark and Hammarström 2005). Moreover, in Olofsson, Andersson and Carlberg (2005), most participants demanded more information on their illness, recovery, prognosis and medication as an attempt to regain their autonomy.

In general, participants wanted to display themselves as being capable, assertive and independent human beings before and after the stroke (Löfmark and Hammarström 2005). Similarly, in the study of Ellis-Hill *et al.* (2009), when talking about their rehabilitation experiences, older stroke survivors suggested and described their models of recovery. Older individuals' models involved a sense of momentum and getting on with their life which indicates how capable they perceived themselves to be in interpreting and making sense of their own life situation and of their self, their current bodily experience, and their interactions with healthcare professionals. Older individuals also highlighted the importance of maintaining the momentum of their therapy (during and after their hospitalisation) in determining the outcome of their discharge. If momentum was lost the discharge was felt very difficult by older individuals, whereas if momentum was preserved discharge was felt as successful (Ellis-Hill *et al.*, 2009). Personal involvement and momentum are important ingredients in achieving well-being and humanity in rehabilitation that is not always possible in the biomedical model of care.

In summary, this category reveals the needs and expectations of older individuals to receive more dignified and humanising care, to be respected and acknowledged as autonomous, independent individuals. Vulnerability and dependence are factors that may impact negatively on the sense of autonomy and dignified care. Older individuals may develop worrying existential concerns and thoughts due to the new conditions and limitations that stroke condition poses to them. Although older individuals may feel joy and hope that they are alive and that they have recovered fast, they also develop many unpleasant feelings caused by their existential thoughts. Nevertheless, older individuals strive to regain their identity and autonomy and to display themselves as being capable and confident individuals. Personal involvement and momentum are identified to be important elements in achieving well-being and humanity in rehabilitation that is not always possible in the biomedical model of care.

2.9.2.2 Gender influences on older individuals’ conceptualisation of ABI condition and rehabilitation process

This category consists of the studies of Andersson and Hansebo (2009) and Löfmark and Hammarström (2005) both conducted in Sweden and adopts a gender perspective to explore the nursing care experiences and conceptualisations of older individuals with stroke during their rehabilitation.

According to Andersson and Hansebo (2009), their research indicates the variety of experiences felt by women and men regarding their nursing care after a stroke with the unexpected changes in their body affect their whole of life. Women are more comfortable with bodily care, describing positively and unemotionally their body care experiences and the help they needed where also there are no feelings of embarrassment in the bodily care. In contrast, men reported feeling vulnerable when they had to rely on nursing care as their masculine identity was threatened and thus felt embarrassment when they were getting naked in front of nurses (Andersson and Hansebo 2009).

While both men and women wished to return to their life as this was prior to the stroke, according to Andersson and Hansebo (2009), women and men had different goals due to the different traditional gender roles that had adopted and maintained at home. These differences in goals further influence older women and men’s attempt to reconnect to their identity and body as these were before the stroke (Andersson and Hansebo 2009). Older women’s goals were linked to housekeeping and regaining their role as housewives while for men, their goals focused on outdoor, leisure-time activities.

However, what men and women had in common where that they both concealed their sorrow about the illness from their nurses, and they generally did not communicate their goals regarding their rehabilitation to health professionals. Some participants felt that nurses were not prepared to share their sorrow; others actively chose not to mention it to their nurses (Andersson and Hansebo 2009). It was further reported that women communicated more with close family members about their sorrow and the loss of control over their bodies, whereas married men avoid talking to their family members, as they felt that they might worry their wives if they showed how sad and vulnerable, they were.

While men and women had difficulty in expressing their sorrow nonetheless the way they tried to deal with this varied. In their study, Löfmark and Hammarström (2005) characterise older individuals' negotiations with staff – as they strive to regain their autonomy – as gendered. On the one hand, women chose to negotiate with the nurse assistants, as they felt in a subordinate position within the medical context. On the other hand, men were trying to build alliances and communicate with nurses, physiotherapists and/or occupational therapists as they perceived themselves to be equal with the health professionals in the hierarchic medical context (Löfmark and Hammarström 2005). However, Löfmark and Hammarström (2005) also indicate that due to the hierarchical medical structure, it was challenging for both the women and men to negotiate with the physician in charge.

In summary, this study indicated that there were differences in the experiences of older individuals with stroke about their nursing care which can be based on the different gender perspectives. As their perceptions are linked with their lives - as women and men - before they had their stroke, the reclaiming of their former abilities, their perceptions of their position in relation to the medical staff and their overall rehabilitation experiences of women and men may differ. However, what men and women had in common was that they both concealed their sorrow about the illness from their nurses, and they were not communicating their goals regarding their rehabilitation to health professionals.

2.9.2.3 Summary of the Theme

Theme two provides an account of older individuals' internal concerns and existential thoughts they have about their identity and their bodily feeling with these concerns affecting their well-being and their recovery. Older individuals focus their descriptions on regaining and/or maintaining their autonomy and independence and the importance to be regarded and treated with dignity, humanity and respect. Vulnerability and dependence are two factors that may impact negatively on the sense of autonomy and dignified care. Differences in the experiences of older individuals with stroke about their rehabilitation care as influenced by the gender roles that older individuals adopt have been reviewed as well. Both men and women wish to return to their old life prior to the stroke but with different goals due to the traditional gender roles they had at home. At the same time, while both men and women had difficulty in expressing their sorrow, the manner in which they tried to deal with this varied.

2.9.3 Theme 3: Institutional factors affecting older individuals' experiences of care and well-being

In this theme, institutional and organisational factors of health settings are examined in terms of their effects on older individuals' experiences of care and well-being. Moreover, the communication and interaction between healthcare staff and stroke survivors are examined based on the experiences and perceptions of older individuals. From the total of seventeen reviewed articles, nine studies fitted in this theme (Table 2.8). Three descriptive categories inform the current theme, namely a) *Treatment burdens and organisational healthcare factors impacting on older ABI survivors' treatment*; b) *Older individuals' negative perspectives and interactions with healthcare service and medical staff*; and c) *Older individuals' positive perspectives and interactions with healthcare service and medical staff*. Each of the categories is examined below concerning the relevant results and discussions.

Table 2.8 *Studies informing theme 3*

<table>
<tr><th colspan="6">Studies informing theme 3:
Institutional factors affecting older individuals’ experiences of care and well-being</th></tr>
<tr><th colspan="2">Category 1:
Treatment burdens and organisational healthcare factors impacting on older ABI survivors’ treatment</th><th colspan="2">Category 2:
Older individuals’ negative perspectives and interactions with healthcare service and medical staff</th><th colspan="2">Category 3:
Older individuals’ positive perspectives and interactions with healthcare service and medical staff</th></tr>
<tr><td colspan="6">Morris, Payne and Lambert (2007)
<i>Patient, carer and staff experience of a hospital-based stroke service</i></td></tr>
<tr><td colspan="6">Löfmark and Hammarström (2005)
<i>Older stroke patients' negotiations within the hierarchic medical context</i></td></tr>
<tr><td colspan="3">Tholin and Forsberg (2014)
<i>Satisfaction with care and rehabilitation among people with stroke, from hospital to community care</i></td><td colspan="3">Galvin, Cusack and Stokes (2009)
<i>Physiotherapy after stroke in Ireland: a qualitative insight into the patients' and physiotherapists' experience</i></td></tr>
<tr><td colspan="3">Loft <i>et al.</i> (2019)
<i>Call for human contact and support: an interview study exploring patients' experiences with inpatient stroke rehabilitation and their perception of nurses' and nurse assistants' roles and functions</i></td><td colspan="3">Mangset <i>et al.</i> (2008)
<i>'We're just sick people, nothing else': ... factors contributing to elderly stroke patients' satisfaction with rehabilitation</i></td></tr>
<tr><td colspan="2">Krishnan <i>et al.</i> (2019)
<i>Stroke Survivors' Perspectives on Post-Acute Rehabilitation Options, Goals, Satisfaction, and Transition to Home</i></td><td colspan="4"></td></tr>
<tr><td colspan="2">Gallacher <i>et al.</i> (2018)
<i>A conceptual model of treatment burden and patient capacity in stroke</i></td><td colspan="4"></td></tr>
<tr><td colspan="2">Olofsson, Andersson and Carlberg (2005)
<i>‘If only I manage to get home I’ll get better’-Interviews with stroke patients after emergency stay in hospital on their experiences and needs</i></td><td colspan="4"></td></tr>
</table>

2.9.3.1 Treatment burdens and organisational healthcare factors impacting on older ABI survivors’ treatment

This category consists of seven studies that reported on burdens related to treatment as well as on organisational/institutional healthcare factors that affect older individuals’ rehabilitation and experiences. In general, the articles reviewed point to the negative experiences and difficulties of older individuals with a stroke that institutional deficits of healthcare services can create.

In their study, which was carried out in Scotland (at individuals' homes), Gallacher *et al.* (2018) demonstrate the considerable treatment burden experienced by stroke survivors and the factors that influence their capacity. According to the study, treatment burden refers to the healthcare tasks and workload that stroke survivors experience during their long-term rehabilitation and the impact these have on individuals' sense of well-being, with excessive treatment burdens leading to negative experiences and negatively impacting on their well-being (Gallacher *et al.*, 2018).

Treatment burden is identified by stroke survivors as arising from either a high volume of healthcare work or because of the endurance of care deficiencies in the way that care is delivered. Stroke survivors describe various types of healthcare workload including understanding symptoms and treatments, prioritising and setting goals, interacting with health professionals, friends and family and receiving support and help from them, taking medications, attending appointments for review, making lifestyle changes and reviewing recovery progress (Gallacher *et al.*, 2018). As regards deficiencies that occur in the delivery of care, based on participants' experiences, these may include: a) lack of information; b) understanding; c) support of care planning and/or psychological support; d) misdiagnosis; e) paternalism; f) poorly-coordinated care and poor communication with healthcare providers; g) waiting times as inpatient; h) substandard home care and i) poor long term follow up for all.

Both treatment-related work and care deficiencies can influence and be influenced by patient capacity. Based on participants' experiences, patient capacity was found to be a dynamic entity, one that is amenable to change, depending on the context and circumstances at any one point in time, including the availability of healthcare services (Gallacher *et al.*, 2018). As such patient capacity, according to participants' descriptions, can be affected by various factors, namely: a) personal attributes and skills (e.g. resilience, independence, disorganisation, worry); b) physical and cognitive capabilities; c) support network; d) the presence and support provided by family and friends; e) financial status (e.g. ability to pay for own mobility or financial struggles); f) life workload (e.g. employment, co-morbidities); and g) environment (location, home, availability of aids) (Gallacher *et al.*, 2018). The quality and configuration of health and social care services can influence the presence and endurance of care deficiencies, the volume of healthcare workload (and hence the treatment burden) as well as the capacity of patients to handle their health.

In Morris, Payne and Lambert's (2007) study, carried out in a hospital setting, they found that while older individuals maintain a positive view of staff, they point to the various service deficits for explaining the insufficient therapy and lack of attention to unpredictable events. According to older individuals' experiences of healthcare deficits include low staffing levels, pressures on staff and problems in staff management (Morris, Payne and Lambert, 2007).

Three reviewed articles referred to the lack of participation of older individuals in their rehabilitation goal setting as a result of institutional hindrances (Tholin and Forsberg, 2014; Krishnan *et al.*, 2019; Loft *et al.*, 2019). In Krishnan *et al.*'s (2019) study participants' experiences about the process of rehabilitation goal setting varied; some participants mentioned that they were involved, some that they were not involved, and others did not talk at all about their involvement. However, as the study reports, even among the participants who were participating in goal setting, some mentioned that their involvement was relatively passive, as they were asked to contribute only by way of asking questions or raising concerns (Krishnan *et al.*, 2019). In a similar vein, Loft *et al.* (2017) report that older individuals felt they were not particularly aware of the week's set goals - and even when some were aware of the goals their participation in the process was challenging, as it was difficult for them to work towards these goals. The study further acknowledges that the motivation of older individuals to participate in goal setting is in part hampered by institutional factors, such as the nursing staff's lack of involvement and support in goal setting (Loft *et al.* 2017). Lastly, most participants in Tholin and Forsberg's (2014) study experienced a lack of participation with respect to their inpatient rehabilitation or the planning of their subsequent care. It is worth noting, however, that views on participation varied as it was perceived differently by older individuals in the study. For some participants not being part in the care or the planning of the continuing care was not a problem, as they believed that the staff are more expert on these matters and knew best (Tholin and Forsberg, 2014). On the other hand, several participants were dissatisfied about the lack of information and lack of participation that they were experiencing in their care, feeling that they were side-lined and that their opinions were not considered (Tholin and Forsberg, 2014). On that note, Olofsson, Andersson and

Carlberg (2005) highlight the limitations and the dominant character of the traditional, established medical model which can explain the passivation and dependency of older individuals. According to the study, older individuals end up passively accepting whatever is offered to them while also being uncertain about the function of care.

In summary, this category delineates the various burdens, deficiencies and issues that affect older individuals' rehabilitation experiences, actions and participation in their recovery. There is also a significant deficit of information, understanding and/or psychological support, which in part results from the poor communication between health professionals and patients. The literature has also found that the passive participation of older individuals in their recovery's goal-setting process can be the result of institutional hindrances. Other deficiencies include shortage of staff levels; pressures on staff and problems in staff management; misdiagnosis; paternalism; waiting times as inpatient; and poor long term follow up for all. All these factors can lead to insufficient therapy, poorly coordinated care and lack of attention to unpredictable events and can thus influence individuals' capacity. Furthermore, the established medical model is characterised by dominance and limitations which can negatively affect older individuals by passivising and objectifying them during the rehabilitation process.

2.9.3.2 Older individuals' negative perspectives and interactions with healthcare service and medical staff

This category consists of three studies and displays older individuals' negative perspectives and interactions with the healthcare staff and the medical model. The poor communication and interaction and the unequal power relations between healthcare staff and participants led to various negative experiences and situations felt by the older individuals, such as a sense of inadequate individual information provision about their condition, their care and their discharge (Löfmark and Hammarström, 2005; Tholin and Forsberg, 2014; Loft *et al.*, 2019). As Tholin and Forsberg (2014) report, some participants felt a strong sense of passivity as the staff decided everything about their daily inpatient routine (e.g. when to eat and to go to bed).

A specific example comes from Löfmark and Hammarström's (2005) study, whereby the health care staff seemed to hold negative attitudes toward the older individuals and that these attitudes intensified the participants' experience of subordination. More particularly, because the older individuals with stroke in this study are seen as severely diseased stroke patients and as temporary visitors in the acute care setting, whose stay on the ward is relatively short, the healthcare staff assumed that these older individuals would adjust and abide by the rules in the ward.

While participants negatively criticised the attitudes and treatment provided by the therapists, nonetheless this criticism appeared to emanate from their criticism of the overall care services rather than directed to specific individuals. For example, Löfmark and Hammarström (2005) report that all older individuals felt that the days in the ward were quite long and that the therapist helped them in their rehabilitation only for a very short time each day. Some older individuals were dissatisfied with the care received by the physiotherapist as the existing medical model has made the therapists to demonstrate indifference to the emotional needs of patients. Older individuals' feeling is that therapists were not interested in keeping a relationship with older individuals and assisting them with their overall therapy (Löfmark and Hammarström 2005).

Lastly, Loft *et al.* (2017) highlight the lack of support, involvement and contact of staff with older individuals. For example, the nursing staff did not address nor recognised the needs and strong desire of older individuals to communicate and discuss the existential thoughts and concerns about the future that they had developed during their rehabilitation. In general, the study's participants had an unclear picture of the nursing staff's role, as a result of the medical model that the rehabilitation ward functioned emphasising the therapeutic aspects rather than the caring aspects and therefore, they judged nurses based the therapy provided and not the caring.

This category describes the negative experiences that older individuals hold regarding the overall care services rather than directed to specific individuals of staff. Thus, poor communication and interaction with the healthcare staff results from the existing medical model. As deduced from the articles reviewed, there are cases where medical staff hold negative attitudes towards older individuals, which reinforces the latter's subordinate and passive positions within the medical context and leads many times to insufficient treatment. Older individuals' descriptions also reveal healthcare staff's lack of support, involvement and willingness to communicate with older individuals.

2.9.3.3 Older individuals' positive perspectives and interactions with healthcare service and medical staff

This category provides evidence of positive interactions between older individuals and the healthcare staff. Specifically, five reviewed articles advise this category as they identify positive experiences and perspectives that older individuals hold with regards to therapists' behaviour and attitudes during rehabilitation.

As Morris, Payne and Lambert (2007) report, interactions and relationships with staff are considered vital by older individuals with regards to the provision of emotional support, encouragement as well as care. The descriptions of participants indicate the positive views that older individuals had for individual staff by mainly pointing to the organisational service deficits for the problems that emerge in the rehabilitation process (e.g. focusing on the shortage of nursing staff). Loft *et al.* (2017) also indicate that older individuals generally had positive perceptions about their nursing staff, viewing them as mostly polite and helpful.

Galvin, Cusack and Stokes (2009) report that older individuals have a positive view of individuals healthcare providers because of their positive attitude of honesty and encouragement, and their willingness to interact and share information. Mangset *et al.* (2008), also demonstrate how the quality of the dialogue and exchange of information between older individuals and health professionals' interaction influences stroke survivors' satisfaction with their rehabilitation. As the findings show, older individuals' trust and confidence in healthcare providers and their positive evaluation of services was more closely associated with satisfaction and high levels of well-being than the level of involvement in treatment decisions (Mangset *et al.*, 2008).

Löfmark and Hammarström (2005), also describe the attempts of older individuals to establish good interpersonal relations with their staff. According to the study's findings, older individuals strive to negotiate and build alliances with medical staff to better their situation on the medical hierarchic context of the ward, namely, to feel more comfortable and freer to ask for help with personal care and about their diagnosis and prognosis. Nevertheless, there is no evidence that this occurs in the specific ward researched in this study.

In summary, this category highlights the link between positive staff and older individuals' interactions and the pleasant experiences that older individuals have about their rehabilitation. The articles reviewed show how important and vital is for older individuals to have good and positive relations and communication with their staff, as it can contribute to the increase of older individuals' satisfaction as well as to the improvement of their emotional support, encouragement as well as care. Older individuals hold positive views about their staff (viewing them as helpful, supportive and polite), but they also have expectations regarding their therapists' attitudes and traits (e.g. to be honest and encouraging) as well as older individuals attempt to build good relations with their medical staff (without however making explicit whether the participants hold these views about their healthcare staff in the cases studied).

2.9.3.4 Summary of the Theme

Theme three examines the various burdens, deficits and general organisational and/or institutional factors that affect older individuals' experiences during their rehabilitation. The overburden of healthcare professionals with work along with organisational deficiencies such as the medical model that staff follows, the poorly coordinated care and poor communication with healthcare staff can lead to insufficient therapy and negatively affect older individuals' capacity. Conversely, interactions of staff and older individuals lead to positive experiences that older individuals have about their rehabilitation. The reviewed articles show that older individuals strive to have good and positive relations and communication with their staff, which they perceive important element for their satisfaction and for achieving the goals of their rehabilitation.

2.9.4 Theme 4: Older individuals' participation in creative activities as part of rehabilitation

The fourth theme explores the participation and the involvement of older individuals in creative activities as part of their rehabilitation. Three studies suggest this theme (Table 2.9). Two descriptive categories are attached to the current theme, namely a) *Art participation and rehabilitation of older individuals living with ABI* and b) *Older individuals' experiences of rehabilitation and participation in innovation and new activities*. Each of the categories is examined below with reference to the relevant results and discussions.

Table 2.9 *Studies informing theme 4*

Studies informing theme 3: **Institutional factors affecting older individuals' experiences of care and well-being**	
Category 1: Art participation and rehabilitation of older individuals living with ABI	**Category 2: Older individuals' experiences of rehabilitation and participation in innovation and new activities**
Morris *et al.* (2015) *Social context, art making processes and creative output: a qualitative study exploring how psychosocial benefits of art participation during stroke rehabilitation occur*	**Nimrod and Hutchinson (2010)** *Innovation Among Older Adults with Chronic Health Conditions*
	White *et al. (*2015) *Exploring stroke survivor experience of participation in an enriched environment: a qualitative study*

2.9.4.1 Art participation and rehabilitation of older individuals living with ABI

This category refers to a study (Morris *et al.*, 2015) introducing the use of novel and innovative stroke rehabilitation methods. Morris *et al.* (2015) study was carried out in Scotland and refers to the psychosocial benefits of art for older stroke survivors during their rehabilitation. According to the results of the study, art participation addressed important psychosocial issues that other rehabilitation approaches did not address and can overall offer many benefits to stroke survivors enhancing their overall experiences of rehabilitation (Morris *et al.*, 2015).

Stroke survivors reported that the art-room, which was outside the rehabilitation ward, provided a more socially stimulating environment than the rehabilitation ward, as it enabled older stroke survivors to interact with each other and to share their personal experiences, forgetting their health condition or their worrying thoughts. These kinds of interactions function as a distraction for older individuals from their physical and health situation, which by extension improve their mood and their sense of well-being. Furthermore, many older stroke survivors mentioned that artwork enabled them to enhance their concentration and feel relaxed. As a result, through art sessions, older stroke survivors developed a sense of enjoyment.

The study also revealed that through the participation in sociable environments - where verbal and non-verbal conversation was fostered - stroke survivors with speech and language difficulties had an improvement in their communication abilities. In addition, engaging with art materials and producing a completed piece of artwork provided stroke survivors with a sense of being empowered and in control. The rapid improvements that survivors experienced due to their involvement in art sessions and the benefit of tailoring creative tasks to their personal abilities and interests supplied older individuals with confidence to control their physical recovery while also providing them with the hope for future successful recovery. Moreover, the art intervention programme included a display of stroke survivors' artwork in a gallery. In this way older individuals presented and shared their work in an encouraging and appreciative environment that further increased the participants' sense of productiveness and self-esteem and also giving them a sense of personal reward. By extension, the cultivation of stroke survivors' artistic identity further affects the way that other people view them. For example, participants felt that others were more appreciative about stroke survivors' creative abilities and the work they could produce – and thus not focusing on what older individuals with stroke were not able to do due to their condition.

In summary, this category examines the connection between taking part in art activities for older stroke survivors with the enhancement of their mood, their communication skills, their sense of recovery and their perceptions about their own social identity. The study of Morris *et al.* (2015), highlights the importance of older stroke survivors' participation in creative activities as this creates many benefits for stroke survivors.

2.9.4.2 Older individuals' experiences of rehabilitation and participation in innovation and new activities

Two studies in this category reported on the significance of innovative leisure activities on the recovery of older individuals during stroke rehabilitation. Nimrod and Hutchinson (2010) conducted their study in Canada interviewing participants at their home environment while White *et al.* (2015) carried out their research in Australia at a hospital setting. Both studies agree that recovery and a sense of well-being for older individuals with stroke can be maximised through the frequent participation of older individuals in creative activities during rehabilitation.

According to Nimrod and Hutchinson (2010), the stimuli or reasons for which older individuals decide to join activities that they have never done before varies. The internal stimulus of older individuals for participating in creative activities includes curiosity, enduring interest and emotional need to connect with others. The external stimulus for older individuals in participating in creative activities includes recommendation made by someone else to join an activity, such as an invitation by a friend to join a church session. Instrumental factors are associated with a practical purpose, such as maintaining or improving the health condition of a stroke survivor. Many older individuals reported that through their participation in innovative activities, they viewed themselves as "innovators" or "lifelong learners".

Older individuals who become involved in creative activities have either a direct or indirect influence. With regards to the stroke survivors who were interviewed, the decision to take up a new activity had a direct association with the progress of their recovery (e.g., continuing their recovery by following formal stroke rehabilitation) or the improvement or keeping stable their physical health or emotional well-being. This applied to all stroke survivors who joined a "stroke club" which provided both an exercise program led by a volunteer physiotherapist and a social activity where participants could socialise and communicate with each other (Nimrod and Hutchinson, 2010).

Overall, creative activities have a positive impact on older individuals' mood and well-being. In particular, innovation and creativity may have an integral part in coping with declined health and physical impairments. All participants reported that new activities during rehabilitation made them feel better about themselves and improved their capacity for remaining well despite their health condition. Also, many of them expressed a sense of pride and usefulness as they felt capable and active members due to the new activities, they took part in (Nimrod and Hutchinson, 2010).

As examined in the study of White *et al.* (2015), an effective and innovative way for older individuals to participate in activities in a hospital setting is for them to be exposed in an enriched environment (EE). According to White *et al.* (2015), an EE provides a place in which these activities can be performed and enhanced recovery achieved. In the EE older individuals are involved in activities of personal interest such as reading something that their family brought in or playing a favourite competitive game with other stroke patients.

Participants in the study perceived several specific and generalised benefits that an enriching environment can provide. For example, through the participation in new activities older stroke patients reduce the unfamiliarity of the rehabilitation ward. Access to EE activities and participation in the communal area of EE provided the opportunity for older individuals to gain more motivation while also interrupting the ongoing cycle of boredom and inactivity experienced by many participants. Additionally, communal EE was found to provide a method for enhancing social interaction among older participants.

However, older participants also experienced barriers towards accessing the EE which often led to lower levels of participation and greater time spent at the bedside. Access and frequency of use of the EE was linked to participants' preferences, motivation, ward restrictions, and the availability of staff to assist with mobility. Redistribution of existing resources, the provision of a greater variety of resources and flexibility of ward routines could accommodate the variety of patient preferences, values and comorbidities and thus increase patients' interest and motivation levels to participate in activities (White *et al.*, 2015).

Overall, this category refers to the importance for an older person with stroke to be active and identifies ways of integrating activities in the process of rehabilitation that takes place at home as well as in a hospital setting. Both studies revealed the potential to improve the activity levels of stroke survivors undergoing stroke rehabilitation as well as their recovery and well-being through participation in innovative activities and environments. On the one hand, the study of Nimrod and Hutchinson (2010), focused on older individuals' new and continuing activities and further identified the reasons/ stimuli for older participants to get involved in such activities, namely internal, external and instrumental factors. Based on this categorisation they conclude that participation in activities manifests a positive impact on older individuals' well-being. White *et al.* (2015), make the case about the benefits of an enriched environment where older participants would have the opportunity to feel like being at home and also to become more familiar and feel more relaxed with the hospital environment.

2.9.4.3 Summary of the Theme

In summary, the fourth theme examines the value of older individuals' participation in creative and innovative activities during their rehabilitation. All three studies remarked on the many benefits that activity participation and involvement can have to older individuals' well-being and recovery. According to the findings, art participation addresses significant psychosocial issues of older participants and offers many benefits and solutions for them. Art participation for older stroke patients is linked with the enhancement of their mood, the improvement of their communication skills, their sense of recovery and their perceptions about their own social identity. Moreover, there are various triggers and stimuli (i.e., internal, external, and instrumental factors) that can lead older individuals to participate in innovative activities during their rehabilitation and make them feel physically active and capable independent individuals in the society. Older stroke survivors reported that their decision to take up a new activity had a direct association with their health condition recovery - in terms of galvanising them for example to continue their recovery by following formal stroke rehabilitation – as well as with the betterment of their physical health and emotional well-being. Older individuals who participate in an enriched environment within the stroke rehabilitation unit, have increased opportunities to enhance their motor, cognitive and sensory skills. Participants also reported that through their participation in activities within an enriched environment, they can keep down boredom by putting an end to inactivity.

2.10 Discussion

The current systematic review of the literature aimed to explore how older individuals diagnosed with Acquired Brain Injury (ABI) experience their physical rehabilitation at home or at a hospital setting. In total, 1418 records were retrieved from the databases' initial systematic search and 14 studies were selected as being eligible for the review. The seventeen included studies were assessed for their methodological quality (trustworthiness), by applying the CASP tool for appraising qualitative research (Critical Appraisal Skills Programme, 2018). The assessment did not recognise any studies of insufficient quality.

The discussion focuses on the overarching ideas and patterns that ensue from the synthesis of the selected studies' results and the identified themes, namely (i) participants' experiences of rehabilitation processes, (ii) individuals' personal identity and embodiment concerns, (ii) healthcare institutional issues and burdens as well as (iv) individuals' participation in creative activities. Overall, the current review sheds light on aspects of ABI rehabilitation that require the attention of health professionals and researchers, while also indicating the extent to which these aspects affect older individuals' physical and non-physical needs and experiences of their well-being.

The current review's findings demonstrate variations regarding older individuals' inpatient service experiences. Participants had an initial positive view of their rehabilitation, but this was tempered by lack in both the rehabilitation processes' content and its application to their daily reality. Long waiting times between physiotherapy sessions and the physiotherapy's shortened duration hampered the rehabilitation content. As Leddy, Kaldenberg and Becker (2003) support, long waiting times can be problematic in all types of health care settings. In addition, Pound *et al.* (1994) highlight that the main priority of stroke inpatients is ''to get as much treatment as possible and to get better'' (p. 73). These shortcomings can therefore be the prime causal factor for patients' dissatisfaction, frustration and distrust towards health professionals and the care system due to the broken promise for timely care. Many older individuals further share the belief that more days of physiotherapy and additional sessions from the ones provided could be more beneficial for their recovery. Evidence shows that more days of care or physiotherapy and additional sessions with more training and intensity can benefit older individuals' care and the rehabilitation process leading to better functional recovery (Luker *et al.*, 2015; Kinoshita *et al.*, 2017). From another perspective, Lewinter and Mikkelsen (1995) found that stroke patients, who did not have the opportunity to continue physiotherapy in weekends described those days as the worst of their hospital stay.

Nevertheless, it should be pointed out that such activities and sessions can be hard and laborious to follow. It could be argued that the available services do not neglect individuals' needs or expectations; instead it is the increased workload and the low staffing numbers that intensify these sentiments. A shortage of health workers exists worldwide, and this has reached a critical point for healthcare services on both the local and global levels (Oulton, 2006; Marć *et al.*, 2019; WHO, 2022). Buerhaus *et al.* (2007) argue that the low number of nursing staff has real consequences that leads to poor quality patient care, to patient safety being compromised and to ineffectively collaborating with other healthcare professionals overall negatively impacting upon nursing tasks. In short, extending the rehabilitation session duration and prolonging the rehabilitation process can impinge on the appropriate staffing levels of health services which are currently critically understaffed.

As the current review asserts, family involvement and the extent of it in the rehabilitation process can significantly contribute to a successful recovery. There is a great deal of evidence suggesting the advantageous role of family involvement in improving individuals' rehabilitation outcomes and well-being. Bellou and Gerogianni (2007) concur with the findings of this review by suggesting that family has a vital role in treating patients providing the necessary and effective psychological and emotional support to patients undergoing hospital rehabilitation. Similarly, Waller *et al.* (2019) and Winstein *et al.* (2016) support the idea that families play a central role in protecting the person's sense of self and building the person's confidence during rehabilitation. In the same vein, Haines (2018) supports the engagement of family in rehabilitation of people who are critically ill by highlighting the benefits of the recovery experience through the provision of emotional support. The reason that family has such a significant role is because individuals feel encouragement and support which can motivate them to continue with their physical rehabilitation. Galvin *et al.* (2011) confirm that family's involvement in therapy sessions could significantly improve individuals' physical function and recovery after stroke and that patients show improvement in balance, motor function, distance they can walk, and other general activities. Additionally, Lawler, Taylor and Shields (2015) support the idea that participation of family members in physiotherapy may improve the physical outcomes for the patients by providing encouragement while also stimulating them to adhere to their exercise programs.

Furthermore, the studies reviewed indicate that healthy and positive interactions and communication with healthcare staff are vital for older individuals to feel that they receive efficient care, emotional support and encouragement. Effective communication is linked to improved quality of care and patient satisfaction, leading to positive health outcomes (Ali, 2017; Skär and Söderberg, 2018). Healthcare staff and by extension the health system must follow a more patient-centred care model to adequately meet the health needs of chronically ill patients, to positively affect recovery and rehabilitation outcomes, and to reduce errors (Sibiya, 2018; Vennedey *et al.*, 2020). In this sense, the relationships built between stroke survivors and members of healthcare staff are significant, affecting the overall recovery. Afriyie (2020) also highlights the importance of healthy and positive communication between nurses and patients claiming that such communication should serve as the basis for all nurse–patient relationships.

At the same time, the findings of the review indicate how the dominance of the medical model can become an impediment to person-centred care. According to Clare (1980), the medical model constitutes an approach to illness that advocates the scientific processes of observation, description and differentiation and ranges from the awareness of symptoms to the identification of the disease causes and the development of specific treatments. A more contemporary view of the medical model is proposed by Shah and Mountain (2007) who define it as a process that enables doctors to advise on, coordinate or deliver interventions for health improvement based on the best available evidence. Lloyd, Elkins and Innes (2018) support that organisational factors such as the reduced numbers of staff along with the high volume of work have set important barriers towards achieving a patient centred care. Esmaeili, Cheraghi and Salsali (2014) found that the lack of organisational support decrease nurses' motivation and ultimately decrease patients' satisfaction. From another perspective, nurses recognise and confirm that there are pitfalls in the standards of care within areas that are particularly important to patients, thus causing nurses to feel overworked by not having the necessary time to perform essential nursing tasks (West, Barron and Reeves, 2005).

The review also identified that older individuals receiving rehabilitation are not actively involved in the goal-setting process during their rehabilitation; instead, they are expected to passively accept what is offered to them. In their systematic review Peoples, Satink and Steuljens (2011) assert that older individuals' collaboration with health professionals in setting goals is a significant aspect that influences stroke survivors' rehabilitation experiences. Also, Bamm *et al.* (2015) corroborate the significance that cooperative work between healthcare staff and older individuals has for improving the well-being of older individuals during their rehabilitation, while also pointing out the passive role that older individuals experience concerning the process of goals-setting. Lastly, Tariman *et al.* (2009) further conclude that patients needed to undertake a more active role during their rehabilitation.

Another issue that emerged from the findings of the studies selected was older individuals' concerns about the insufficient information and the overall lack of support they receive at or after discharge. Cobley *et al.* (2013) indicate that older individuals have a limited understanding of stroke and its causes, limited information about possible secondary preventative measures, and limited support for lifestyle changes. The limitations referred by Cobley *et al.* (2013) are further based on the assertion made in Everall *et al.* (2019) that individuals should be engaging in decision making regarding their rehabilitation as well as in their discharge planning.

The review supports the idea that older individuals believe that healthcare staff or family members do not see them as capable and autonomous human beings, which by extension leads them to feel that there is a lack of autonomy and a loss of their personhood. Such feelings strongly affect stroke survivors by impacting on their well-being and recovery. The value that older individuals attribute to the notions of independence and autonomy has also been reported in other studies (Dixon, Thornton and Young, 2007; Proot *et al.*, 2007). From the perspective of biomedical ethics, respect for autonomy is considered a central value (Beauchamp and Childress, 2012). Literature has also highlighted the importance of autonomy for individuals in terms of maintaining and increasing the quality of life and satisfaction for older individuals while also observing that autonomy is associated with the improvement of recovery and individuals' well-being (Edwards and Staniszewska, 2000; Edwards, Staniszewska and Crichton, 2004; Moller, Ryan and Deci, 2006; Welford *et al.*, 2010). Another issue that follows from the sense of diminished autonomy and personhood, which concerns older individuals in the current review and is mentioned in the broader literature as well, is the fact that in many cases older individuals are not able (or not encouraged) to be involved in the selection of the place or setting where they will be placed after their acute rehabilitation - with medical staff or their family usually making the choice for them. Autonomy is threatened when individuals are not given the sufficient information or the opportunity to understand fully their diagnosis and also to make informed choices about their care (Smith *et al.*, 1997; Kelson, Ford and Rigg, 1998; Stevenson *et al.*, 2000). In addition, cases of limited patient-centredness and dysfunctional relationships between individuals and healthcare professionals – together with the silencing of older individuals' preferences – seem to disempower older individuals from setting attainable rehabilitation goals, by inhibiting their potential to self-regulate and self-monitor their physical activities and having adverse effects on their adaptation to the rehabilitation process and their sense of well-being (Rosewilliam, Roskell and Pandyan, 2011; Shilts, Horowitz and Townsend, 2004). Furthermore, such goal setting limitations can become restrictive for older individuals' sense of autonomy, which leads health professionals to assume a more controlling role, by limiting the provision of information and setting (or influencing) goals on behalf of the older individuals (Stevenson *et al.*, 2000; Barnard, Cruice and Playford, 2010; Levack *et al.*, 2011). When individuals are not viewed as autonomous persons and their choices are ignored, it is possible for them to distrust or disregard health professionals' recommendations and as a result to risk the effectiveness of their treatment by not following the medical advice (Jonsen, Siegler and Winslade, 2015; Zolkefli, 2017).

The limitation of choice for older individuals is further compounded by health and social disparities. The range of options that older individuals have regarding the rehabilitation services they would like to receive is highly limited by various socio-economic discrepancies. Studies suggest that various clinical and non-clinical factors such as patient's insurance, quality of the facility, prognosis for functional improvement, and stroke severity often play a key role in choosing the post-acute care for patients with stroke. In this sense, individuals are not always able to control and/or make decisions about their rehabilitation services and processes, unless if they have the financial ability to afford to buy private services (Putman *et al.*, 2007; Hakkennes, Brock and Hill, 2011; Magdon-Ismail *et al.*, 2016). Therefore, it can be argued that the way older individuals with ABI are viewed and the efficacy of the rehabilitation services they receive depend largely on socio-economic factors and not just on their health needs, with poorer people having greater limitations of choice and therefore greater dissatisfaction with rehabilitation process.

The review's findings about older individuals' concerns are in accordance with the broader literature regarding the significant change that older individuals experience about themselves when returning home - as they are not able undertake the same activities as prior to the stroke incident (McCabe and Kennelly, 2015; Darby *et al.*, 2017; Jönsson, Appelros and Fredriksson, 2017). However, when returning home individuals diagnosed with ABI experience many positive feelings and thoughts as well. Home feels to be a "safe place" for them where self-esteem and pleasant emotions are revived (Eriksson, Asplund and Svedlund, 2009). In general, home and family are always vital aspects for living well in this world. According to the existential theory of well-being, as presented in Todres and Galvin (2010) and Galvin and Todres (2013), dwelling offers a sense of peace; but to experience the deepest possibility for well-being, individuals must also experience embodied mobility. Therefore, Nordin, Sunnerhagen and Axelsson (2015), claim that coming home for individuals is ultimately a difficult situation as their abilities and capacities have changed compared to before stroke. The initial sense of joy for coming home thus turns into an illusion of returning to normality for stroke survivors as most of them quickly realise that this normality no longer exists or at least not in the same way as they thought it would be since they are no longer the same person due to their limited mobility. In the literature, normality has been explored through various theoretical approaches, having acquired various meanings and implying different conditions. According to Boorse (2014), who discusses normality through the lens of biostatistical theory, normality can be interpreted as the absence of illness or the absence of any pathological condition. From a different point of view, Koeslag (1993) supports that normal is associated with the usual. What the findings of this review indicate is that the way normality is considered and experienced by older individuals is largely influenced by their subjective feelings as well as by their available capacities and abilities after the stroke.

Beyond a daily 'normal' older individuals with ABI are concerned about their future and the need to renegotiate their identity concerning their condition (Kvigne, Kirkevold and Gjengedal, 2004). As people experience dependence in different ways, some patients might not feel comfortable to depend on others to complete various tasks, such as getting dressed or washed, during their rehabilitation. According to Nilsson, Jansson and Norberg (1999), many patients during rehabilitation struggle with internal concerns and existential thoughts which tend to appear after their stroke. Therefore, patients need to set future goals in order to feel independent and to renegotiate their identity. Goal-setting is considered an important strategy for improving well-being and has been also proved as effective in changing physical activity in adults (Cullen, Baranowski and Smith, 2001; Shilts, Horowitz and Townsend, 2004).

The dismissal of dependence by older individuals as a constraining state that limits autonomy and selfhood can be traced to the ideals of individual self-reliance and responsibility. These are heavily promoted by the socio-political and economic paradigm of neoliberalism which frames the meaning of everyday reality for people in Western cultures (McGuigan, 2014). As David Harvey (2007, p. 23) argues, 'neoliberalism has, in short, become hegemonic as a mode of discourse... [with] pervasive effects'. The ideal type of neoliberal selfhood is a mosaic of idealistic views and values that promote personal freedom and individualisation, encouraging individuals to make their own personal choices during their life-course, without being looked after by a paternalistic state (Beck and Beck-Gernsheim, 2002; McGuigan, 2014). However, such an approach to life also requires individuals to take sole responsibility for the consequences of the choices they make or, indeed, have not made. In this sense, the phenomenon of individualisation and the overall type of neoliberal self can be both appealing and terrifying: freedom and self-dependence are at the core of the neoliberal way of life but if things go wrong there will be no support, regardless whether it is due to personal failure or because of bad luck (McGuigan, 2014).

The pursuit of self-reliance and autonomy can thus explain the reaction against the vulnerability and lack of self-confidence that older individuals with ABI experience but also as a result of the hegemonic neoliberal trend and the ideals that this trend promotes. While personal independence and freedom to make choices are vital and necessary, it is also important to consider the contribution of health professionals who are striving to re-shape older individuals' sense of 'normal' reality. Healthcare staff assist older individuals with their recovery, making important decisions about their rehabilitation and alleviating many health burdens. In this sense, dependence can also be approached from an alternative point of view, as a necessary, normal condition for some people who are in need of care to rely on and receive support from others. Based on that, it is worth considering whether the confusion and difficulty that older individuals feel can be alleviated, if the perception they have about dependence changes, by accepting for instance that it is normal to be dependent on other people during rehabilitation.

Some studies have also highlighted the influence that gendered perspectives and imperatives can have on older individuals' experiences and conceptualisations of their physical rehabilitation and goal-setting process. Overall, the review's findings indicate that despite the similarities between men and women have concerning their experiences of rehabilitation, differences emerged as well. The most important difference relates to the divergent goals that they have about returning to their self-image and roles prior to the stroke, largely influenced by the traditional gender roles they had at home. As emphasised by De Beauvoir (1974) and reinforced by McCormick and Bunting (2002), the impact of illness might be different for women and men. Within the older generation, men in the traditional view of gender find their self-actualisation outside the house whereas women find theirs in the house. The fact that ABI can make individuals housebound leads men to experience greater difficulties with rehabilitation as they are focused more on activities outside the home. A similar conclusion is reached by Kvigne, Kirkevold and Gjengedal (2004) who demonstrated that women with stroke were trying to regain their family lives and retain the feminine role of mother housewife.

The review also deals with the many psychosocial benefits that creative activities can offer to older stroke survivors regarding their rehabilitation. A creative, stimulating and enriching social environment can be developed within the rehabilitation ward, and can be facilitative for more easily adjusting older individuals to their new reality following ABI and rehabilitation by limiting stroke survivors' passivity. Higgins, McKevitt an Wolfe (2005) agree that art activities provide an appropriate and safe occasion for social interactions between stroke survivors. Such interactions and generally art participation helps older individuals to forget their worrying thoughts and their health condition and improve their self-esteem, mood, and sense of well-being (Tamplin *et al.*, 2013). In their systematic review, Lo, Lee and Ho (2018) support the point that art interventions can enhance individuals' mood, and improve their well-being.

It could be further argued that through the involvement in creative activities, older individuals can (re)create their own social identity and become more active, by expressing themselves and their own ideas and promoting their worldview (Howie, Coulter and Feldman, 2004). Furthermore, the review has shown that creative activities can also offer physical benefits, such as improving the communication abilities of older stroke survivors with speech and language difficulties. As Kongkasuwan *et al.* (2016) report in their study, creative art therapy can enhance stroke survivors' rehabilitation and recovery. The study further argues that the improvement of physical functions and increased quality of life of older individuals would not be successful with physical therapy alone (Kongkasuwan *et al.* 2016).

Lastly, the current review concludes that creating an enriched environment during physical rehabilitation can facilitate and improve older stroke survivors' recovery. Environmental enrichment refers to an intervention to increase motor, sensory, cognitive, and social activity by providing a stimulating environment for individuals (Rosbergen *et al.*, 2017). An enriched environment for older stroke patients can reduce the unfamiliarity of the rehabilitation ward, by reconstruing it as a familiar and pleasant place to participate in innovative activities and interact with other stroke survivors. Ball, Mercado and Orduña (2019), argue that enriched environments reduce patients' stress and anxiety and enhance learning and memory mechanisms. Similarly, Sampedro-Piquero and Begega (2017), highlight the encouraging benefits and positive outcomes of an enriched environment compared to just medical interventions for patients diagnosed with brain injuries.

2.11 Synopsis of the literature review

This systematic review provides an overview of the literature relating to the well-being and rehabilitation experiences of older individuals living with ABI. Family involvement in rehabilitation processes was one of the most important factors in individuals' successful recovery and improvement of their well-being. In contrast, long waiting times between physiotherapy sessions, disconnecting rehabilitation from individuals' daily reality, and shortening the physiotherapy duration, were found to adversely impact older individuals' autonomous decision-making and goal setting potentials - while further research has linked them with low numbers of health staff. In addition, inadequate and ineffectual interaction between health professionals and older individuals who suffered ABI, the dominance of health professionals' voices in decision-making, gender imperatives and health disparities further impede older individuals' decision-making, limiting their sense of personhood in the post-acute care phase. Also, the dissonance between expectations and the reality of returning home from acute hospitalised rehabilitation, and the illusionary and unfulfilled returning to a socially constructed normality added another layer of difficulty for older individuals with ABI, that negatively affected their sense of well-being during their rehabilitation. Efficient and effective communication, emotional support, recognition of personhood, family involvement in the rehabilitation process, and creating a stimulating and enriching social environment can ease and humanise older individuals' adjustment to their new reality following ABI and also facilitate the need for rehabilitation, leading to potential phycosocial and physical benefits.

It should be noted that most studies in this review included both older and younger individuals, with just three studies focusing exclusively on older individuals. This limitation indicates the need for more studies focusing exclusively on older individuals living with ABI. Moreover, the small number of results generated through the systematic search constitutes another limitation of this review, which at the same time reveals the scarcity of use of the term ABI - as an inclusive term that encompasses both nTBIs and TBIs - especially when dealing with older individuals' rehabilitation.

Overall, the literature review provides significant insights into the experiences of individuals living with ABI undergoing physical rehabilitation that would be useful for practitioners and researchers in understanding the linkages between ABI, well-being, and physical rehabilitation. Nevertheless, it also reveals the scarcity of qualitative studies on the topic, thus indicating the need for more comprehensive exploration of the dimensions and significance of humanising care, and more specifically the factors that affect older individuals' emotional condition and sense of well-being during physical rehabilitation. Consequently, this review lays down the path for further investigation into how dignified care and emotional support for older individuals with ABI can be achieved or enhanced within formalised healthcare systems.

2.12 Aim, Research Question and Objectives of the research study

The above systematic literature review provided the foundation for this PhD thesis. The current study intends to interpret and thoroughly explore what it means to be an older individual in need of care. In particular, the study aims to fill the gaps identified in the literature review by acquiring an in-depth understanding of older individuals' experiences of their lifeworld when undergoing physical rehabilitation focusing on their felt sense of well-being during care provision within the Greek Healthcare System. The overall intention is to provide a framework for explaining the ways older individuals' feelings may link to their well-being or ill-being as well as the role of the healthcare system in impacting on older individuals' sense of well-being. Consequently, this framework will contribute to the potential modification of the care system, lending originality to the thinking, structure and construct of care for this patient group.

Therefore, the aim of the study is:

> *To develop an in-depth understanding of older individuals' lived experiences undergoing physical rehabilitation after an acquired brain injury and provide an*

interpretive exposition illustrating the impact that Greece's healthcare and rehabilitation system has on older individuals' felt sense of well-being.

Drawing on the aim and following the findings of the literature review the research question of this study was developed as follows:

What are the lived experiences of older individuals undergoing physical rehabilitation after an acquired brain injury (ABI) in relation to their sense of well-being within the Greek formalised healthcare system?

To answer the research question, the following objectives were formulated to guide and facilitate the design and research process of the study:

- **Objective 1:** To explore how older individuals living with an ABI sense well-being when undergoing physical rehabilitation.
- **Objective 2:** To explore how older individuals living with an ABI undergoing physical rehabilitation feel about themselves and the context within which they exist
- **Objective 3:** To explore how older individuals living with an ABI undergoing physical rehabilitation experience the lifestyle changes that may occur after the injury.
- **Objective 4:** To understand what are the felt experiences of older individuals living with an ABI undergoing physical rehabilitation of their interaction with health professionals.
- **Objective 5:** To examine the impact of Greece's healthcare and rehabilitation system on the felt experiences of well-being of older individuals undergoing physical rehabilitation.

CHAPTER 3: THEORETICAL FRAMEWORK

3.1 Introduction

This chapter presents and discusses the theoretical framework used in this thesis, which informs the data analysis and discussion of the findings. Considering the results of the systematic literature review as well as the research objectives of this study, this thesis draws on the lifeworld-led humanising care approach as developed by Galvin and Todres (2013). The chapter commences with a general discussion and analysis of the lifeworld concept within the phenomenological tradition and in relation to healthcare practice, focusing on its intertwining constituents of embodiment, mood, identity, spatiality, temporality and intersubjectivity. Subsequently, the Humanising Framework of Care as well as the existential theory of well-being developed by Galvin and Todres (2013) are presented focusing on the existential possibilities of well-being and suffering in the dwelling-mobility matrix. Overall, the lifeworld perspective constitutes the philosophical foundation of the humanising care framework, while its domains provide an analytical and explanatory framework towards an existential approach to well-being. Lastly, the chapter explains how the different types of well-being will be used to analyse and discuss this study's results.

3.2 The notion of Lifeworld

The notion of lifeworld comprises a fundamental concept in the field of phenomenology. Being introduced and extensively discussed by Edmund Husserl, particularly in his book *Crisis of the European Sciences and Transcendental Phenomenology* (1936/1970), the lifeworld view has been quite influential in contemporary European philosophy as well as in social and human sciences (Moran, 2012). Although Husserl's treatment of the lifeworld varies in his works, offering different characterisations and meanings depending on the context, his core conception of the notion pertains to a pre-theoretical and pre-scientific qualitatively grounded world, which appears meaningfully to human consciousness (Todres, Galvin and Dahlberg, 2007; Moran, 2012; Galvin and Todres, 2013). His intention was to make a distinction from the "true, natural, objective" world as described by science. Husserl was at odds with the idealisation and quantification of the scientific world, arguing that it neglects to capture the qualities of the human experience. According to Husserl, the lifeworld can be perceived as an all-inclusive horizon of experience, that is, it includes everything that can be experienced. In contrast, the scientific world results in an inexperienceable world "in-itself":

> "The contrast between the subjectivity of the life-world and the 'objective', the 'true' world, lies in the fact that the latter is a theoretical-logical substruction, the substruction of something that is in principle not perceivable, in principle not experienceable in its own proper being, whereas the subjective, in the life-world, is distinguished in all respects precisely by its being actually experienceable."
>
> (Husserl, 1936/1970, Part III/A, p. 127)

In this sense, the lifeworld recognises the importance of subjectivity without being reduced to an innate subjective world in itself nor to an objective world "out there". It is rather a humanly "all-embracing" subjective-relative reality, incorporating all the aspects of the surrounding world that humans *live in* and *with it* (i.e., both the natural and the cultural world) (Todres, Galvin and Dahlberg, 2007; Moran and Cohen, 2012; Bengtsson, 2013). Husserl further conceptualised lifeworld as the 'subsoil' of our practices, the realm that underlies scientific practices and remains constantly functioning, providing meaningful knowledge of the social and cultural world. It is the place where a-priori or pre-given understandings of the world occur and are given naturally and pre-reflectively to our experience of the everyday life (van Manen, 2002; Todres, Galvin and Dahlberg, 2007; Moran and Cohen, 2012;). Overall, the lifeworld consists of everything possible that an individual can experience before they begin to define or conceptualise it (Laverty, 2003; Moran, 2012; Bengtsson, 2013):

> "It is this world [the pregiven world] that we find to be the world of all known and unknown realities. To it, the world of actually experiencing intuition, belongs the form of space-time together with all the bodily [*köperlich*] shapes incorporated in it; it is in this world that we ourselves live, in accord with our bodily [*leiblich*], personal way of being. But here we find nothing of geometrical idealities, no geometrical space or mathematical time with all their shapes."
>
> (Husserl, 1936/1970, Part II, p. 50)

This focus on lifeworld involves a pre-reflective process of making sense of and experiencing the genuine and authentic aspects of the phenomena as these appear prior to engaging scientific understandings (Finlay, 2011; Rich *et al.*, 2013). Husserl calls this state our natural attitude, where we find ourselves immersed in our existence as this unfolds, intuitively experiencing and acting in the world without reflecting on what our experience means, as we are in the natural attitude (Finlay, 2009). This further demands a different type of phenomenological inquiry and investigation of the lifeworld. Husserl argues that a special process of reduction is required (which Husserl calls *epoché*) where the philosopher attempts to be open by "bracketing" (suspending) the judgments, theories and habitual ways of interpreting the world that stem from the natural and cultural sciences, in order to capture directly and immediately the lifeworld in its essence (Finlay, 2009; Moran 2012). However, this approach raises many questions on the nature of the lifeworld and its relation to the scientific world, especially whether the lifeworld can be free from historical and cultural dimensions.

While Husserl remained committed to *epoché* as a methodological principle, in his late work, he did recognise the cultural embeddedness of human beings and how their horizons could be determined by their cultural contextualisation (Moran, 2018). He thus makes an additional distinction between the two fundamental methodological ways in which lifeworld can be captured: the natural attitude to life, which refers to the pre-scientifical and pre-reflective connection to the lifeworld, and the reflective attitude to life, which draws on the natural attitude but takes place in a later stage (Husserl, 1936/1970; van Manen, 2002).

Following Husserl, several scholars (from Heidegger to van Manen) argued that the investigation of the lifeworld further entails a reflective attitude by humans. Focusing on the ontological exploration of what "being-in-the-world" means (*Dasein*), Heidegger (a student of Husserl) argues that the lifeworld and lifeworld experiences cannot be separated from their historical and cultural context (Heidegger, 1962; 1993). As such, individuals' lived experiences are always influenced by their surrounding world and thus can only be interpreted within the social, cultural, and historical context that the lifeworld is intertwined with (Laverty, 2003). He further rejects bracketing, believing that researchers cannot completely suspend their own experiences, pre-conceptions, and theoretical leanings. For Heidegger, the lifeworld has a genuine historical nature in contrast to the scientific world which he perceives as a-historical (Moran, 2012).

Therefore, it is not possible to leave out history and context to achieve a better or more genuine understanding of the lifeworld. On the contrary, according to Heidegger, we can gain a deeper and more accurate understanding of our lived experiences by considering our history and background.

As such, the concept of lifeworld incorporates an explicit reflective awareness of what the philosophical literature refers to as *noema* and *noesis*, namely the perceived thing, the event we imagine, what we remember and so on and the act of capturing the things we experience through the conscious, subjective tools of perception, imagination, memory, and judgment (Ashworth, 2015). For Husserl, the combination of noema and noesis invokes the mechanism of intentionality which is essential for the building up of any lived experience (Moran and Cohen, 2012; Ashworth, 2015).

Intentionality is the essential feature of our conscious acts and lived experiences, signifying their intentional quality of referring, aiming or being about something (Moran and Cohen, 2012). It essentially refers to a person's directed awareness of an object or the events of their experience, which further entails reflective explanations of their experiences (Dahlberg, Dahlberg and Nyström, 2008). In other words, there is always an intentional relationship between us (as conscious human subjects) and the things that make up our daily lives (the external taken-for-granted, meaning-giving world), which we experience as things or events that have meaning for us (Dahlberg, Dahlberg and Nyström, 2008; Finlay, 2011). At the same time, the meaning of the objects and events that we experience is never independent but is correlated, shaped and depends on their context within the lifeworld, which entails features such as our preoccupation with time, space, our relationships with others, as well as our mood or disposition (Rich *et al.*, 2013; Asworth, 2015). Thus, the lifeworld has an inevitably subjective but also intersubjective character and therefore cannot be considered fully objectified (Moran, 2015).

3.3 Towards a lifeworld-led care approach: the Humanising Framework of Care

The dehumanisation and depersonalisation of care has been an emergent problem linked mainly to the commercialisation, automatisation and standardisation of care, and the fragmentation of healthcare professional pathways (Lovato *et al.*, 2013). The tendency to treat the patient as a 'group of symptoms' rather than as a human who has individual needs can, on the one hand, negatively affect the relationship between the healthcare staff and patients and, on the other hand, weaken patients' and caregivers' trust in the healthcare system (Stange, 2009; Behruzi *et al.*, 2014). In this context, Husserl's philosophical exposition of the lifeworld provides the necessary foundation for developing a lifeworld-led approach to humanising healthcare.

By articulating an existential view of being human and an existential view of well-being, lifeworld-led care recognises individuals' possibilities of vulnerability and freedom when coping with a health-related condition. In this respect, it differs from patient-led or patient-centred care as it goes beyond the mere interpretation of cure and caring practices; rather, it provides a deeper understanding of people's struggles and vulnerabilities by highlighting the well-being possibilities for vitality, movement and peace (Dahlberg, Todres and Galvin, 2009). Central to this approach is the concept of humanisation, which provides a particular view of what it means to be human and what it means to practice in a manner that makes individuals feel more human rather than passive recipients of care services (Dahlberg, Todres and Galvin, 2009; Galvin and Todres, 2013). By establishing the notion of humanisation of care as its core value, lifeworld-led care claims that the impersonal systems of care and technology need to be balanced and moderated with humanising practices and forces (Galvin and Todres, 2013). As further explained:

> "this value is based on the intuition that individual lives matter and that the quality of human life cannot be quantitatively measured or defined. This intuition and understanding is given to human beings with their subjectivity and as beings that can humanly care for self and others (the potential to see oneself in others)."
>
> (Galvin and Todres, 2013, p. 32)

Galvin and Todres have expanded the above principles into a theory-driven and philosophically based framework for humanising healthcare and existential well-being (Todres, 2005; Galvin and Todres, 2013). Founded on a phenomenological, lifeworld-led approach, the humanising theoretical framework integrates the notions of humanisation of care and the lifeworld to raise awareness around the concepts of care and well-being. In particular, this framework seeks to explore and understand the manifold interrelated horizons of meanings that consist of people's lifeworld through the qualitative and subjective descriptions of their lived experiences (Galvin and Todres, 2013). As such, it can provide a holistic description of healthcare practices by illuminating the qualitative and subjective dimensions of the complex living situations of individuals during healthcare (Galvin and Todres, 2013).

The humanising theoretical framework offers eight dimensions that represent the fundamental constituents of humanisation in caring practices, as informed by the notion of the lifeworld (Todres, Galvin and Holloway, 2009; Galvin and Todres, 2013). Each dimension represents a continuum that stretches from the possibility of humanisation, that is, when a person feels "more" human, to the state of dehumanisation that brings barriers to the potential of humanisation, thus making them feel "less" human (Todres, Galvin and Holloway, 2009; Galvin and Todres, 2013). Together these eight dimensions constitute a comprehensive set of criteria for considering the potentially humanising or dehumanising elements in caring systems and interactions (Galvin and Todres, 2013). The conceptual framework of humanisation and dehumanisation and the various points of emphasis are presented in Table 3.1.

Table 3.4 *The eight dimensions of the humanising care framework (adapted from Galvin and Todres, 2013)*

Forms of humanisation		Forms of dehumanisation
Insiderness	↔	Objectification
Agency	↔	Passivity
Uniqueness	↔	Homogenisation
Togetherness	↔	Isolation
Sense-making	↔	Loss of meaning
Personal journey	↔	Loss of personal journey
Sense of place	↔	Dislocation
Embodiment	↔	Reductionist body

Furthermore, Galvin and Todres (2013) assert that the forms of humanisation and dehumanisation in each dimension should not be conceptualised as binary opposites nor as static conditions but rather as different points of emphasis within a "spectrum of possibilities" that are interrelated and can overlap or co-occur. Different points of emphasis regarding individuals' state can thus stand out along these continuums according to their relevance and dependence in each situation and by considering the context in which they are situated (Galvin and Todres, 2013; Galvin *et al.*, 2020).

Overall, this model contributes to the more technical and measurable assessments in care practices by raising awareness of the complex human dimensions of one's lifeworld. Therefore, these dimensions can provide a sensitising background that can help professionals assess overcoming issues in healthcare practice with the aim of improving care delivery by achieving humanising and efficient care (Todres, Galvin and Holloway, 2009; Borbasi *et al.*, 2012). Furthermore, it should be noted that the goal of the humanising care framework is not to attribute or overemphasise negative values to dehumanising practices but to examine what makes individuals feel more human in situations in which they receive care (Galvin and Todres, 2013). In fact, there may be times when moments of dehumanisation are also appropriate and necessary for effective care to take place, for example, when there is a need for professionals to focus on the technological monitoring of patients' biological functions, an action that patients come to terms with as an essential parameter of their care and rehabilitation (Todres, Fulbrok and Albarran, 2000; Todres, Galvin and Holloway, 2009; Galvin and Todres, 2013).

3.3.1 The constituents of the Lifeworld

The humanising framework of care consists of holistic qualities corresponding to interrelated domains that must be understood to grasp the overall meaning of individuals' lived experiences (Merleau-Ponty, 1962; Todres, Galvin and Dahlberg, 2007; Dahlberg, Todres and Galvin, 2009). Focusing on individuals' lifeworld and how individual human experiences relate to others and to their immediate context, the Humanising Framework of Care consider five domains that constitute the lifeworld, namely, temporality, spatiality, intersubjectivity, embodiment and mood (Table 3.2) (Todres, Galvin and Dahlberg, 2007; Dahlberg, Todres and Galvin, 2009; Galvin and Todres, 2013). Some of these dimensions were already considered (though not explicitly) by Husserl, who mainly focused on the implications of time, space and embodied manifestations of the lifeworld in human experience. The experiential domains of lifeworld were further developed within the phenomenological-philosophical tradition by incorporating ideas and suggestions from other scholars concerning the understanding of the lifeworld (Heidegger, 1962; Merleau-Ponty, 1962; Van den Berg, 1972; Boss, 1979).

While these dimensions are interdependent and interconnected, their distinct elaboration and assessment can further help to understand the particular nuances of lived experiences (Todres, Galvin and Dahlberg, 2007). The exploration of these dimensions forms the basis of the experiential theory of well-being adopted in Galvin and Todres' (2013) matrix by shedding light on the different well-being or suffering possibilities and their phenomenological interpretations.

Table 3.5 *Lifeworld constituents (adapted by Galvin and Todres, 2013)*

Temporality	Refers to the continuities and discontinuities of time as it is humanly experienced. Time is viewed both quantitatively and qualitatively. Through the experience of time, individuals try to make sense of the temporal flow of events, seeking to understand the past and present and anticipate the future.
Spatiality	Refers to the surrounding world of places (either social or physical environments) where things have meaning to living and where individuals can experience their lives. Through the experience of space, individuals are able to understand their surroundings and make sense of the physical and social relations that shape their environment.
Intersubjectivity	Refers to how we understand ourselves by interacting with others, the culture and tradition. As individuals, we cannot be understood without reference to how our lives take place within a social world. Through the experience of intersubjectivity, individuals are able to understand the experiences and perspectives of others and make sense of their own experiences in relation to others.
Embodiment	Refers to the concrete "here" of ourselves, our "lived body". It is the feeling of "being" or belonging; the sense of how we bodily live, experience and understand our own bodies in meaningful ways in relation to the world and others. Through the experience of embodiment, individuals are able to understand their own physical sensations, movements and feelings as well as the physicality of others.
Mood (or Emotional Attunement)	Refers to internal feelings and emotions such as happiness, loneliness etc. It can be influenced by the physical and mental situation and by all the above domains. Through the experience of mood, individuals are able to understand their own emotional states and make sense of the emotional states of others. The experiences of specific moods further enable individuals to make sense of the surrounding atmosphere of a particular place or situation.

3.4 The existential theory of Well-being

Understanding and interpreting the individual sense of well-being becomes pivotal to the Humanising Care Framework. In the literature, the concept of well-being and its various dimensions have been conceptualised and researched through multiple approaches, including psychological, physical, socioeconomic and mental (Diener, 2009). Well-being entails both health and quality of life, while the sense of "being well" as perceived (and experienced) by the individual relates to experiential and emotional aspects of health (Sarvimåki, 2006). The lifeworld approach proposed by Todres and Galvin places particular emphasis on these aspects, adopting an existential theory of well-being (Dahlberg, Todres and Galvin, 2009; Galvin and Todres, 2013; Lundin, Berg and Muhli, 2013) that draws on the phenomenological understanding of Heidegger's existential philosophy of "being in the world" (*Dasein*) (Heidegger, 1962). The particular approach and theory of well-being within the Humanising Care Framework can provide the background for healthcare staff and caregivers to assess well-being levels according to the individual's degree of adjustment and self-management and to identify the appropriate actions that they need to take to help individuals with disabilities and chronic conditions, such as older individuals with ABI to attain a state of well-being.

Galvin and Todres' (2013) definition of well-being captures the subjective, experiential and dynamic nature of well-being, thus rendering it a much deeper and more complex phenomenon than the mere absence of disease and suffering. In this light, the existential theory of well-being emphasises the positive and strength-based nature of well-being that can enable individuals to access and unravel a full range of experiential and behavioural possibilities towards progress, development and adaption to any difficult life changes (Todres and Galvin, 2010; Galvin and Todres, 2013).

These possibilities are actualised through the existential constituents of the lifeworld, namely the dimensions of temporality, spatiality, embodiment, intersubjectivity and mood - in other words, to the individual's sense of self-identity, to their social relationships and interactions with others, to their sense of space and time, and in short to all of their lived experiences that constitute their lifeworld (Sarvimåki, 2006; Dahlberg, Todres and Galvin, 2009; Galvin and Todres, 2013).

Apart from the experiential dimensions of the lifeworld (temporality, spatiality, intersubjectivity, embodiment and mood), the existential theory of well-being informed by a lifeworld perspective focuses on the notions of well-being and suffering. Specifically, Galvin and Todres (2013) argue that well-being and suffering are regarded in terms of a continuum that is not reduced to a one-dimensional, linear relationship but rather to a more dynamic spectrum where both states relate to one another. Only when both concepts are realised can someone fully grasp the sense of well-being (Galvin and Todres, 2013).

Informed by Heidegger's concept of homecoming, the existential theory of well-being deploys the notions of dwelling and mobility for exploring the lived experience of well-being while also providing a third experiential potential of well-being that includes an amalgamation of these two dimensions (*Gegnet* = abiding expanse) (Galvin and Todres, 2013). The dwelling/ mobility framework builds on the idea of well-being as the interlocking between peace and movement, between being at home and experiencing an adventure (Dahlberg, Todres and Galvin, 2009). It should be mentioned that the two concepts of dwelling and mobility are not to be understood as mutually exclusive categories: peace can be the origin of movement, and movement can be the origin of peace. The togetherness of existential dwelling and existential mobility, as expressed by Heidegger's idea of *Gegnet*, can further contribute to the possibility of well-being.

The notion of mobility refers to the individual's potential and ability to move forward, the quality of seeking and anticipating future possibilities and meaningful activities (Galvin and Todres, 2013). In this sense, it refers to the ability of the individual to make future plans by finding meaning in his present situation and identifying it as a starting point for actualising a variety of behavioural and experiential possibilities in the future. Existential mobility can be metaphorically described as an adventurous and vibrant experience of movement that gives our lives a sense of flowness and aliveness (Galvin and Todres, 2013). The different experiential possibilities of existential mobility are connected with the existential dimensions of the lifeworld, including a focus on the spatial, temporal, intersubjective, embodied, and emotional manifestations of mobility. Well-being can emerge or be limited through each and all these existential emphases of mobility, thus designating the complex variations of the experiential state that can occur in individuals living situations.

By the term dwelling, Galvin and Todres (2013) refer to the individual's potential to come to terms (to "come home") with their situation and to use past experiences to arrive and settle into the present moment by accepting things as they are. Heidegger (1993) uses the term *Gelassenheit* ("letting-go") to refer to acceptance and peace. Thus, when such dwelling is able to be fully supported and embraced, there may be a mood of peacefulness. As with mobility, dwelling is also connected to the existential dimensions of the lifeworld, signifying the different possibilities that dwelling can be experienced and manifested. Individuals can come to dwelling in many different ways, such as through sadness, suffering, relaxation, or even patience (Galvin and Todres, 2013). The term dwelling for Galvin and Todres (2013) does not necessarily indicate the elimination of pain or disease but instead signals the intentional process of treating ill-health or disease as an awakening for accepting and adapting to the present moment.

From these two concepts of dwelling and mobility, Galvin and Todres (2013) extrapolate a third dimension of dwelling-mobility (*Gegnet*). Heidegger's notion of *Gegnet* can open up an understanding of how dwelling and mobility are implicit in the most profound experience of well-being (Galvin and Todres, 2013). The dwelling-mobility dimension is essentially the unification of the dwelling and mobility dimensions where the individual blends feelings of acceptance of the current situation (a sense of "rootedness" and "homecoming") with feelings of intense energy and willingness to move forward (being open to the novelty of new horizons) thus reflecting the sense of well-being at its deepest fullness. This combination of compromise and acceptance of the new situation, along with the desire for planning and moving towards the future, can lead to a complete sense of well-being (Galvin and Todres, 2013).

3.4.1 Kinds of well-being and suffering

Galvin and Todres (2013) recognise that the above three dimensions of well-being do not occur in a vacuum but within the context of humanising care. This considers the lifeworld's fundamental structure, which includes the experiential realms of spatiality, temporality, inter-subjectivity, mood, identity and embodiment. It should be noted that while the domain of personal identity is not explicitly discussed by some scholars (namely Heidegger and Boss), Galvin and Todres (2013) have decided to incorporate it as a constituent of the lifeworld in their existential theory of well-being as it provides an additional helpful nuance to the articulation of the different well-being and suffering possibilities by indicating the different ways that individuals actualise and experience their selfhood. By using the basic experiential dimensions of the human lifeworld, Galvin and Todres (2013) move on to develop a typology of well-being by delineating the various well-being variations that may be experienced and encouraged within healthcare practices (Table 3.3) (Galvin, 2021).

The left-hand side of Table 3.3 lists the six experiential domains of lifeworld within which well-being can occur, whereas the top horizontal row delineates the different well-being possibilities. Each well-being quality/ variation indicates a particular kind of well-being that can be experienced within the individuals' lifeworld.

Table 3.6 *Well-being typology (adapted by Galvin and Todres, 2013)*

Experiential dimensions of the lifeworld	**MOBILITY**	**DWELLING**	**DWELLING-MOBILITY**
SPATIALITY	**Adventurous** A sense of adventure and movement (metaphorically or literally) that provides spatial possibilities.	**At-homeness** A sense of being at-home, a sense of settlement or stillness within the physical environment. This physical environment can correspond to familiar surroundings or being close to personal objects that make us comfortable.	**Abiding expanse** Feeling both a sense of at-homeness and a sense of movement. Being deeply connected to a familiar place but also energised by spatial possibilities towards adventurous horizons (metaphorically or literally).
TEMPORALITY	**Future orientation** Being motivated by temporal possibilities for future movement (metaphorical or literal). A sense of flow, continuity and meaningful purpose.	**Present centredness** Absorbed in the present moment in a way that is valued or wanted. Sense of belonging, a deep connection with the present situation.	**Renewal** Unification of future orientation with present centredness. A rooted flow - being satisfied with the now and a sense of potential movement towards a welcoming future.
INTERSUBJECTIVITY	**Mysterious interpersonal attraction** In tune with interpersonal possibilities of meeting and finding out more about others. Attracted to the mystery of people's "otherness". A desire to develop a sense of bonding, or a sense of gravitation towards another.	**Kinship and belonging** A sense of kinship and 'at-homeness' with others. An effortless being together with one another - "we" rather than "I" and "you."	**Mutual complementarity** Both a sense of kinship/togetherness by maintaining existing relationships and excitement at developing new ones with others — merging familiarity/"homelike oneness" and the unknown/difference.
MOOD	**Excitement** A felt "attunement" that has the quality of buoyancy and movement. Looking forward to an inviting and desired world or a special event.	**Peacefulness** Stillness, settledness or reconciliation. A sense of welcomed pause and "letting-be-ness". An acceptance of "what has been given".	**Mirror-like multidimensional fullness** A complex mood that encapsulates both a sense of accepting oneself and the energy of "giving oneself" without reservations. The sense of risk brings an elevated mood, but without worry of failure.
IDENTITY	**I can** Sense of personal accomplishment and competence. Experiencing oneself as "being able to" move towards a desired future and achieve goals that are in accordance with one's self-knowledge and personal possibilities.	**I am** A feeling of acceptance and contentment with one's sense and state of being, which is supported by continuous histories and contexts. Ontological security.	**Layered continuity** A continuous sense of "I can" and a strong sense of "just being" in a foundational sense. An acceptance of one's present identity and a positive orientation towards possible future identities.
EMBODIMENT	**Vitality** Tuned into a valued bodily movement (metaphorical or literal) towards different desired outcomes. Referring to the possibilities of a literal "bodying forth or an energised bodily feeling without literal physical movement (e.g. in imagination or eroticism).	**Comfort** Experiencing one's body as warm, full, relaxed, still, satiated. A felt sense of familiarity, intimacy and "being at home" with the internal rhythms of one's body.	**Grounded vibrancy** Experiencing a gentle energised flow and a felt sense of being deeply at-home and settled. Involves potential and a readiness to look forward. A bodily sense of fullness ("being") along with a "humming" sense of vibrancy that offers the potential and readiness towards unfinished horizons ("becoming").

In contrast to the kinds of well-being, Galvin and Todres (2013) have developed a typology of suffering. Similarly, as with the well-being typology, they define each kind/ variation of suffering according to the combination of the experiential domain and the suffering possibility within which it takes place, which in turn reveals a particular level of suffering that can be experienced within the individuals' lifeworld (Table 3.4).

Table 3.4 *Suffering typology (adapted by Galvin and Todres, 2013)*

Experiential dimensions of lifeworld	**MOBILITY**	**DWELLING**	**DWELLING-MOBILITY**
SPATIALITY	**Imprisoned** A felt sense of "confinement". Feeling unable to move, trapped, with no room or any horizon that can give respite. Developing a sense of "claustrophobia" that may lead either to the anguish of wanting to get out, or the despair of being locked in.	**Exiled** Feeling a sense of estrangement and alienation in an inhospitable place with limited opportunities for relief or breathing space. A sense of being cast out and being far from home with a painful longing for a return to a familiar or homelike place.	**Roomless** A deeper sense of despair than the anxiety of entrapment or the longing of exile. There is both a feeling of longing for home but also a sense of being so trapped in homelessness: there is nowhere to return to nor a future place 'worth looking for'.
TEMPORALITY	**Blocked future** A sense of temporal stagnation. Feeling "stuck" or frozen in time and by extension blocked or cut off from any sense of future movement.	**Elusive present** A sense of temporal unsettledness. Being unable to "stand still" and simply "be present" due to the unpleasantness of the present moment or excessive attachment to the past or future.	**No respite** One is lost in a relentless temporal limbo where neither the future nor the present provide possibilities of respite. The present feels unbearable while there is also an aversion to the future, with no way forward.
INTERSUBJECTIVITY	**Aversion** An interpersonal aversion towards being with another or others that polarises the 'Me' from the 'You', leading to conflict and a lack of attraction or interest. One feels the aversion or becomes the victim of it, resulting in feelings of shame and disgust, or a lack of interpersonal spark.	**Alienated isolation** A ruptured sense of interpersonal belonging and kinship with others, causing feelings of exclusion or being cut off from meaningful engagement. This can lead to a literal or existential sense of loneliness - feeling like an unwanted outsider - and to a longing for familiar connections.	**Persecution** Feeling at great threat from others with no way out; a painful rupture of interpersonal belonging and a sense of being an unwanted outsider or victimised. This condition is deeper than aversion or alienated isolation on their own, carrying the possibility of both despair and terror.
MOOD	**Depression** A 'closed in' mood of limited or dark horizons. Marked by a lack of energy and motivation, a pessimistic outlook and a felt inability to move forward. It can lead to a sense of unworthiness, guilt, hopelessness, despair, or even a desire to die.	**Agitation** Unsettled restlessness characterised by a feeling of irritation, disturbance, a sense that something is wrong. There is a felt quality of unpleasantness and lack of harmony, resulting in anxiety and a feeling of never being at home.	**Restless gloom** Complex mood encapsulating an intense and overwhelming feeling of gloom that is intolerable; one is trapped between being condemned to this feeling, and at the same time, being preoccupied with running away from it. The intensity of this painful liminal mood causes agitation to find a way out.
IDENTITY	**I am unable** Perceiving oneself as lacking ability. A felt sense of incompetence, failure, pessimism, and helplessness that leads to self-enclosure and a pervasive sense of failure.	**I am the object of 'thing'** Feeling objectified, either by oneself or others, resulting in a feeling of being unacceptable and unloved. A sense of self that is being injured or deformed leading to ontological insecurity.	**I am fragmented** One's sense of self has become fragmented, carrying with it a loss of coherence, personal impotence and lack of agency. This can lead to feelings of helplessness, passivity, and a sense of being dead inside.
EMBODIMENT	**Stasis and exhaustion** An inability or lack of desire to move, or a felt sense of impaired or threatened bodily functions. This can include literal problems such as paralysis or weakness, as well as a lack of energy or vitality.	**Bodily discomfort and pain** A difficulty to simply settle or feel at home in one's body due to a palpable sensation that something is wrong. It can manifest in various sensations such as itchiness, tenderness, and dizziness.	**Painful closing down** A felt sense of "the body closing down", being exhausted and overwhelmed in uncomfortable and painful ways. Physical pain is accompanied by a loss of mobility or energy and a feeling of depletion.

The well-being and suffering typologies, as presented above, will be employed to analyse and discuss the findings of the current study. The different kinds of well-being and suffering will be used to convey and interpret the sense of well-being or suffering experienced by older individuals with ABI during physical rehabilitation. Additionally, these typologies will aid in assessing their sense of well-being and personhood in relation to the rehabilitation care they have received. By considering the different dimensions of well-being and suffering, we can gain a comprehensive understanding of their overall experience and evaluate the impact of the provided care.

3.5 Conclusion

The lifeworld approach of experiencing, knowing and adapting to challenges will provide the basis for the discussion of the results, focusing on the meaning of care and well-being and suffering through older individuals' lived experiences. This phenomenological approach to care will guide the analysis and the discussion of older individuals' rehabilitation experiences and well-being conceptualisations by providing a more holistic perspective on the concept and state of being human. Specifically, this study will use a lifeworld-led approach drawing on the Humanising Framework of Care and the existential possibilities of well-being and suffering in the dwelling-mobility matrix. The well-being and suffering typologies adopted in this study are based on the notions of dwelling, that is "feeling at home" with one's own life, and mobility which refers to the potential of the individuals to move towards the future, by making plans and regaining their sense of personhood once significant changes and challenges occur in their lives. These domains will assist the current study by indicating the different variations of well-being or suffering as experienced by older individuals with ABI undergoing physical rehabilitation as well as the different possibilities of humanisation within care practices.

CHAPTER 4: RESEARCH METHODOLOGY

4.1 Introduction

This chapter sets out the methodological and analytical approach that was employed for this study. It starts with a discussion of the philosophical assumptions that shape and inform the current study and proceeds with the description and justification of the phenomenological approach that was adopted for the purposes of this study. Subsequently, I discuss in detail the data resources that were used for the empirical research along with the rationale behind the choice of this type of methods. These pertain to semi-structured interviews that were conducted with older individuals who are living with ABI and who had received physical rehabilitation. The interview process is reviewed in detail, by discussing the sampling method and recruitment strategy as well as the fieldwork process that took place. Consequently, I present the qualitative analytical approach used for processing and analysing the data in this study, which consists of a synthesis of van Manen's (1990) phenomenological approach to data analysis and Clarke and Braun's (2013) thematic analysis approach. Lastly, I discuss the issues of rigour and trustworthiness concerning this qualitative research, demonstrating how these are demonstrated and established in the current study.

4.2 Philosophical Approach of the Research

A good research study needs to make explicit the set of beliefs and assumptions or the general worldview that the researchers embrace and shape their understandings of the world and eventually sculpts their approach to the research design and approach (Creswell, 2007; Tracy, 2013). These assumptions and beliefs usually combine questions of ontology (the nature and form of reality), epistemology (the nature of knowledge), and methodology (the strategies and tools used by the inquirer to find out whatever they believe can be known) (Lincoln and Guba, 1985; Laverty, 2003; Denzin and Lincoln, 2018).

Denzin and Lincoln (2018) encapsulate the researcher's worldview using the term *paradigm*. The term paradigm in Denzin and Lincoln's (2018) work refers to the set of epistemological, ontological, and methodological premises that the researcher is bound to, and which guide research action. As Creswell (2007) notes, different terms and categorisation schemes have also been used in the literature when describing the various paradigms. Furthermore, paradigms constantly shift or change over time and occasionally overlap or merge. While ontological and epistemological beliefs can be presented together (as constituting parts of a paradigm or as if the one was an extension of the other), in research philosophy there are clear demarcations between the elements of ontology and epistemology, with each level referring to specific aspects of philosophical enquiry (Crotty, 1998; Bryman, 2012; Denzin and Lincoln, 2018). Ontology relates to the nature of existence while epistemology deals in a distinct level with the processes of producing and acquiring knowledge about the world. When designing a research study, the two concepts need to be explicated and clarified in order for the researcher to generate and use the appropriate methodological framework and research methods (Denzin and Lincoln, 2018).

There is undoubtedly a fundamental bond between epistemology and ontology, as it is often hard to infer one without the other. Nevertheless, both ontology and epistemology hold an autonomous status within philosophy. As a consequence, there is a broad debate among scholars about which one comes first. On the one hand, there is the belief that ontology precedes epistemology on the premise that we first come to define what exists in the material or social world that is useful to acquire knowledge of, which then influences the ways we approach that knowledge. On the other hand, epistemology is viewed as preceding ontology in the sense that the ways we produce or acquire knowledge influences and determines our perceptions of reality and beliefs of what the world consists of and whether we believe that there is an external world independent of our consciousness and experiences or not. My personal orientation falls into the latter group, considering epistemology as preceding ontology. In my view, producing knowledge and understanding of the world constitutes the core aim of philosophy. Furthermore, I believe that the explication of the source and of the ways of knowledge production clears the way for the classification of being and the definition of what we believe as reality.

This section deals with the philosophical assumptions that shape and inform the study's methodology. The most commonly referenced and differentiated epistemological and ontological variations are firstly presented. The section then concludes by displaying my beliefs and philosophical assumptions while also justifying the epistemological and ontological positions that I have selected to follow in this research project (see section 4.2.3).

4.2.1 Epistemology

Epistemology refers to the study of knowledge and deals with the assumptions we make about the nature and scope of knowledge, its´ very possibilities and limits, and finally provides answers on how knowledge is produced, attained and communicated (Cohen, Manion and Morrison, 2007; Holloway and Wheeler, 2010; Sum and Jessop, 2013). Epistemology provides information that identifies the researcher's theoretical perspective and the conceptual framework that guides the whole research project (Crotty, 1998). By defining the epistemological position, researchers get the opportunity to clarify the ideas, claims and beliefs they hold about reality and the knowledge of it and to lay out the ways they believe knowledge can be created and acquired for their research (Crotty, 1998; Creswell, 2007; Denzin and Lincoln, 2018). In this sense, epistemology is concerned with questions such as *how do we know what we know*, *how what is assumed to exist can be known*, *what is the relationship between the knower or would-be knower and what can be known* and *what counts as valid knowledge* (Blaikie, 2000; Creswell, 2007; Holloway and Wheeler, 2010; Lincoln, Lynham and Guba, 2018).

There are various categorisation schemes and distinctions of the available types of epistemological positions in the research literature. Tracy (2013) notes that, since different disciplines and authors use different terms and select different epistemologies, researchers should seek out the specific categorisations relevant to their field. One major epistemological classification frequently appearing in the literature concerns the broad distinction between positivist and non-positivist positions.

4.2.1.1 Positivism

Positivism focuses on the importance of objectivity in searching the truth and view the knowledge of the world as being unaffected by the researcher, which implies a clear-cut distinction between the object of inquiry and the inquirer (Laverty, 2003; Snape and Spencer, 2003). From a positivist epistemological position, research focuses on observing, measuring and predicting facts and empirical phenomena to produce rigorous, tangible and generalisable knowledge (Le May and Holmes, 2012; Tracy, 2013). For positivism human biases and personal backgrounds should be minimised (or even disappear) as these can hinder the study's objectivity and affect the overall study's potential in revealing the objective knowledge and the single truth (Tracy, 2013). By using deductive reasoning and maintaining an unprejudiced, impartial and value-free stance, researchers can acquire and know the single truth of the object/ phenomenon of inquiry (Laverty, 2003; Tracy, 2013; Lincoln, Lynham and Guba, 2018).

4.2.1.2 Non-positivism

Researchers espousing non-positivism epistemological positions seek alternative approaches and use new and different ways and means of producing knowledge and developing understandings from those used from the positivist epistemology. Non-positivist epistemologies arose as a response and critique towards the dominance of positivism in social sciences (Alessandrini, 2012). Consequently, non-positivism constitutes a distinct epistemological school of thought underpinned by a consistent set of assumptions (Ashworth, 1997; Alessandrini, 2012). For non-positivists, the attempt to acquire objective knowledge and uncover the single "truth" of an externally governed reality is not only undesirable, but constitutes an unattainable goal (Trochim and Donnelly, 2006; Stahl, 2007). In specific, non-positivism epistemology asserts that there is no single 'true' position nor an objectively acquired knowledge (Alessandrini, 2012).

Furthermore, while non-positivism espouses the above assertation (that does not accept the single "true" and the single objective knowledge approach), nonetheless there is no uniform non-positivism approach, but there are variations of non-positivist epistemologies that encompass a diverse range of positions (Ashworth, 1997; Alessandrini, 2012). Non-positivism can thus be viewed as an umbrella term under which different epistemological strands have emerged, which in turn are classified and labelled in diverse ways by various authors.

For example, Lincoln, Lynham and Guba (2018) distinguish between critical theory, constructivism and participatory action epistemologies. Tracy (2013), using different terminology, follows similar line of thought differentiating between interpretivism, critical theory and postmodernism/ poststructuralism. Among the different non-positivist approaches, the Literature identifies the interpretivist epistemological variation as the most often used and sometimes pose it as an opposite/ counterpart to positivism (Laverty, 2003; Stahl, 2007; Bryman, 2012; Lincoln, Lynham and Guba, 2018). The present study adopts a non-positivist stance, as it purports that positivism is incompatible with the research aim of this study to thoroughly investigate the subjective experiences of older individuals undergoing ABI rehabilitation concerning their well-being. Non-positivism proves also to be appropriate in answering the research question that involves understanding and interpreting the personal accounts and multiple meanings attributes to older individuals' unique experiences.

4.2.1.3 Interpretivism

Developed as a critique to the ideas of positivism, the interpretivist point of view claims that positivism cannot provide the researcher with answers on complex research questions where the researcher wants to explore the subjective realities of life (Le May and Holmes, 2012; Tracy, 2013). For interpretivism, knowledge of reality is constructed, created and reproduced intersubjectively through the communication and interaction of the different views that each individual holds on their existence (Crotty, 1998; Creswell, 2007; Lindsay, 2007; Bryman, 2012; Tracy, 2013). Reality cannot be clearly and objectively explained, captured or translated by the researcher (Tracy, 2013). In this sense, interpretivists assert that there are multiple understandings, meanings and ways of knowing. Therefore, they view knowledge as the best understandings that social actors have produced thus far (Laverty, 2003; Levers, 2013; Lincoln, Lynham and Guba, 2018). This epistemological stance further recognises an interactive relationship between the knower and the known and claims that research cannot be free from researchers' values and beliefs (Laverty, 2003; (Laverty, 2003; Levers, 2013; Denzin and Lincoln, 2018; Lincoln, Lynham and Guba, 2018). The goal of interpretivism is to recognise, understand and interpret meaning within human experiences and actions with the ability to describe aspects in depth as well as to generate or expand existing theories rather than testing theories (Fossey *et al.*, 2002; Le May and Holmes, 2012).

I adopt the epistemological position of interpretivism as it fits with my research aims and concerns. My focus on the distinctive and subjective experiences of older individuals as a means for acquiring knowledge of their life-worlds, correlates with the interpretivist position of multiple interpretations and ways of knowing based on human perceptions and experiences. The choice of the interpretivist epistemology also stems from the assumption that the process of knowing and knowledge is produced, co-created by and emerges from the subjective views and meanings that people attribute to reality.

4.2.2 Ontology

Ontology is the study of "being" (Crotty, 1998) and is concerned with the nature, properties and structure of reality and existence (Snape and Spencer, 2003; Sum and Jessop, 2013; Denzin and Lincoln, 2018). In social research, ontology is concerned with human beings' and more specifically the researcher's relationship with the nature of reality (Creswell, 2007; Denzin and Lincoln, 2018). From a philosophical point of view, this relationship relates to the ontological debate about whether reality exists independently of human consciousness and experience or within our consciousness and through experience (Levers, 2013).

As with epistemology, the Literature identifies a variety of ontological positions that the researcher can adopt. Broadly speaking, the research literature categorises ontology into two basic positions, namely objectivist ontology and relativist ontology – correlating respectively with the epistemological distinction between positivism and non-positivism (Bryman, 2012; Levers, 2013; Denzin and Lincoln, 2018).

4.2.2.1 Objectivism

The objectivist ontological position claims that reality is something existing 'out there', which can be understood and perceived objectively (Crotty, 1998; Denzin and Lincoln, 2018; Lincoln, Lynham and Guba, 2018). This could be considered to hold true for the material world where objects and their attributes can be seen to be universal and exist in the world independently from humans or human interactions. Following this thinking, social phenomena and their meanings would exist independently of social actors and human action, that is they could be seen to be beyond the influence and reach of human consciousness and subjectivity (Bryman, 2012). In view of that, the objectivist ontological position can seek the single, absolute truth that explains the social phenomena (Bryman, 2012; Crotty, 1998). This implies a world structured by the laws of physics or some generic societal laws that can be generalised to all individuals enabling predictions, manipulations, and control of such generalities leading to a valid singular truth, statements and universal theoretical assumptions (Munhall, 1989; Laverty, 2003). Based upon the positivist epistemology, the objectivist ontology has been useful for the natural and applied sciences that focus on the universality, measurability and objectivity of concepts and means for categorising an external, material world.

4.2.2.2 Relativism

Contrary to the objectivist view, the relativist ontological position postulates multiple realities - rather than an objective reality ‘out there’ - that are socially created and can be altered by the knower (Guba, 1992; Laverty, 2003; Levers, 2013). In other words, reality and its meaning is continually created by the perceptions, experiences, and consequent actions of social actors, as the actors engage with the world they are interpreting (Crotty, 1998; Bryman, 2012). Production of social phenomena and categories constitutes a dynamic and fluid process, and the social order is in a constant state of change and revision (Bryman, 2012). From this ontological viewpoint realities are not more or less ‘true’ or ‘valid’; instead they are simply more or less informed while their ‘truths’ are negotiated (Crotty, 1998; Laverty, 2003; Denzin and Lincoln, 2018; Lincoln, Lynham and Guba, 2018). As Levers (2013) notes, from a relativist ontological position, research seeks to understand the subjective experience of reality and its multiple truths that stem from individuals’ various interpretations.

The relativist position seems to be more closely aligned with my personal ontological assumptions, that the nature of reality is reflected and co-created by the subjective experiences and perceptions of human-beings. Moreover, there is an apparent consistency between the relativist premises and the viewpoint adopted in this study, namely that the different personal perceptions and well-being conceptualisations of older individuals living with ABI constitute different and multiple truths of the same phenomenon leading to a dynamic co-creation of meanings in reality, which lends itself to the adoption of a subjectivist ontological perspective.

4.2.3 Epistemological and ontological principles guiding this study

During my professional career as a registered nurse, I have witnessed how personal views and experiences determine individuals' understanding of important health issues and phenomena. Knowing and the production of knowledge was always a synergetic process that stemmed from the subjective views, meanings and constructs attributed to the phenomena. For example, when I was caring for individuals with heart failure, I witnessed how their medication adherence swayed according to their personal experiences of their disease and care. While the majority of individuals were conscious and attentive of their medication schedule, there were a few who were experiencing difficulties in adjusting to the new reality of coming to grips with heart complications, which then disturbed the balance regarding their care and medication schedule. The healthcare staff (including myself) realised the significance of being more attentive to the personal experiences and opinions of individuals' personal well-being. Such attention can improve the skills and knowledge concerning the ways that similar challenges could be addressed more effectively in similar cases. Building on my personal and professional pre-understandings, my philosophical stance accepts the existence of multiple realities and interpretations of health and nursing phenomena, as expressed in the different narratives of individuals regarding their personal experiences and perceptions. Therefore, when considering the exploration of human subjectivity, the positivist epistemological and ontological tradition does not fit the aims of this study, as I do not assume that a unique and objective human reality exists out there, nor that human knowledge and truth can be indisputable, eternal and independent of the space and context within which they are embedded.

I further accept the belief that the researcher's background and personal reality may affect the conduct of the study. In my view, researcher's biases are an inescapable and inseparable part of qualitative research that can contribute to the final discussion, interpretation and explanation of the investigated topic (Mantzoukas, 2005). I also believe that the explicit reflection on my background and the ways I may be biased or affect the study if transparently presented, may reinforce the robustness of my conclusions and trustworthiness of my findings. As particular individuals conduct research, it is hard to imagine these individuals as detached researchers not involved in any way in their research, despite any possible efforts to remain uninvolved and maintain objectivity. The personal voice, perspectives and unique interpretations of the researchers are inevitably and sometimes unconsciously infused into the research. Therefore, the opposite assumption, that any interference or bias on the part of the researcher should be diminished or not considered at all seems contradictory and unattainable. Having in mind the above, the interpretivist and relativist traditions seem to be more congruent with my own epistemological and ontological principles (Figure 4.1).

Figure 4.1 *Epistemological and ontological principles adopted in the study*

Epistemology	**Ontology**
Interpretivism The process of knowing and in-depth understanding stems from the interpretation of subjective views and meanings that individuals attribute to (their) reality. ↓ Subjective experiences of older individuals as a means for understanding their lifeworlds and acquiring knowledge of phenomena.	**Relativism** Multiple realities, truths and interpretations exist, emerging from and co-constructed by the various subjective experiences and perceptions. ↓ The nature of reality is perceived as stemming from their experiences in relation to their well-being and rehabilitation

Researcher's bias – reflexive stance

Researcher's bias is an inescapable and inseparable element of qualitative study that should become part of the research. Its inclusion can secure validity provided that it has been transparently acknowledged.

↓

The researcher reflects on her pre-understandings before the commencement of the study as well as on her research journey after its completion. The methodological and analytical used in this study is also presented and discussed in detail in the thesis.

The current study aims at exploring the experiences of older individuals undergoing ABI rehabilitation as well as their sense of the phenomenon of well-being in order to acquire an in-depth understanding of their lifeworld experiences. Older individuals' experiences and perceptions are placed at the centre of enquiry by perceiving the nature of reality as stemming from the participants' experiences in relation to their well-being and injury rehabilitation.

Therefore, subjective experiences of participants become necessary for exploring the nature of well-being, for producing knowledge about the phenomenon of well-being and for making sense of it. The study will address the research questions and objectives by interpreting the participants' realities, experiences and understandings regarding the phenomenon of well-being when undergoing ABI rehabilitation. Lastly, the intention of the study is not to pursue the acquisition of an accurate and absolute type of knowledge and truth, given that the philosophical assumptions adopted by the researcher as well as the nature of this study's question do not warrant for answering it with absolute terms. Instead, the study will focus on thoroughly understanding and interpreting the participants' experiences and personal realities as these emerge in their particular spatio-temporal context.

4.3 Methodology

Progressing with the research design of the study the methodology used to conduct the study was developed. The methodological aspects of a study guide the research process by setting the rules, principles and procedures that the researcher follows to seek and provide answers to the research question (Bogdan and Taylor 1975; Carter and Little, 2007; Sarantakos, 2013). Essentially, it deals with the description, explanation and justification of the processes that seem to be most appropriate for gathering evidence and analysing the data (Carter and Little, 2007).

When looking at the literature I could identify various research methodologies, with each one adopting a particular research orientation and specific procedures for answering unique research questions (Ellis, 2010; Bryman, 2012). Broadly the variety of research methodology can be distinguished and grouped within two core methodological research approaches or strategies; namely, quantitative research methodology and qualitative research methodology (Creswell, 2009; Ellis, 2010; Bryman, 2012). There are also cases where researchers combine qualitative and quantitative methodologies in a single study to produce a mixed-method methodology (Bryman, 2012).

At first glance, the distinction between qualitative and quantitative research seems to relate exclusively to the different methods and strategies followed in each approach. Nevertheless, more profound differences can be identified between the two approaches as each approach reflects specific epistemological and ontological beliefs (Creswell, 2007; Bryman, 2012). Therefore, the choice of methodological approach is not irrelevant and to a large extent depends on the epistemological and ontological choices already made with regard to the research and the knowledge that the researcher can and wants to reveal, acquire or develop.

4.3.1 Quantitative methodology

Researchers using quantitative methodology focus primarily on collecting and analysing numerical data seeking to answer questions relating to quantifiable and measurable issues or aim at addressing causal relationships between phenomena (Ellis, 2010; Moule and Goodman, 2014). According to Ellis (2010), quantitative methodology can be divided into two broad classifications: the interventional (or experimental) methodology and the observational methodology.

The first focuses on demonstrating and proving cause and effect relationships by measuring the effect that the exposure to a specific parameter or phenomenon (independent variable) has on the participants demonstrating a direct and linked outcome as a result of the exposure (dependent variable). Such studies are usually experimental and include conducting experiments or measurements in controlled environments or situations, with participants most often being randomly sampled (Lindsay, 2007; Glasper and Rees, 2013). For the health sciences, this type of experimental methodology often involves the use of clinical trials and specifically randomised control trials (RCTs) (Glasper and Rees, 2013).

Unlike the experimental studies, quantitative observational methodology in healthcare research explores associations or correlations - rather than a causal relationship - between a natural independent variable and a dependent variable (Ellis, 2010). In essence, this type of methodology seeks to investigate the possible (known or unknown) causes that lead to an outcome without necessarily implying a causal effect relationship (Ellis, 2010). It should be pointed out that there are also forms of observational methodology associated with qualitative research (such as qualitative participant observation), which entail the subjective process of immersing in a social setting to observe, describe and interpret the behaviors and interactions among the members of that setting (Bryman, 2012).

In general terms, the main objective of the quantitative researcher is to develop predictions related to a phenomenon, usually following a deductive logical process. This logical process involves the formulation of a hypothesis to be tested (i.e., confirmed or rejected) through measurement and statistics (Morse and Mitcham, 2002; Bryman, 2012; Tracy, 2013; Moule and Goodman, 2014). Quantitative methodology is primarily used when the researcher aims to produce generalisable results by covering large groups of population and presenting the results in a numerical or statistical fashion (Morse and Mitcham, 2002; Ellis, 2010; Gerish and Lacey, 2010; Moule and Goodman, 2014). Common quantitative methods/ tools for collecting data in nursing research include amongst others: questionnaires, surveys and clinical (physiological) data (Ellis, 2010).

There is a strong link between quantitative methodologies, positivist epistemology and objective ontology. Quantitative research has its roots to the practices of the natural scientific model, and more specifically to the positivist paradigm, in which social reality is perceived as an external, objective reality where human phenomena can be measured and objectively studied (Bryman, 2012; Moule and Goodman, 2014). As such, in quantitative studies the researcher incorporates predominantly positivist practices and perspectives to gain knowledge (Creswell, 2009).

Quantitative methodologies could not be free of various criticisms. More specifically, the researcher's intervention and the control of situations to identify causal relationships (usually the case in experimental methodologies) can create a one-dimensional representation of social life. This static view may not correspond precisely to people's everyday life and could also hinder the application of research outcomes in real situations (Lindsay, 2007; Bryman, 2012). Criticism has also been levelled at how quantitative methods depend heavily on standardised research instruments (such as structured interviews and self-completion questionnaires), limiting how subjects relate their input in the research to their daily lives (Bryman, 2012).

4.3.2 Qualitative methodology

Qualitative methodology is associated with methods of enquiry that focus on people’s perspectives, opinions and feelings, with the aim of describing and understanding in depth the different and unique experiences and perceptions of individuals (Ellis, 2010;

Holloway and Wheeler, 2010). Qualitative research differs from quantitative in the way it approaches research questions. It deals with the nature and quality of human experience and social processes, and more generally, with issues that cannot be easily measured or quantified (Ellis, 2010; Tracy, 2013). As a result, qualitative research is usually concerned with broad and open research questions. Qualitative researchers try to reach out to the people or social processes they are investigating to obtain and explore the participants' insider perspectives and social views (Ellis, 2010).

According to the Literature, an additional feature of qualitative approaches is its emphasis on inductive reasoning (Ellis, 2010; Bryman, 2012; Tracy, 2013). Unlike quantitative research, where the focus is on proof and theory testing, qualitative researchers allow the collected data to lead them to understand the phenomenon or process under investigation, and in many cases to the production of generalised knowledge and theories (Bryman, 2012). Nevertheless, qualitative methodology can work with both deductive and inductive approaches. Therefore, qualitative researchers may use established theoretical models as guides during the analysis and interpretation of data or even review general theories during the discussion of their findings to see how their emerging results could complement or reformulate existing ideas (Tracy, 2013).

The process of data collection in the context of qualitative methodology requires the researcher's in-depth commitment. In contrast to quantitative methodology, where the research instrument and the researcher constitute two separate and different entities, qualitative researchers themselves are seen as instruments of data collection (Ellis, 2010; Tracy, 2013). In other words, they are not viewed as someone who controls data collection instruments but as an inseparable and integral part of the data collection process. Overall, qualitative research emphasises verbal data over quantification during data collection and analysis (Bryman, 2012). Key tools for collecting quality data in nursing research include semi-structured or unstructured interviews, focus groups, participant observation, and analysis of records.

While each qualitative methodological type is rooted in different philosophical and academic disciplines, the general philosophy and epistemology that permeates qualitative methodology remains the same: the nature of reality is viewed as both subjective and multiple (Ellis, 2010). Qualitative methodology rejects the practices and rules of the natural scientific model and positivism, as they take the view that social reality is constructed by individuals' interpretations of what is around them (Bryman, 2012). For qualitative researchers, reality constitutes an ever-changing and emerging construct as it is subject to personal interpretation and thus differs significantly from person to person (Glesne, 1999; Ellis, 2010; Bryman, 2012). Therefore, in qualitative studies researchers often focus on constructivist or interpretivist perspectives (Creswell, 2009).

Qualitative methodology has been the subject of various criticisms. First of all, the subjective nature of the qualitative findings makes it difficult for the research to be reproduced and for its findings to be generalised, as the views, attitudes, ideals and beliefs of the people studied are inextricably linked to the context of the research (Ellis, 2010). In response, qualitative researchers argue that the purpose of their research is not to produce generalisable findings. Instead, they intend to produce what Popay, Rogers and Williams (1998) call logical generalisations, through careful consideration and in-depth exploration that can be relevant to similar situations and contexts and build theory and knowledge that can have a practical impact (Ellis, 2010). Qualitative research has also been criticised for lack of scientific rigour and reliability, as the relevant procedures can be heavily influenced by the values and beliefs of the researcher while often making it difficult to avoid bias in data collection (Ellis, 2010). From their side, qualitative researchers support that rigour can be achieved by being self-reflective, namely by making explicit and transparent all the aspects of the research process as well as their own positionings, interests and possible biases (Popay, Rogers and Williams, 1998; Tracy 2013; Wodak and Meyer, 2015).

4.3.2.1 Qualitative methodologies

Qualitative methodology can be categorised in many ways with each one addressing specific types of enquiry and research issues and rooted in specific academic and philosophical territories. Some of the most common qualitative methodologies used in social and health sciences include grounded theory, ethnography and phenomenology.

The ethnographic methodology aims to examine social groups or communities by describing and understanding the group's culture, namely the rules of behaviours, norms, beliefs, and meanings shared within the group (Ellis, 2010; Petty, Thomson and Stew, 2012; Glasper and Rees, 2013). The origins of this type of methodology can be traced to the discipline of anthropology (Ellis, 2010). In ethnography, the researcher seeks the views and perspectives of group members (the emic perspectives) about the culture of the group being studied (Ellis, 2010). The ethnographer usually engages in direct participant observation for collecting data, including additional clarifying field interviews (Tracy, 2013). Tradtionally, researchers who use ethnography tend to immerse themselves into the cultures under investigation, living among the cultural members and becoming part of the group for months or even years (Ellis, 2010; Petty, Thomson and Stew, 2012; Glasper and Rees, 2013; Tracy, 2013).

Grounded theory constitutes a qualitative methodology that has been closely associated with the discipline of sociology (Ellis, 2010). Developed by Glaser and Strauss (1967), grounded theory tries to create new, or expand upon existing ‘theories’ or explanations for and about social processes and human activities (Bryman, 2012; Ellis, 2010; Tracy, 2013). Strauss and Corbin (1998, p. 12) explain the grounded theory approach as “theory derived from data, systematically gathered and analysed through the research process”. The ensuing theory then is closely interrelated with the processes of data collection and analysis (Bowen, 2006). The researcher using grounded theory applies a systematic inductive analytical approach to explore individuals’ perceptions and interpretations of social processes and interactions through interviews, observations and documents, with the aim to develop or discover a theory that explains the phenomena under investigation (Ellis, 2010; Petty, Thomson and Stew, 2012; Glasper and Rees, 2013; Tracy, 2013).

Lastly, the phenomenological methodology refers to the study of specific phenomena as experienced from individuals’ first-person point of view (Smith, 2009). Essentially, the researcher seeks to obtain and understand individuals’ subjective point of view about the phenomenon under investigation by focusing on individuals’ unique conscious perceptions and experiences on the phenomenon – as this appears to them (Langdridge, 2007; Smith, 2009; Petty, Thomson and Stew, 2012). The Literature further distinguishes between two phenomenological methodological approaches, namely: (a) the descriptive or transcendental phenomenology and (b) the interpretive or hermeneutic phenomenology (Petty, Thomson and Stew, 2012; Sloan and Bowe, 2014).

Qualitative research is closely associated with interpretivist epistemology and relativist ontology. It recognises the subjective, experiential lifeworld of individuals and allows for rich data and extensive knowledge to be generated, leading to an in-depth description and investigation of individuals’ perspectives. As a result, this study considers qualitative research and specifically the phenomenological approach to be the most appropriate methodology for exploring in depth the lived experiences of care and sense of well-being of older individuals who live with ABI and undergo physical rehabilitation within formal care systems in Greece.

The following section expands on the philosophical movement of phenomenology and its methodological extensions, explaining which type of phenomenological methodology will be followed in this study.

4.3.3 Phenomenology

Phenomenology emerged as a significant philosophical movement in Germany in the early 20th century. The term derives from the ancient Greek phenomenon, which comes from the verb *φαίνεσθαι* (phaínesthai), meaning to show itself, to appear and *λόγος* (logos), meaning discourse (Moustakas, 1994). As its etymology implies, phenomenology is a discipline concerned with phenomena, that is, with the things themselves, as these appear to us in our immediate lived experience (van Manen, 1990). Rooted in philosophy and psychology, phenomenology is a qualitative research approach which explores the experience of those living a particular phenomenon, leading the researcher to gain a full and deep understanding of the experience as conveyed by the person living the experience first-hand (Seidman, 2006; Creswell, 2007; Sloan and Bowe, 2014). A main goal of phenomenological research is obtaining complex, vivid descriptions of a human experience as it was lived in the context of time, space, and relationships (van Manen, 1990; Finlay, 2009).

As mentioned above, there are two main approaches to phenomenology. Historically the first approach was the descriptive or transcendental phenomenology developed by Edmund Husserl, often referred to as the father of phenomenology (Polkinghorne, 1983; Cohen, 1987; Scruton, 1995; Koch, 1996; Spinelli, 2005). The second approach is the interpretive or hermeneutic phenomenology developed by Martin Heidegger (Laverty 2003; Langdridge 2007; Connelly 2010). Although both approaches share the same goal of exploring the lived experiences of individuals, they have many philosophical and epistemological differences (Dahlberg, 2006; McConnell-Henry, Chapman and Francis, 2009).

4.3.3.1 Descriptive/ Transcendental phenomenology

Edmund Husserl developed the descriptive or transcendental phenomenology as an alternative to the extensive use of natural scientific methods to study human experiences (Velarde-Mayol, 2000). His purpose was to design a science focused on phenomena by explaining how objects are experienced and appear as themselves in human consciousness (Spinelli, 2005). He focused more on the epistemological considerations of phenomenology. More specifically, he supported the principle of *intentionality*, that knowledge stems from the internal experience of being consciously aware of objects; in other words, every mental practice is directed towards some entity (Moran, 2000; Crowell, 2005; Moran and Cohen, 2012). Overall, the purpose of descriptive phenomenology is to identify and describe "the things themselves" by focusing on the essence of a phenomenon (the 'what') in correlation to its "how it is experienced" (Smith, Flowers and Larkin, 2009; Sloan and Bowe, 2014).

A key aspect of Husserl's work was developing the concept of *lifeworld* (*Lebenswelt*) (Langdridge 2007; Smith, Flowers and Larkin, 2009). Husserl described lifeworld as the "world of immediate experience", the "pregiven" world that is "already there" (Adams and van Manen, 2008, p. 618). Descriptive phenomenology asserts that the lifeworld is understood pre-reflectively as experienced in the primaeval "natural attitude", without resorting to any kind of explanations or interpretations (Husserl, 1936/1970; Husserl, 1999; Caelli, 2000). This can be achieved by applying what Husserl called the phenomenological *epoché* or *bracketing.* Essentially, this process enables the researcher to put aside all preconceived ideas about the world or the phenomenon being studied to understand and describe the essential features of a phenomenon as free as possible from the historical and cultural context (Dowling, 2007; Finlay, 2009; Moran 2012; Sloan and Bowe, 2014). Husserl believed that true understanding of a phenomenon was obtained only when bracketing was performed. This process is hard to take place as it is almost impossible for researchers to discard their feelings or their prior knowledge of a phenomenon or experience. However, as Ellis (2010) points out, most phenomenological researchers reflect on their own preconceptions about the phenomenon under investigation before collecting and analysing their data.

4.3.3.2 Interpretive/ Hermeneutic phenomenology

Interpretive/ hermeneutic phenomenology derives from the philosophy of Heidegger and strives to understand the meaning of being in the world (Ironside, 2005). While Heidegger's approach also looks at the lifeworld or human experience, it differs from Husserl's in that it incorporates the use of hermeneutics and interpretation in the exploration of the subjective nature of human existence (Dahlberg, 2006; Dowling, 2007; McConnell-Henry, Chapman and Francis, 2009). Hermeneutical phenomenology relies on both interpretation and description of the lived experience. As van Manen (1990) explains:

> "It is a descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena."
>
> (Van Manen, 1990, p. 180).

In his approach, Heidegger shifts the focus of phenomenological research from epistemology to ontology. His method endorses the notion of *'Dasein'*, which can be translated as 'being in the world', 'the mode of being human' or 'the situated meaning of a human in the world' (Laverty, 2003). According to Heidegger's approach, people by nature are beings that interpret and our interpretations of our life (what we see, feel and experience) shape human existence and experiences (Parahoo, 2014). In other words, the hermeneutic phenomenology asserts that knowledge and the experiences of individuals derive from their interpretations of their lifeworld (Dahlberg, 2006; McConnell-Henry, Chapman and Francis, 2009). In Heidegger's (1962) view, consciousness is intertwined with the world and thus lived experiences are historically and culturally defined. Therefore, for Heidegger individuals cannot discard or step outside of their interpretations of lived experiences as our understandings and pre-understandings are integral parts of being in the world and define human existence (Polkinghorne, 1983; Laverty, 2003).

The purpose of hermeneutic phenomenology is to grasp and interpret individuals' perspectives on their lived experiences about the phenomenon being studied by paying attention to the interrelation of lived experiences with the social and cultural context (Ellis, 2010). In other words, Heidegger brings to phenomenology the importance of context. He asserts that historical context – our background, values, and beliefs –lends additional understanding to the present and future. Thus, researchers adopting a hermeneutic phenomenological approach are further encouraged to import in their study their previous assumptions and knowledge to explore the lived experiences of participants and interpret the research phenomenon (Dahlberg, 2006; McConnell-Henry, Chapman and Francis, 2009).

Given the epistemological (interpretivist) and ontological (relativist) principles that guide the current study, the interpretive/ hermeneutic phenomenological approach is considered to be the most appropriate methodology for exploring, understanding and interpreting older individuals' lived experiences of ABI rehabilitation and their sense of well-being when undergoing physical rehabilitation. More specifically, the interpretivist and relativist stance adopted in this study aligns with the interpretive/ hermeneutic phenomenological approach in that both subscribe more or less to an inductive methodological logic by means of hermeneutically exploring and depicting (as accurately as possible) the individual experiences with the aim of reaching and generating a synthesised description and interpretation of the phenomenon under investigation. The particular attention to interpretation and to individual perceptions and experiences renders this methodology the right one for answering the research question and objectives of this study. In addition, this study recognises that the previous knowledge obtained from the systematic literature review conducted on the topic will (and should) have an effect on the research process. Interpretive/ hermeneutic phenomenology is congruent to this assumption as it enables the researcher to engage with the topic under investigation in a great deal of depth, while embracing their own preconceptions, personal opinions and previous knowledge during the data analysis and interpretation of the findings (Ellis, 2010).

4.4 Interviews

4.4.1 Interview types

Within qualitative research interviews have become the most common form of data collection (Holloway and Wheeler, 2010). Phenomenological research studies using interviews aim to gain an in-depth understanding of participants' perspectives, experiences, feelings, and perceptions in relation to a specific phenomenon decided by the research question (Marshall and Rossman, 2006; Silverman, 2006; Ellis, 2010). Interviews can be categorised as structured, semi-structured and unstructured (Holloway and Wheeler, 2010). Generally, qualitative studies employ the unstructured or semi-structured types of interviews.

Qualitative researchers usually do not conduct structured interviews as this contradicts the overall aim of qualitative research that is to explore in more depth the participants views, opinions and feelings (Holloway and Wheeler, 2010). This kind of interview process has the potential to allow the researcher to keep the participant focused on the topic under investigation with specific, standardised questions. However, this type of pre-planned interview directs the informants' responses and does not allow their way of seeing the world to be captured. Structured interviews also do not give the option to the researcher to participate and interact with the interviewees to unveil important elements of their experiences doing follow-up questions (Holloway and Wheeler, 2010). Consequently, the current research study does not follow the particular type on interview as the researcher will not be able to generate or ask further questions during the interview in order to reveal more information and thus fully understand the experiences of older individuals living with ABI.

In unstructured interviews there are no predetermined questions. Only at the very beginning of the interview, the interviewer typically has only an agenda or a list of general topics that will be covered (Bryman, 2012). However, researcher's direction and control of the interview is minimal as there is only a general question in which the participant develop his/ her answer (Holloway and Wheeler, 2010). Because of its open nature it seems that this type of interview can offer the richest data but at the same time can give a high amount of data material that are not useful for the research especially when the interviewer has no experience (Holloway and Wheeler, 2010). This study does not employ this type of interview as there is a risk of missing important aspects of rehabilitation experiences and well-being conceptualisations in case participants get distracted and focus on other, not relevant aspects – which may result in not addressing the research question of the study.

Lastly, qualitative research and more specifically, phenomenological studies often employ semi-structured interviews. The questions are contained in an interview guide with a focus on the issues or topic areas to be covered and the lines of inquiry to be followed (Holloway and Wheeler, 2010). This type of interview process offers flexibility to the researcher to explore the issues that are of importance by doing follow-up questions (Ellis, 2010). Semi-structured interviews fit better with the aims of phenomenological research, that is to explore the meaning of an experience for the participant (Ellis, 2010). Due to the phenomenological approach that this study follows, the semi-structured interview method is employed as it allows the researcher to uncover new important aspects of the phenomenon through the flexibility of questions and the interaction with the participants (Ellis, 2010; Holloway and Wheeler, 2010; Seidman, 2006). For example, follow-up/ probing questions such as “How do you feel about this?” or “Can you tell me more about that?” were used to explore more thoroughly the meaning of individuals’ lived experiences. This method of data collection provided the critical information necessary to better comprehend the phenomenon and address the research questions.

4.4.1.1 Interview questions

The initial development of the interview guide was influenced by various factors such as

a) The findings of the systematic literature review.

The published systematic literature review conducted for the purposes of this research, revealed the need to explore the factors that affect older individuals' emotional condition and their sense of well-being. Furthermore, it points towards further research on participants’ perspectives about how dignified care for older individuals living with ABI can be achieved or enhanced within formalised healthcare systems.

b) The phenomenological tradition followed in this study.

The hermeneutic phenomenological approach influenced the way interview questions were shaped in seeking out the meaning in the participants’ lived experiences (Creswell, 2007). Phenomenological interviews need to acquire rich descriptions of the lifeworld of the participants, and subsequently interpret these descriptions into meaningful experiences (Seidman, 2006; Brinkmann, 2013). Therefore, the interview guide includes questions that provide the space to the participants to explain their experiences related to their ABI rehabilitation and their sense of well-being.

The literature further considers that the way the interview questions are sequenced as well as how the process commences, constitute important factors for achieving a successful semi-structured interview (Price, 2002; Creswell, 2007; Bryman, 2012; Rubin and Rubin, 2012). Drawing on the relevant literature concerning the ordering and sequencing of the interview questions, this study followed the laddered question technique, as presented by Price (2002), whereby the interview starts with the least invasive questions and proceeds to deeper and more invasive topics.

The least invasive questions, which the interview starts with, are those that invite participants to describe actions and events, by focusing on 'what' or 'how' the interviewee has done something or what their opinion is (Price, 2002). In general, with these description or action questions the researcher can gather contextual and historical information of actions while also helping to set up the scene for the deeper questions that will follow (Price 2002). In this way the interviewer can show to that they are indeed interested in what the interviewee has been doing, thus helping the interviewee to relax, open and feel more comfortable (Price, 2002).

The interview then progresses to knowledge questions which relate to more invasive matters. Knowledge questions usually take the form of "what do you know?" or "what do you think" thus asking the interviewees to provide details of their experiences and actions and also to ask them to consider the reasons behind their actions (Price, 2002).

Lastly, following the knowledge questions and after making sure that the interviewee feels comfortable, even more in-depth questions are employed which pertain to the personal philosophy of the participants, that is their personal values, beliefs, motives and feelings (Price, 2002). These personal philosophy questions focus on deeper matters such as what meaning does the interviewee attribute to their experiences, how these experiences feel, or how the present experiences link with past and future experiences (Price, 2002).

Following this format, the interview guide of this study developed a core set of description/ action, knowledge and personal philosophy questions and topics for exploration:

a) The first group of description/ action questions were used to gather information of each interviewee's contextual and historical background regarding their ABI rehabilitation process but also to ease up the interview process and prepare the ground for the more invasive questions.

b) The second group of knowledge questions were used to understand in greater detail what they think about the process of ABI rehabilitation, what they think of their lived experiences with ABI, what sense do interviewees make about the concept of well-being, and what are their thoughts about the participation of their family in their rehabilitation.

c) The third group of personal philosophy questions were employed to explore and understand more thoroughly the interviewees' sense of well-being, their personal beliefs about their lives before and after the ABI diagnosis, and what sense they make of potential changes due to ABI or about any future plans after their rehabilitation.

d) All interviews ended with a more open question to allow the participants to expand on their views or express any additional thoughts that they might have. Finally, each interview ended with a brief informal discussion to ensure that participants were comfortable and were not left feeling sad due to topics covered in the interview.

Moreover, each question also corresponded to one or more objectives of the study (see Appendix E). The interview guide format was finalised after the piloting phase. It should be noted, however, that even after the piloting phase the interview questions were being developed and modified as the data collection was progressing and as the researcher was exposed to new material and knowledge. For example, some additional issues were raised by some of the initial participants, which were then incorporated in the questions of later interviews. Therefore, the researcher tried to be well prepared before each interview by checking the content of previous interviews and by taking into account the profile of each participant (e.g. their specific ABI condition). Taking into consideration the piloting phase and the particularity of each interview it was ensured that there were clear connections between each question and that their order would make the discussion flow smoothly - making it easy for the interviewees to participate (Price, 2002; Seidman, 2006; Bryman, 2012).

4.4.2 Pilot study: Reflections and finalisation of the interview guide before the interviews

Pilot interviews can be significant in identifying problems with the overall interview process; for example, through the pilot interviews the researcher can determine the adequacy of information provided to the participants (Bryman, 2012; Yin, 2011). Problems regarding the interview questions can also be identified and handled appropriately, such as questions that could make participants feel uncomfortable, or questions that cannot be easily understood by the respondents (Bryman, 2012).

The purpose of conducting pilot interviews was to ensure that the research instrument of interviewing functions and flows well as a whole (Bryman, 2012). Specifically, through the pilot interviews I sought to practice and test the interview guide and questions and to refine aspects of their design and of the fieldwork procedures in general (Yin, 2011). Piloting the interview guide also provided me with some experience while also giving more confidence of using it (Bryman, 2012).

The pilot phase involved practicing the interview questions with two older individuals. Both pilot interviews were conducted at the rehabilitation clinic. The participants were interviewed about their rehabilitation experiences - following verbal and written consent from them. The interviews were then utilised for assessing whether the interview design operated well in acquiring the information required and also for identifying any potential problems of the interview guide and specifically on the questions content and the way these were asked by the researcher.

The first issue identified after the piloting of the study, was that the participants were not familiar with the process of scientific research, nor were very much aware about the purpose of the interview. At this point, I noticed that the information provided about the aim and the value of the study should be presented in a clearer and simpler manner, in an easily understood language without much technical and scientific jargon.

Secondly, I realised that while the laddered technique of sequencing the questions was quite useful and helpful making the participant feel comfortable during the interview, it was not very efficient in maintaining a smooth flow as some topics were repeated. Therefore, I reconsidered the order of questions, by modifying the sequence based on the topics that the questions were referring to (see Appendix F). This however did not substantially change the main structure of the laddered sequence: the interview process was still commencing with less invasive questions, whereas the deeper and more philosophical questions were asked towards the end of the discussion.

4.4.3 Sampling and recruitment of participants

4.4.3.1 Sampling strategy

The sampling strategy refers to the process of selecting participants who would provide rich data for the analysis of the phenomenon of interest (Polit and Beck, 2017). In qualitative research, all researchers are encouraged to sample deliberately, since the data and their research question complement each other (Tracy, 2013). Among the many different sampling types those that are mostly used in qualitative designs are: a) purposive sampling, b) convenience sampling c) theoretical sampling and d) snowball sampling (Creswell, 2007; Ellis, 2010; Polit and Beck 2017).

The sampling method most often used in phenomenological research is purposive (Ellis, 2010). The aim of purposive sampling is to select participants who have experienced the phenomenon of interest, be in a specific (health) condition or a type of care (Ellis, 2010; Holloway and Wheeler, 2010) and can share their experience of that phenomenon with the researcher. Grounded theory researchers start with purposive sampling and then move on to theoretical sampling by selecting participants based on the emerging findings, and who can best contribute to the developing theory (Moser and Korstjens, 2018). Convenience samples are most appropriate when the priorities are speed and low cost and can be often applied in content analysis (Tracy, 2013; Moser and Korstjens, 2018). Lastly, snowball is a sampling technique in which the researcher recruits initially a small group of people relevant to the research question, and these sampled participants propose others who have had the experience or characteristics relevant to the research. The snowball sampling technique is used in studies where researchers cannot identify useful informants or where informants are not easily accessible (Holloway and Wheeler, 2010; Bryman, 2012).

The current phenomenological study recruited participants by employing a purposive sampling strategy. The study participants were selected according to their specific characteristics, knowledge and lived experiences, and because these experiences are relevant to the topic under investigation. At the same time, some specific criteria for excluding individuals from the sample were also defined to assist the sampling process. The inclusion and exclusion criteria for participation in the study are specified in Table 4.1:

Table 4.1 *Inclusion and exclusion criteria for participation in the study*

Inclusion criteria	Exclusion criteria
• Individuals are 65 years or older and have been diagnosed with some type of ABI. • They are able to make the decision to take part in the study by giving their informed consent to participate in the research. • They are able to take part in an interview and effectively communicate with the researcher. This means that they can articulate meaningful and logical sentences and there is a minimum level of speech clarity. For example, participants who may suffer from dysarthria or cluttering (because of ABI) but their speech can be understood and followed would be included. • They are or had been receiving rehabilitation from a formalised healthcare setting within the regional unit of Epirus, in north Greece after an acquired brain injury. • They have started their rehabilitation at least one month before the interview. Being in rehabilitation less than a month would not be enough for individuals to adequately formulate their rehabilitation experience.	• Participants were excluded if they had severe cognitive difficulties which would preclude an interview. This was assessed by consulting the doctors and nurses who were caring the individuals. • Individuals who had received physical rehabilitation services more than once and for another health reason were also excluded from the sample, as this would alter their initial ABI rehabilitation experiences.

The setting of the current research is a formalised rehabilitation clinic in the regional unit of Epirus, in northern Greece. The particular clinic is one of the few organised sites operating outside Athens that provides vital formalised rehabilitation services to patients.

The decision to conduct research in a healthcare setting outside the main urban areas - namely, the municipalities of Athens and Thessaloniki in Greece, the former being the capital of the country and the latter being the second biggest city- has been affected by the fact that rural areas have limited and underdeveloped healthcare services provision especially for the elderly population (World Bank, 2020). As regards the focus of research on the region of Epirus, this was based on the fact that the region scores high on the elderly dependency rate (35-40%), while also having the most aged population in Greece - having the highest average age of residents (44,2 years) (Hellenic Statistical Authority, 2014; OECD, 2020). This renders the specific case study an ideal one especially for looking at the rehabilitation services that take place within Greek formalised healthcare settings from the perspective of older individuals.

To gain access to the setting the researcher had an initial meeting with the unit's nurse in charge as well as with other health professionals to inform them about the aim and the possible future impact of the research study. The researcher also shared with healthcare staff two posters (see Appendix G) and the information sheet of the project (see Appendix H) to attract the interest of potential participants. Furthermore, the head of the unit of the department who is also one of the supervisors of this research, acted as a gatekeeper by notifying potential participants in person about the research using the information sheet provided by the researcher. The researcher was then informed by the head of the unit about the individuals who were interested in participating in the research. Finally, the individuals who were interested in participating were contacted (by telephone) to arrange an appointment for the interview.

4.4.3.2 Sample size

In qualitative research, there is no specific agreement on what an ideal sample size of a qualitative study should be. The size of the sample depends each time on the research question and aims of the study (Kvale and Brinkmann, 2009). The aim in phenomenological research is not statistical representativeness but instead the chance to look in detail at the lived experiences of the selected individuals, the number of participants. Various authors have discussed a range of different sample sizes in phenomenological studies without agreeing on an ideal one. More specifically, Thomas and Pollio (2002) indicate that an optimal sample size for phenomenological research can range from 6 to 12 participants, claiming that after the 6 interviews there will be a thematic repetition. Depending on the depth and complexity of the analysis, Creswell (2007) proposes a wider range, from 5 to 25 participants, whereas Boyd (2001) prescribes a more flexible range of 2 to 10. According to Brinkmann (2013), as a general principle qualitative research studies tend to have 15 participants, a number that allows a more practical handling of the data.

For determining whether the size of the sample - and therefore the data - will be as sufficient as possible the researcher has to consider a number of criteria. The exact number of the research sample depends on available funding and resources, time restrictions as well as access to participants (Kvale and Brinkmann, 2009; Seidman, 2006; Ellis, 2010;). Another important element for defining the appropriateness of the sample size is the concept of data saturation. Met as theoretical saturation, the term was originally pioneered within grounded theory to designate that categories are fully accounted for, the variability between them is explained and the relationships between them are tested and validated, and thus a theory can emerge (Glaser and Strauss, 1967; Green and Thorogood, 2004; Morse, 2015).

Nevertheless, in qualitative studies, the concept of data saturation usually denotes the point where the researcher achieves a comprehensive understanding of data. In this broader sense, it is used to refer to the point where adding new data does not improve the interpretation of the topic at hand, nor does it produce new relevant information and knowledge about the phenomena under investigation (Fusch and Ness, 2015; Morse *et al.*, 2014). This happens when the same (or similar) themes and meanings arise, or when data repeats itself in the already collected interviews (Edwards and Holland, 2013; Richards and Morse, 2013).

Specifically, in the phenomenological research, the sample size depends on the criterion of informational redundancy, by which sampling reaches to an end when no new themes or insights are emerging by gathering more units (Lincoln and Guba, 1985). Sim *et al.* (2018, p. 8) posit that “in the phenomenological approach, the effect on sample size is mediated through the richness of the data obtained from an individual informant”. Thus, a saturation of meaning is achieved when rich data information has been gathered and can adequately answer the research question (Hennink *et al.*, 207; Hennink, Kaiser and Weber, 2019). In the current phenomenological research, an accurate sample size could not be established beforehand as this is contingent on achieving data/ meaning saturation (Ellis, 2010; Dahlberg, 2011). Instead, the ideal sample size was decided by assessing the data from the interviews as the study was progressing and ending the interview process when rich data had been achieved. This became apparent when same viewpoints and meanings kept coming back from the respondents. At that stage the data gained from the interviews were deemed adequate and useful for addressing the research as it became evident that no new meanings would be gained from potentially more interviews.

Initially, in this study a range of 10-15 interviews were expected to provide rich data, having in mind the possibility of requiring additional participants to enable deep rich descriptions to answer the research question. As described above, the current study commenced with two pilot interviews to check the appropriateness of the interview schedule, and after a few minor amendments on the topics of the questions, the researcher carried out the interviews. The first pilot interview was included in the research, as the participant met all the inclusion criteria and the interview worked well and was quite successful. However, in the second one the participant did not meet the inclusion criterion of being diagnosed with an ABI type and so it was excluded from the research.

After the completion of the twelfth interview, it was felt that the research question was almost addressed, so two more interviews were conducted to confirm that no new themes or new understandings could emerge. It was then observed that no additional interviews were needed, as the knowledge gathered from the available data so far provided a complex and deep understanding of the phenomenon. Overall, the sample size of the current research study was 14 participants in total.

4.4.4 Conducting the interviews

The researcher in the current study conducted in total 14 semi-structured interviews with older individuals living with ABI. The interviews took place in the rehabilitation clinic (n=1), the researcher's office (n=2), or the participants' home (n=11). As the interview venue may affect the interview process and data collection it was very important to find a setting that would be convenient and comfortable - as well as free from any potential disruptions - for both the participants and the interviewer (Holloway and Wheeler, 2010; McGrath, Palmgren and Liljedahl, 2019). Initially, the researcher tried to carry out the interviews at the rehabilitation unit. Due to the noisy and busy environment (or sometimes the tiredness of the participants because of earlier treatment appointments), the researcher decided that this was not a suitable location for the interviews to be held. Thus, participants were orally offered the option of arranging an interview appointment either at the researcher's office or at their homeplace for their convenience. These two options provided a quieter venue for interviewing participants, while also facilitating the interview process especially for individuals who had mobility difficulties.

The researcher's office was also easily accessible for those participants who did not wish to be interviewed at their homeplace but were still experiencing mobility issues, as it was located near the main entrance of the building, on the ground floor. Moreover, participants were more time flexible when interviewed at the researcher's office as they had not any other treatment appointment before or after the interview and as such they felt more "open" to talk about their stories and their rehabilitation experiences. Lastly, it was observed that the interviews which took place at participants' homes created not only a comfort place for the interview process but also were felt as a safe place for the participants. Nevertheless, sometimes it was felt that the office environment was more appropriate in terms of not having any interruptions from family members which occurred in many instances at participants' homes.

In addition, there were many times that the researcher had to travel, as many participants were in remote rural areas. This brought additional challenges to the researcher, such as fatigue and time pressure due to the long trips. Nevertheless, the researcher was well prepared beforehand as she was already aware of these practical considerations.

All interviews were conducted face to face and were audio recorded in two devices (as a back-up strategy). Audio recording of interviews is highly important as they contain the exact utterances (along with the specific tone and volume of the words) of the interviewees, thus helping the researcher to gather all the important answers, phrases and words as these were precisely expressed by the participants (Edwards and Holland, 2013). At the same time, audio-recording enables the researcher to maintain eye contact and pay attention to what participants say during the interview, instead of spending time on keeping handwriting notes (Holloway and Wheeler, 2010; Edwards and Holland, 2013). Prior to each interview, the researcher was informing the participants that the interview will be recorded (as also stated in the consent form).

In regard to the length of the interviews this can be influenced by various factors, such as the participants disposition, the topic under investigation and the methodological approach. It is helpful for the researcher to suggest an approximate amount of time to inform the participants, but this also depends on factors such as the age of the participants or the health condition (Holloway and Wheeler, 2010). In addition, because of the reflective character of the phenomenological interviews, the participants may become tired as they uncover their feelings (Holloway and Wheeler, 2010). Hence, the researcher may not be able to continue the interview process for too long. As the current study recruited older individuals, the length of the interview ranged from 35 minutes to one hour as the majority felt tired while others were emotionally charged.

Overall, the whole process of approaching, getting access and interviewing the participants was easier than it was expected given the constraining condition of the COVID-19 pandemic. Moreover, all the participants were happy and willing to contribute to this research. This was a positive development throughout the interview process and greatly facilitated the conduct of the research. The data collection process lasted approximately five months (early July 2021 – early December 2021). The two pilot interviews were conducted in July 2021 and the rest of the interviews were carried out from the 22nd of September until the 6th of December 2021. During August no interviews were conducted as many participants were unavailable due to the summer period. The final list of interviews that were carried out in this study is presented in table 4.2. The participants are pseudonymised to preserve their anonymity. The table also includes the age and gender of the participants, the setting of the interview and the ABI condition for which have received rehabilitation, the date of their first diagnosis and the duration of their inpatient rehabilitation.

Table 4.2 *Number of the interviews conducted and sample characteristics*

#	*Name*	*Age*	*Gender*	*ABI type*	*Setting*	*Rehabilitation*	*1st Diagnosis*
1.	P1 (Pilot interview)	73	Female	Ischemic stroke	Rehabilitation clinic	2 months in rehabilitation clinic	2021
2.	P2	75	Female	Ischemic stroke	Researcher's office	1½ months in rehabilitation clinic	2014
3.	P3	73	Male	Haemorrhagic stroke	Participant's home	1½ months in rehabilitation clinic	2021
4.	P4	73	Female	Stroke	Participant's home	2 months in rehabilitation clinic	2011
5.	P5	67	Male	Stroke	Participant's home	2 months in rehabilitation clinic	2019
6.	P6	72	Male	Stroke	Participant's home	2½ months in rehabilitation clinic	2019
7.	P7	79	Male	Ischemic Stroke	Participant's home	1½ months in rehabilitation clinic	2010
8.	P8	75	Male	Haemorrhagic stroke	Participant's home	4½ months in rehabilitation clinic	2012
9.	P9	70	Male	Stroke	Participant's home	5 months in rehabilitation clinic	2014
10.	P10	68	Male	Haemorrhagic stroke	Researcher's office	1 month in rehabilitation clinic	2011
11.	P11	85	Female	Stroke	Participant's home	3½ months in rehabilitation clinic	2017
12.	P12	84	Female	Stroke	Participant's home	1½ months in rehabilitation clinic	2019
13.	P13	71	Male	TBI	Participant's home	1 month in rehabilitation clinic	2021
14.	P14	68	Male	TBI	Participant's home	2 months in rehabilitation clinic	2020

4.5 Research ethics

Before data collection started, the researcher ensured that all the accepted principles of ethical and professional conduct and the requirements for obtaining data in a safe and secure manner had been followed and ensured. After submitting the proposed research protocol which described in detail the research design and ethical principles of the study to each interested party; ethical approval was granted from the University of Ioannina, the Ethical Scrutiny and Advisory Board of the INNOVATEDIGNITY project and the healthcare setting where the participants came from (Appendix I). The measures taken for ensuring that this study has successfully met the ethical standards for conducting research are described in detail below.

With regards to the strategies for accessing and registering volunteer participants, I firstly sought permission and approval from the managers of the clinic where potential participants could be recruited. Once their permission was granted, I made an open invitation to potential participants (in line with the inclusion criteria mentioned in Table 4.1) through the use of posters that were displayed on the walls of the rehabilitation clinic. The participants were approached with respect and discretion. In particular, I made an initial contact with anyone interested in participating, during which I briefed them about the study and answered any questions they had.

The study adhered to the nursing research principles identified by NMBI (2015), that is by considering each one of the participants as an independent individual, able to make informed decisions of participating in the research. Nevertheless, considering the potential difficulties and vulnerabilities that the specific sample of this study's participants may had been experiencing due to their ABI condition, I also sought the consent from the head of the unit (who is also a healthcare professional) as to whether each participant fulfills the following inclusion criteria (see Appendix J):

- they are mentally healthy,
- they are able to make autonomous decisions, and
- they are able to communicate effectively.

Those who met the inclusion criteria and were willing to volunteer to participate in the study were asked to give oral and written consent before the interview was carried out. The consent form included the names of the participant and the researcher, their signatures and the date of completion of the form (see Appendix K for a sample of the participants' consent form). To ensure that their consent was valid, informed and voluntary, an information sheet was also given to the participants which detailed the purpose of the study, the overall process of the data collection and how the data would be processed and used (see Appendix H). The consent form and participant information sheet were written in simple and easily to understand language, free of any academic jargon.

In particular, each potential participant was provided with detailed (written and oral) information about the aims of the research and their participation, the process of safeguarding their anonymity and protecting their personal data and also about their right to withdraw from the study at any stage without any consequences if they wished so (Richards and Schwartz, 2002). In addition, the participants were specifically informed that the study would not provide any direct or tangible benefits, such as financial benefits (e.g., offering vouchers or being paid for their participation) but their participation may involve indirect benefits (e.g., feeling satisfied that they helped scientists develop a new theory). While it is common in qualitative research that participants may not directly benefit from their involvement in the research study, it is also worth noting that participants can experience a cathartic effect from telling and having their story heard (Elmir *et al.*, 2011; Rossetto, 2014). The study was considered to have no physical and emotional consequences for the researcher and the participants. Furthermore, none of the questions was intended to create stress or increase anxiety among participants. I also explained to each participant the process of archiving the anonymised data of this research in the "UK Data Archives" repository three years after the end of the study. This information was also clearly described in the participant information sheet. Lastly, each participant was informed that they could have access to their interview data in case they wished to. Up until the time of submitting the thesis no participant has requested to review or get access to their interviews.

Before the start of each interview, the participant's name, gender, age and type of rehabilitation/ reason for hospitalisation were collected (see Appendix F). The interviews were audio recorded; however, the researcher also took handwritten notes of the discussions when needed and by paying attention not to include any sensitive or identifiable information about the participants. All partners in this project have complied fully with the General Data Protection Regulation (EU) 2016/679 (GDPR) on the protection of natural persons with regard to the processing of personal data, for ensuring the anonymity of all participants and the confidentiality of their personal information during the processing and editing of all data, as well as during the publication of the research findings (General Data Protection Regulation, 2016).

More specifically, in terms of confidentiality, all collected data are anonymised and participants' details will be remained confidential at all times, ensuring that no information regarding the identity and personal details of the participants will be able to be identified in the entire range of the proposed research nor in any publication resulting from it. Further measures to protect participants' anonymity and confidentiality were also considered in case their answers include identifiable information (e.g., by pseudonymising the data). Finally, according to the principle of justice, the participants of this study were treated fairly and equitably throughout the research process.

Appropriate measures were also taken with regard to the protection of the collected data. The digital audio files of the interviews along with the transcription text files were stored with double encryption in the personal computer of the researcher (i.e., the files and the folder in which they are saved are protected with each one having different passwords known only by the researcher). Finally, the paper files of the transcriptions are kept in a secure cabinet in the researcher's office, accessible only to the researcher and the project director. Lastly, in keeping with the requirements of the open data access mandate of the INNOVATEDIGNITY programme, all the research data of this study will be archived in the "UK Data Archives" repository (https://www.data-archive.ac.uk/) three years after the end of the study, after firstly certifying that any private, sensitive or identifiable information about the participants, both direct and indirect, have been properly removed within the data.

4.6 Data analysis process

4.6.1 Qualitative data analysis

In this section, I will present, discuss and justify the data analysis process that has been adopted. Qualitative data analysis refers to the systematic process of searching and arranging textual data (such as interview transcripts, medical or nursing records, observation notes) or other non-textual semiotic materials (images or audio-visual data or other multimedia materials) gathered and structured by the researcher for the purposes of exploring, understanding or interpreting the inquiry under investigation (Bogdan and Biklen, 1982). The collection of qualitative data involves the accumulation of subjective, rich and in-depth information through various methods. In this study, interviews were conducted with older individuals living with ABI who are undergoing (or have undergone) physical rehabilitation. Analysing qualitative data entails a dynamic creative and iterative process (Braun *et al.*, 2019). In practical terms this means reading and re-reading the transcripts, breaking down the text into relatively small units of content and managing the data by identifying unifying patterns of meaning (Richards and Morse, 2013; Braun *et al.*, 2019). Essentially, qualitative analysis involves a process of reducing the volume of raw information (through the identification of significant and meaningful patterns) in order to make sense of huge amounts of data, and finally generate meaning to the findings and communicate them in a logical and structured manner (Patton, 2015; Parahoo, 2014). In this study, this analytical process translates into a standardised approach of coding textual units, forming categories based on the codes and finally conceptualising the categories into meaningful, more abstract groupings (themes).

4.6.2 Hermeneutic phenomenology and van Manen's model: towards the selection of a qualitative analytical approach

The selection of the qualitative analytical approach depends on the research question, the theoretical framework and the epistemological assumptions that underpin the study (Richards and Morse, 2013; Moule and Goodman, 2014). The current study is founded on an interpretive epistemological and a relativist ontological position which then form a solid basis for the hermeneutic phenomenological approach that I follow in my research. Subsequently, the theoretical framework adopted links to an existential phenomenological orientation around the notions of lifeworld, humanising care and well-being. However, the different ways phenomenology is viewed and defined in the literature as both a philosophical and methodological approach, demands further elaboration and clarification on the methodological connotations of the hermeneutic phenomenological approach, to sufficiently answer and justify which qualitative analytical approach is most appropriate.

In contrast to first generation phenomenologists who viewed phenomenology as a philosophy, second-generation phenomenologists such as Giorgi, Colaizzi, van Kaam and van Manen contributed to the remolding of phenomenology into a method of inquiry, proposing specific guidelines for analysing phenomenological data (Munhall, 2007). Van Manen stood out from the second-generation phenomenologists proposing a view of phenomenology as both a philosophy of being and a methodological practice (Munhall, 2007). Specifically, van Manen (1984; 1990; 2014) asserts that the phenomenological analysis seeks to construct possible interpretations to find the essential meaning of human experiences by incorporating the thoughtfulness and reflection of the researcher (Munhall, 2007; Mitchell-Levy, 2018). The literature acknowledges van Manen's development of Heidegger's phenomenology from philosophy to a method of inquiry, with his method of analysis contributing to the designation of the interpretive, reflective and constructive nature of phenomena that hermeneutic phenomenology seeks to create (Dowling, 2007; Munhall, 2007; Sloan and Bowe, 2014).

In this regard, van Manen's (1990) approach is compatible with the epistemological and methodological choices of this research, as it encourages a creative and interpretive process of data analysis with the intent of (re)constructing the participants understanding of their lived experiences (Munhall, 2007; Sloan and Bowe, 2014). In particular, van Manen (1990) proposes a list of six methodical activities to conducting hermeneutic-phenomenological research (Table 4.3):

Table 4.3 *Van Manen's research activities for hermeneutic phenomenology*

Activities	Definition
1. Turning to the nature of lived experience	Identifying the phenomenon of an interest and formulating a research question. In this study the phenomenon under investigation is the sense of well-being of older individuals with ABI undergoing physical rehabilitation.
2. Investigating experience as we live it	Capturing and studying the phenomenon through methods of investigation. Interviews with older individuals with ABI were conducted.
3. Reflecting on the essential themes which characterise the phenomenon	Seeking the overall meaning of individuals' experiences by identifying and reflecting on the essential themes typical to the phenomenon.
4. Describing the phenomenon in the art of writing and rewriting	Presenting and communicating the feelings, thoughts and attitudes of the individuals through the process of writing and re-writing.
5. Maintaining a strong and orientated relation to the phenomenon	The researcher should strive to remain focused on the research question.
6. Balancing the research context by considering the parts and the whole.	Constantly reviewing the link between the overall design of the study and the separate parts to ensure a clear focus on the phenomenon under study.

Van Manen provides a useful guide for hermeneutic phenomenological research, and the guidelines that he suggests serve as an exploratory approach that stimulates insight and can guide the analytical procedures; but they do not correspond to a specific step-by-step process of analysis (Spaten, Byrialsen and Langdridge, 2011; Mitchell-Levy, 2018). Therefore, an analytical model is further required that would provide a set of specific, practical steps for analysing the phenomenological data.

4.6.3 Supplementing van Manen's model with thematic analysis

Following van Manen's guide, this study employs the thematic analysis strategy for the analysis of the data. Thematic analysis provides a purely qualitative, detailed, and nuanced investigation of data (Braun and Clarke, 2006). This approach can be broadly defined as "a way of seeing" and "making sense out of seemingly unrelated material" (Boyatzis, 1998, p. 4). It provides a rich, detailed and complex account of the data, that applies minimal description and interprets various aspects of the research topic (Braun and Clarke, 2006). Going beyond description, thematic analysis is “the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work” (van Manen 1990, p. 78). In thematic analysis, the process is data-driven: all data are reviewed for meanings and nuances that the researcher interprets which then leads to the development of the findings (Braun and Clarke, 2006; Richards and Morse, 2013; Vaismoradi, Turunen and Bondas, 2013).

The research question of the current study and the philosophical underpinnings of the current research signal towards the use of thematic analysis as the most appropriate method to carry out the analysis of the data. The current study represents a phenomenological study based on interpretivism and intends to acquire an in-depth understanding of older individuals lived experiences regarding their ABI rehabilitation and their sense of well-being. All the findings will arise from the data collected as the aim of the study is to fully understand what it means for older individuals to live with ABI. Based on the aim and on the philosophical underpinnings of the study, the goal is to interpret and give meanings to individuals’ descriptions and not to simply count phrases or words in the text.

Thematic analysis is also claimed to be particularly compatible with phenomenological research as it can focus on participants' subjective experiences and their interpretation (Dapkus, 1985; Guest, MacQueen and Namey, 2012). Especially within hermeneutic phenomenological study, thematic analysis has been a popular analytical approach and interpretive strategy for identifying themes in transcribed interviews and deducing meaning out of them (Benner, 1985; van Manen, 2014). Moreover, the literature acknowledges an interrelation between the philosophy of interpretive phenomenology, van Manen’s phenomenological method of inquiry and thematic analysis (Dowling, 2007; Joffe, 2011; Braun, Clarke and Hayfield, 2019). In fact, the third activity of van Manen’s (1984) method guide explicitly indicates the use of thematic analysis in hermeneutic phenomenology to identify the themes typical to the phenomenon under investigation. He moves on suggesting a series of thematic analysis processes for interpreting and generating meaning from the phenomenological data (van Manen, 1984) (Table 4.4):

Table 4.4 *Van Manen's heuristic guide for phenomenological thematic analysis*

1. Uncovering thematic aspects in lifeworld descriptions
2. Isolating thematic statements
3. Composing linguistic transformations
4. Gleaning thematic descriptions from artistic sources
5. Determining essential themes

As a final note, it should be clarified how thematic analysis is understood and used in this research. The many different variations of thematic analysis and the different ways these are typified and distinguished in the relevant literature has admittedly created a confusing picture for qualitative researchers. In contrast to most other qualitative analytic approaches, such as discourse analysis and narrative analysis, thematic analysis is often understood as and treated either as a methodology or as a stand-alone analytic method or technique (Clarke and Braun, 2013; Elo *et al.*, 2014; Braun, Clarke and Hayfield, 2019). In this study I adopt Braun, Clarke and Hayfield's (2019) view, by conceptualising thematic analysis as an umbrella term that designates different approaches for analysing qualitative data, and more specifically of analysing patterns of meaning (Braun, Clarke and Hayfield, 2019). More specifically, I adopt a reflexive approach to thematic analysis, which corresponds to a "fully qualitative approach" that places importance on the qualitative philosophy or paradigm that should underpin the data collection and analysis techniques (Braun, Clarke and Hayfield, 2019). In reflexive thematic analysis, the aim is "to provide a coherent and compelling interpretation of the data, grounded in the data" (Braun, Clarke and Hayfield, 2019, p. 848). Themes are conceptualised as patterns organised around a core concept that reflect a shared meaning. Themes result inductively from the data (as the output of the process of coding) requiring "considerable analytic work on the part of the researcher to explore and develop an understanding of patterned meaning across the dataset" (Braun, Clarke and Hayfield, 2019, p. 848). Consequently, they move on in providing a particular "six-phase" framework for conducting thematic analysis (Table 4.5) (Clarke and Braun, 2013).

Table 4.5 *Six phases of reflexive thematic analysis (adapted by Clarke and Braun, 2013; Braun, Clarke and Hayfield, 2019)*

Familiarisation with the data	The researcher must immerse themselves in, and become intimately familiar with, their data; reading and re-reading the data and noting any initial analytic observations.
Generating codes	This involves generating pithy labels for important features of the data of relevance to the research question guiding the analysis. Coding captures both a semantic and conceptual reading of the data. The researcher codes every data item and ends this phase by collating all their codes and relevant data extracts.
Searching for themes	A theme is a coherent and meaningful pattern in the data relevant to the research question. If codes are the bricks and tiles in a brick and tile house, then themes are the walls and roof panels. Searching for themes is an active process and it is like coding your codes to identify similarity in the data. The researcher ends this phase by collating all the coded data relevant to each theme.
Reviewing themes	Involves checking that the themes 'work' in relation to both the coded extracts and the full data-set. The researcher should reflect on whether the themes tell a convincing and compelling story about the data and begin to define the nature of each individual theme, and the relationship between the themes.
Defining and naming themes	Requires the researcher to conduct and write a detailed analysis of each theme, identifying the 'essence' of each theme and constructing a concise, punchy and informative name for each theme.
Writing up	Writing is an integral element of the analytic process in TA (and most qualitative research). Writing-up involves weaving together the analytic narrative and (vivid) data extracts to tell the reader a coherent and persuasive story about the data and contextualising it in relation to existing literature.

In this study van Manen's (1990) thematic analysis approach (as embedded in the third methodic activity of his heuristic guide) is supplemented in an explicatory manner with Clarke and Braun's (2013) thematic analysis framework which provides greater guidance in terms of practical application. In the following Table 4.6 van Manen's heuristic guide and Clarke and Braun's thematic analysis framework are juxtaposed to clarify each other and identify overlapping aspects:

Table 4.6 *Merging van Manen’s model with Clarke and Braun’s thematic analysis framework*

van Manen’s model		**Clarke and Braun's thematic analysis framework**
3rd activity: Reflecting on the essential themes which characterise the phenomenon.		Familiarisation with the data
	Uncovering thematic aspects in lifeworld descriptions	Coding
	Isolating thematic statements	
	Composing linguistic transformations	Searching for themes
	Gleaning thematic descriptions from artistic sources	Reviewing themes
	Determining essential themes	Defining and naming themes
4th activity: Describing the phenomenon in the art of writing and rewriting.		Writing-up

The merging of van Manen’s heuristic guide and Clarke and Braun's thematic analysis framework is useful and relevant to the current study. However, it requires further clarification on practical issues surrounding the implementation of the analysis process. Thus, this study is further based on a more practical process of managing and developing the raw data into meaningful themes that would facilitate the interpretation of older individuals’ experiences, which is subsequently merged with the above matrix between van Manen’s model and Clarke and Braun's framework (Table 4.7).

Table 4.7 *The matrix among van Manen's model, Clarke and Braun's thematic analysis framework and the practical steps of coding, categorising and thematising*

van Manen's model		**Clarke and Braun's thematic analysis framework**	**Coding, categorising and thematising steps**
3rd activity: Reflecting on the essential themes which characterise the phenomenon.		Familiarisation with the data	
	Uncovering thematic aspects in lifeworld descriptions	Coding	In Vivo Coding- 1 cycle
	Isolating thematic statements		In Vivo Coding - 2n cycle
	Composing linguistic transformations	Searching for themes	Categorising codes
	Gleaning thematic descriptions from artistic sources	Reviewing themes	
	Determining essential themes	Defining and naming themes	Generating themes
4th activity: Describing the phenomenon in the art of writing and rewriting.		Writing-up	

Therefore, the thematic analysis process used in this study is actualised through the phases of coding, categorising and thematising which are operationalised in a reiterative manner (Morse, 2008; Richards and Morse, 2013; Gale *et al.*, 2013; Saldana, 2015)

1) **Coding** refers to the descriptive or conceptual labels assigned to raw data excerpts. Codes reflect the least abstract level and represent very small chunks of text. This phase is further divided into two major cycles of in vivo coding:
    i.) In the first cycle the actual language found in the raw data is divided into smaller units/ chunks of text (e.g., words, phrases or paragraphs). Essentially, those phrases or paragraphs that were deemed to be of significance were isolated and listed separately from the raw data (Saldana, 2015).

ii.) The second cycle refers to the analytical thinking in which the researcher embarks by assigning labels to the textual units identified in the first cycle, and by also teasing out the meaning from the raw data in a phrase, hence providing preliminary interpretations for the raw data (Saldana, 2015).

2) **Categorising** refers to the process of analysis where codes are grouped around similar and interconnected ideas or concepts. Specifically, during this phase the codes are read and re-read to identify similarities between codes or codes that share common characteristics. Consequently, the analysis process proceeds by clustering together Codes that share characteristics and have similarities are then clustered together to allow for the emergence of patterns (Gale *et al.*, 2013; Saldana, 2015). The emerging patterns of the clustered codes create categories that demonstrate relationships between codes (Richards and Morse, 2013). While categories are closely related to the primary data, the formation of categories constitutes a distinct process, signifying the commencement of the data extraction process. Categories are more abstract than codes and represent larger textual clusters.

3) **Thematising** refers to the interpretive concepts that explain aspects of data, signifying the final output of the analysis of the whole dataset. The researcher compares each category with other categories to identify relationships between categories, e.g. complementary or antithetical relationships. The researcher groups together the categories that share some form of relationship creating in this manner themes. Themes correspond to much more abstract pieces of text that encloses a meaningful essence that runs through the data and interprets the meaning and essence of the participants' lived experiences (Morse, 2008; Richards and Morse, 2013).

4.6.4 Operationalising the thematic analysis

The processing and analysis of the interview transcripts followed the steps of thematic analysis described above. The transcripts were translated in English and were read multiple times in order for the researcher to familiarise herself with the participants' narratives. Subsequently each interview transcript was tabularised and divided into separate extracts based on the participants' answers and the semantical load that they carried. For example, an extract could pertain to a whole answer or to some part of it. The tabularised extracts contained three different columns reflecting in a sequential manner the coding steps that were followed: the first column from the left contain the transcribed text of the interviews, while the other two present the first and second coding cycles respectively (Table 4.8). In the first coding cycle the raw data of the extracts are divided into smaller textual units according to their salience – i.e., phrases, sentences or paragraphs that point to an important feature or aspect. These textual units are then processed in the second coding cycle by assigning semantic labels to each unit and providing an initial meaning and interpretation to them.

Table 4.8 *Example from the coding process of an extract*

	Transcribed text	**1st cycle coding**	**2nd cycle coding**
Extract 1	**Researcher:** Could you please tell me about your experiences in general after your diagnosis with a stroke and about your rehabilitation? **Participant A:** 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.	1) It was difficult. I was in the hospital, I didn't understand, I didn't speak well, I didn't walk... 2) the nurses and the doctors were of course attending to me, I had no complaints. 3) a hospital environment which is not the most pleasant thing. 4) Just knowing what would follow, but also my situation, I was very sad.	1+3 = situational and environmental limitations / unpleasant factors Difficult period of time in the hospital. Views hospital as an unpleasant environment. **(Part.A-1-i)** 2 = Participant talks about the healthcare staff without being asked about this. No complaints about healthcare staff **(Part.A-1-ii)** 4 = Participant thinks about the future - felt sad and insecure **(Part.A-1-iii)**
Part. A = 1st Participant, Part. B = 2nd Participant, Part. C = 3rd Participant, etc. 1 = 1st extract, 2 = 2nd extract, 3 = 3rd extract, etc. i = 1st code, ii = 2nd code, iii = 3rd code, etc.			

The short interpretive statements and comments produced in the second coding cycle comprised the final list of codes. Each statement has been assigned a specific identifier which includes the participant code and the number of extract where it is found. All codes were then assessed, reviewed and refined by moving constantly back and forth across the list, to ensure that there is coherence between their meanings (Creswell, 2009). Overall, 464 preliminary codes were developed, reflecting the salient meanings and key concepts identified in the raw data. The codes were then categorised according to similarities and differences. Essentially, codes that addressed the same issue or were related to one another were united into semantically meaningful clusters, forming 11 descriptive categories. From these categories 4 overarching themes were identified (Table 4.9). An overview of the thematic breakdown – including all the codes, categories and themes developed – is presented in Appendix L.

Table 4.9 *Connection between categories and themes*

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

4.7 Rigour of the study

Establishing and evaluating rigour in qualitative research constitutes a significant process for ensuring the quality of the methodological and analytical approach used in the study as well as the robustness of the findings' interpretation. Evidently, the process of assessing and establishing rigour in qualitative studies differs in many respects from the one followed in quantitative research. Several viewpoints and perspectives have been conveyed in the literature about the applicability of the traditional terms of validity, reliability, generalisability and objectivity that are generally applied for assessing the merit of quantitative studies. Some scholars have rejected these terms as inappropriate or inadequate for qualitative enquiry, while others support their use provided that these have been accordingly modified (Leininger, 1994; Altheide and Johnson, 1998; Morse *et al.*, 2002; Holloway and Wheeler, 2010; Bryman, 2012).

While qualitative enquiry is more open and flexible, qualitative researchers are still urged to be methodical, honest and well organised, in order to achieve and ensure rigour in their research (Holloway and Wheeler, 2010). This study supports the view that qualitative studies should and can be evaluated, by using however different and distinct terminology and standards for the quality of research (Bryman, 2012). Therefore, instead of reliability and validity, the concepts of trustworthiness and authenticity respectively have been proposed as alternatives standards for assessing the robustness of qualitative studies (Lincoln and Guba, 1985). Trustworthiness is further expanded into four sub-criteria: credibility, transferability, dependability and confirmability.

Credibility refers to the degree to which the presentation and interpretation of the findings by the researcher are believable, accurate and congruent with the viewpoints of the participants (Lincoln and Guba, 1985; Tobin and Begley, 2004; Bryman, 2012). This further entails that both the researcher and the participants have confidence and recognise that participants' perceptions and construals are credible and that these are accurately reflected by the research findings (Lincoln and Guba, 1985; Holloway and Wheeler, 2010). Credibility of a study can be demonstrated and assessed, by presenting for example the findings to the respondents and checking whether the participants confirm or feel that the researcher's representation of their perspective is accurate and fair (member check or member validation) (Lincoln and Guba, 1985; Holloway and Wheeler, 2010; Bryman, 2012). Other strategies include triangulation of data sources, methods, and investigators, prolonged engagement in the field and persistent observation (Tobin and Begley, 2004; Creswell, 2007; Bryman, 2012).

To establish credibility in this study a field journal was kept detailing my interactions with participants and stakeholders, by recording my personal reactions and the feelings of the participants during the interviewing process. This reflective description of the work done during the data collection gives a straightforward and comprehensive account of the interviewing process, while ensuring that the participants' accounts are represented as accurately as possible. It was also ensured that the research was conducted with thoroughness and integrity, by using the appropriate methods and procedures for the particular topic under investigation. The methodology process was presented in detail, providing all the necessary information about how the data were processed, analysed and interpreted. Lastly, peer debriefing sessions with the project supervisors were carried out (and recorded) throughout the duration of this researcher. These provided useful feedback and guidance about the whole research process, but most importantly they served as a significant external check about the techniques used for collecting and analysing the data and for interpreting the research findings.

The criterion of **transferability** (or fittingness) implies that a study's findings 'hold' and can be transferred to similar settings or populations outside of the study situation. This can be established in qualitative research through thick description, that is by providing a detailed account of the research process, the data collection procedures as well as of the overall context and culture in the research (Holloway, 1997; Holloway and Wheeler, 2010). Therefore, qualitative researchers are encouraged to present enough information to assess the possible transferability of findings and their potential implications for other contexts or populations, by reflecting on whether the knowledge acquired and the concepts used in their research are meaningful, relevant and applicable to other contexts (Bryman, 2012).

In this study, the data collection methods and procedures are thoroughly and clearly documented, providing a detailed account of the interviewing process. As such the time period of data collection, the sampling procedures and limits of this sample are clearly explained and presented in detail, so that readers may decide for themselves whether the findings apply to a similar situation or group (Shenton, 2004). In particular, participation was limited to older individuals living with ABI who receive or have received rehabilitation and who are located within the region of Epirus in northern Greece. The narrow focus of the research findings (i.e., the exploration and interpretation of older individuals' well-being experiences during ABI rehabilitation) is clearly presented and methodically discussed in the analysis and discussion sections to prevent unsubstantiated transferability.

Dependability refers to the stability and consistency of the research findings over time and across different researchers or research settings (Creswell, 2007). This criterion is evident when researchers adopt an 'auditing approach', which entails a rich description of the research process, the setting and the participants. More particularly, dependability can be established by ensuring that the decisions made before and during the research process are recorded clearly and in detail, and that the information are accurate and they can be easily accessed and traced (Tobin and Begley, 2004; Holloway and Wheeler, 2010). This creates an audit trail, where peers can audit and evaluate - possibly during the research and certainly at the end - the researchers' theoretical and methodological decisions and the overall procedures that were followed during the research (Tobin and Begley, 2004; Bryman, 2012).

This study makes use of the audit trail strategy by providing a transparent description and justification of all the research steps and decision taken from the start of the research project. The systematic literature review that was conducted for the purposes of this research is clearly recorded and presented in the thesis, giving information about every step that was taken. A detailed account and description of the methods and analysis used in this study was also provided. The thematic analysis of the data and the synthesis of the results was thoroughly documented, followed by the detailed discussion of the findings in the discussion chapter. Lastly, all major ethical issues have been properly considered and addressed to ensure that the overall research process has been transparent and scientifically robust. In particular, it was guaranteed that the participants have given their informed consent to voluntarily participate in the research. Detailed oral and written information was provided to the participants about the aims of the research and the ways that their input will be used and analysed in the study. Participants have been also informed about their right to get access to their records if they asked so. All contact with participants was carefully documented and stored, and appropriate measures have been taken to ensure that their privacy and confidentiality is secured, protected and preserved during and after the completion of the research. The data collected will be easily accessed by participants if they asked so. In line with the open data access mandate that underlies this research project, all the collected data will be deposited in the "UK Data Archives" repository three years after the end of the study - provided that all the confidentiality requirements have been properly addressed beforehand. This further supports the dependability of the study as the data will become openly accessible for anyone who wishes to audit, validate and/or replicate the study and analysis of the data.

The last stage of establishing trustworthiness is to achieve **confirmability** of a study. Confirmability refers to the degree to which the research findings are free from the researcher's biases, values, or preconceptions (Guba and Lincoln, 1989; Tobin and Begley, 2004; Bryman, 2012). This can be established by ensuring that the researchers' preconceptions have not deliberately influenced the data, findings and conclusions of the research study (Guba and Lincoln, 1989; Tobin and Begley, 2004; Bryman, 2012). It is therefore important for researchers to keep in line their prior assumptions or personal values and ensure that findings have not been biased towards a particular viewpoint (Holloway and Wheeler, 2010). This again entails an audit trail through which the peers and readers can assess the way that the researchers have carried out the interpretation of participants' accounts and have arrided to their conclusions (Holloway and Wheeler, 2010). Reflexivity is another central strategy for demonstrating confirmability. Through this strategy researchers get the opportunity to clearly reflect on their own potential biases and presumptions and also scrutinise their background, feelings and viewpoints in relation to the participants' accounts and actions (Holloway and Wheeler, 2010).

To demonstrate confirmability in this study, I have documented in detail how conclusions and interpretations arose from the data. This was achieved through the use of the following elements of this study:

a. the audio-recordings and high-accuracy transcripts of the interviews,

b. detailed notes taken during the interviews about the participants' postures and nonverbal expressions but also about the researchers' feelings and thoughts,

c. a detailed audit trail of analysing the data and interpreting the experiences of the participants.

Being a crucial issue for this study, the strategy of reflexivity was also applied in this study, being elucidated both in the beginning of the research but also at the end. In particular, my personal beliefs and pre-understandings have been explicitly discussed, focusing on the ways that my background may have influenced the process of conducting the study. An explicit reflection of my potential biases throughout the research is also provided at the beginning as well as at end of the study, which contributes to the robustness of this study's findings and conclusions (see sections 1.2 and 8.5).

In short, the rigour and trustworthiness of this study was established by ensuring that the criteria of credibility, transferability, dependability and confirmability have been demonstrated. Credibility, dependability and confirmability were met with transparent, exhaustive record keeping including audit trails, field notes, and personal journals. The careful sample selection, the intricate and detailed record-keeping as well as the dedication to preserve and meticulously follow the methodological procedures outlined in this chapter have further contributed to the transferability of the study.

CHAPTER 5: ANALYSIS OF FINDINGS

5.1 Introduction

This chapter presents the findings that were identified from the analysis of the interviews. The thematic analysis produced in total four overarching themes that encompass specific categories. The first theme explores the challenges and struggles older individuals with ABI experience in their life that emerge from emotional, existential and exogenous factors. The second theme deals with the emotional and practical support that older individuals with ABI have sought during their rehabilitation through social interaction. The third theme identifies the contextual processes of rehabilitation in terms of assessing the rehabilitation interventions and pointing out any structural issues that reinforce or hinder the care provision. Lastly, the fourth theme refers to older individuals' attempts to understand themselves after their diagnosis and making sense of any changes that have occurred with regards to their autonomy. Each theme along with the incorporated categories are analysed in depth by interpreting and reflecting on direct quotations of the interviews. The analysis of the findings is further linked with the objectives of the study by highlighting how their interpretation contributes to their achievement (Table 5.1). The analysis of the data is phenomenologically guided, focusing on the interpretation of the subjective experiences, conceptions and assumptions of the participants in relation to the topics under investigation.

Table 5.1 *Connection between categories, themes and research objectives*

CATEGORIES	THEMES	RESEARCH OBJECTIVES
• *Processing of emotional struggles and existential concerns* • *Temporal distribution of past and future life* • *Emotional variations on returning home*	**Theme 1: Challenges of new life situation**	**3**
• *Strengthening the sense of belonging through social interactions* • *Emotional support and encouragement by family* • *Adopting the role of "good patient" as a coping mechanism*	**Theme 2: Seeking emotional and practical support through social interaction**	**1**
• *Impact of clinical environment on rehabilitation process* • *Identifying structural issues in relation to care provision*	**Theme 3: Identifying contextual processes of rehabilitation**	**4, 5**
• *Passivity and sense of dependency* • *Self-reliance and involvement as a means for independence* • *Making sense of the new identity*	**Theme 4: The felt sense of self in the aftermath of ABI**	**1, 2**

Research objectives:

1. To explore how older individuals living with an ABI sense well-being when undergoing physical rehabilitation.
2. To explore how older individuals living with an ABI undergoing physical rehabilitation feel about themselves and the context within which they exist
3. To explore how older individuals living with an ABI undergoing physical rehabilitation experience the life changes that may occur after the injury.
4. To understand what are the felt experiences of older individuals living with an ABI undergoing physical rehabilitation of their interaction with health professionals.
5. To examine the impact of Greece's healthcare and rehabilitation system on the felt experiences of well-being of older individuals undergoing physical rehabilitation.

5.2 Theme 1: Challenges of new life situation

The first theme illustrates the challenges and struggles that the participants have been facing in their life after their ABI diagnosis. These are translated into existential concerns and emotional variations that participants have experienced throughout their rehabilitation process and with which they try to cope. These felt experiences and emotions are perceived by participants in distinct temporal and spatial terms but they also related to other contextual factors. Specifically, the participants express their perceptions and emotions regarding their past and present life and how they experience any felt differences. They also try to make sense of their experience of returning home as well as their adaptation to their new way of life following their hospitalisation.

This theme is related with the third objective of the study which aims to explore and understand how older individuals living with an ABI experience the life changes that may occur after the injury throughout their physical rehabilitation.

5.2.1 Category 1: Processing of emotional struggles and existential concerns

This category presents the struggles of the participants in their attempt to cope with their emotions after their ABI diagnosis. Their new life situation prompted them to reconsider their existence within their new life conditions. The following examples illustrate the negative thoughts and existential concerns that the participant has been feeling after the stroke:

> *I used to joke around, I was happy, I did my chores, everything! Now you can't do anything and you get sad... I don't enjoy things easily. I'm sick now... People should not live so long. You reached 80 at most, you should leave if you are [not] well, to not suffer. Normally that's how it should be...*
>
> ***(Participant K)***

> *To tell you the truth I'm thinking about dying! I don't want to live anymore... Well, ok 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)***

The participant indicates that she has lost the joy and happiness that she was feeling before. The everyday activities and chores that she was performing in the past provided her with a sense of completeness. This routine was conceived and experienced as a life pattern through which she was finding significance and meaning in her life. However, the participant notes that after the stroke she has been unable to do any of these activities, leading to emotions of sadness and hopelessness and to a sense of not being able to carry on. As a result, she experiences a mood of depression which is characterised by an overtly pessimistic outlook on life. Her new situation has convinced her that it is meaningless for older people to live that long; that they do not deserve to suffer anymore, if they are sick or unwell. Shortly afterwards she plainly expresses her desire to die. Her despair and anguish are intertwined with her experience of illness. There is a clear sense of unworthiness but also a feeling of guilt as the participant believes that her family and her husband in particular are suffering due to the felt duty of taking care of her. For the participant the only solution to her family's suffering is to not live anymore.

The quotation below indicates a similar existential concern by a participant who experiences strong emotions of sadness and guilt:

> *I'm sad that I have the children... that I call my child and he is tired... To be in his sleep, to have his fatigue... Why God doesn't take me...*
>
> ***(Participant L)***

The participant believes that her process of rehabilitation and treatment is tiring her children. She prefers to not exist anymore so as to relieve her relatives from the burdens of care. The felt experiences of inability due to their ABI condition have led many participants to believe that they do not deserve the care they receive by their relatives. At the same time, they consider themselves a burden as they are convinced that their relatives are exhausted from taking care of them. These emotional struggles aggravate the existential guilt and desire to die.

In some cases, the existential considerations of participants after their ABI diagnosis involved more pleasant experiences and positive feelings:

> *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)***

In the quote above the participant notes how the whole experience of ABI and his rehabilitation improved his behaviour and attitude towards other people. He became more confident and good-natured, while also managing to control his short-temperedness. According to the participant his new life situation motivated him to reconsider his view on life leading to his self-enhancement.

5.2.1.1 Interpretative Summary of Category

This category presents the different ways through which older individuals perceive their new life situation after their ABI diagnosis and process their emotions and existential concerns. The impact on their emotional state has been mainly negative as the majority of participants have developed a sense of dullness and meaninglessness, feelings of guilt and helplessness, and a lack of energy and motivation. Furthermore, many participants seem to be mainly concerned about the wellness of their family, believing that the overall process of their rehabilitation has emotionally and physically overwhelmed their relatives. These perceptions and emotions have led them to adopt a quite pessimistic existential view on life, thinking even to die so as to relieve themselves and their family from suffering. Paradoxically, some participants managed to take advantage of these life-changing conditions, by reconsidering and reviewing their behaviour and attitude and by improving themselves. These participants expressed mainly positive experiences and emotions and a desire to try to find meaning in their new life situations.

5.2.2 Category 2: Temporal distribution of past and future life

Participants also expressed their perceptions about making plans about their future. This relates to perceptions of moving forward, progressing to better state or even to full recovery. This category further presents the temporal distribution that some participants highlight in their narratives talking about their present situation as well as about their future in juxtaposition to their past life and self.

The majority of participants did not express a strong sense of future movement. The following example illustrates the participant's lack of interest in making future plans about himself:

> *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)***

The participant believes that making plans for the future is pointless as he is not able to be autonomous anymore and do things by himself. There is a clear sense of futility felt by the participant as he does not identify any meaningful progression into the future. Here, the older individual expresses his desire to experience this sense of looking forward to the future and to be able to make tangible and tenable plans about himself, albeit he realises that he is not able to do so due to his health situation. The only thing that can give meaning and a sense of purpose to his future direction is the wellness of his kids. However, being interested in his children's wellness makes him to neglect his own well-being, thus feeling "stuck" and cut off from any sense of moving forward in the future.

For some participants their sense of looking forward to the future involves being able to do things that they could do in the past before their ABI diagnosis:

> *I want [this]! I want to go to the shop! But we are afraid that I might fall. We 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 did not sit... I couldn't sit still. I just couldn't.*
>
> *[...]*
>
> *Just 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)***

In the above quotations the participant feels nostalgic and proud for the days when he was able to work. He mentions that he was very energetic and diligent, working hard all the time. However, in the present he still feels weak and not strong enough to independently go back to his shop. For him the main aspiration is to recover and be able to perform the everyday activities that he used to do in his business. This constitutes his future direction, his main goal, which gives him hope and strength for moving forward during his rehabilitation regardless of how long this will take. The participant here expresses a sense of temporal movement which is expressed in the form of a personal journey through time: from his past self and abilities to his present condition and emotions of fear and weakness, and eventually to his future ambition and plans of getting better and returning to his business.

5.2.2.1 Interpretative Summary of Category

This category presents the perceptions and feelings that older individuals with ABI have about their future condition and on making plans about themselves. In most narratives, there was a lack of expectations about their future as well as a lack of meaningful purpose and temporal movement. The participants felt meaningless and pointless to make plans for the future either due to their health condition or because of their older age. In most cases, participants further acknowledged the challenges they face during their rehabilitation by juxtaposing their present state to their past more active and energetic self. Some participants, however, felt a strong sense of moving forward and future possibilities which motivates them to hold a positive attitude towards a welcoming future, by overcoming their present strains and anticipating the retrieval of their past self and capabilities.

5.2.3 Category 3: Emotional variations on returning home

The third category presents the variations in participants' experiences and feelings regarding the process of returning home after their in-patient rehabilitation. Returning home is experienced differently by participants as they strive to make sense and adapt to their new life at home. As regards the change of environment from hospital to their residence and the possibilities that this physical relocation provided, it offered a sense of familiarity to many participants that was not felt during their hospitalisation. In the following examples, participants express pleasant feelings and experiences about going back home and continuing their rehabilitation there:

> *I felt rejuvenated. <laughing> I felt alive again!*
>
> ***(Participant N)***

> *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 after Easter for two 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, your home is always your home - oh, my God - I didn't want to come to the hospital anymore. There was an improvement and so I did not go to the hospital again.*
>
> ***(Participant A)***

In the first quote above, the participant shows his enthusiasm for returning home. The experience of relocating to their residence was felt as an invigorating event, that made him feel alive again. Being reconnected to his own place contributed to the improvement of his emotional state. Similarly, in the second example, participant *I* felt better at home than when he was in the hospital. Being at home was positively experienced as a physical reconnection with surroundings that felt more familiar and comfortable than the hospital environment. In a more metaphorical sense, the occasion of coming back at home symbolises the return to his old life and to his family. Emotionally the participant appears to have felt more confident when he returned at home in contrast to the more alienated experience that he seems to have had in the hospital.

Lastly, participant A indicates her dislike in returning to the hospital. For her, home is a safe place whereas hospital feels as an unpleasant environment. Moreover, her experience of home rehabilitation seems to be much more pleasant, effectively contributing to the improvement of her emotional and physical state. The strong sense of familiarity that she feels at home is not perceived only in terms of her physical recovery but also emotionally as a place of serenity and peace that reinforces her well-being.

However, the experience of returning home was not identified as exclusively positive by all participants. As the examples below illustrate, some participants were concerned of going back home as they have felt safer within the hospital environment:

> *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)***

In the first example, the participant feels ambivalent about whether his return at home will improve his health condition. He expresses his fear of leaving the hospital as he felt safer there. This example indicates that the positive sense of ‘feeling at home’ is not necessarily linked to one’s own residence but can occur in whatever place or environment makes individuals feel safe and comfortable. This is also evident in the second quotation above where participant K expresses the unpleasant feelings and effects of coming back home. He preferred to have stayed in the hospital, as his treatment by the healthcare staff had created a familiar and safe environment for him that boosted his sense of well-being and made him feel more comfortable than at his residence. The two examples above may also indicate the dissonance between older individuals’ initial expectations and feelings of returning home and the reality after their hospitalisation. The initial joyful anticipation for returning home seems to have been overturned by a desire to stay in the hospital due to the fear of losing the support and security that they were experiencing during their in-patient rehabilitation but also due to their concerns about the impact that their functional limitations would have on their everyday life and activities at home.

In certain cases, participants highlighted their mobility limitations as a significant determinant that contributed to their unpleasant feeling upon their return at home:

> *There are times that I get sad at home. Inside me, I have this urge to do everything myself, because I was the person who did everything by myself; or if they have their own way of doing things, I have another way and I want to do it by myself and in my way […] now I'm sad that all these things are over! I may not do these things but I say thank God as long as my hand gets well I can do at least a few things at home.*
>
> ***(Participant A)***

In the above example, the participant expresses her sadness about her inability to perform the activities she used to do at home before the incident. Although she has a strong desire and a felt need to do the household chores, her impaired hand function prevents her from doing them in her own way – and sometimes not allowing her to do them at all. She still feels thankful that her hand movement is getting better and she can even do some of the chores. Nevertheless, the participant is overwhelmed with unpleasant feelings due to the mobility difficulties and the life changes she experiences, which in turn negatively affect her overall sense of returning home.

5.2.3.1 Interpretative Summary of Category

This category presents the different experiences and emotions that participants expressed regarding their return at home. Being at home was perceived both literally as a sense of physical relocation and metaphorically as a symbolisation of pleasant or unpleasant emotions. Similarly to the previous categories, the narratives of older individuals reflect a variety of experiences and perceptions. On the one hand, participants encountered their return at home as a positive transition from the alienated and unfamiliar hospital environment. Returning home created positive feelings despite the challenges of adjusting to this new reality. They felt secure and more comfortable when they returned to the familiar surroundings of their own residence, experiencing relief, calmness and a sense of settling. In these cases, going back home correlated to a positive sense of 'being and feeling at home', which in turn strengthened their sense of well-being. On the other hand, many participants experienced disappointment upon or after their return at home. Due to the positive experiences, they had during their hospitalisation and the uncertainty that their return at home was posing on the continuation of their rehabilitation, some participants perceived hospital environment as a safer and more secure place for pursuing their successful recovery. The felt sense of familiarity within the clinical environment, generated a series of unpleasant feelings about their homeplace, which negatively affected their emotional state upon their return at home. Furthermore, the realisation of the difficult new reality at home that stems from their mobility limitations has aggravated these participants' view of their home as an unpleasant environment.

5.2.4 Summary of Theme 1

This theme focused on the struggles, challenges and concerns that participants experienced during their physical rehabilitation in relation to their new way of living. The various emotional and existential considerations expressed by the participants are related to their sense of moving forward and their feelings from physical relocation. The phenomenological analysis of the data in relation to the first theme meets the third objective of this study by demonstrating how older individuals living with ABI experience and cope with the life changes that may occur after the injury throughout their physical rehabilitation.

Participants dealt with various emotional and existential concerns regarding their new life situation after their ABI diagnosis. Several participants experienced a mood of depression that was characterised by a sense of pessimism and meaninglessness with respect to their life and recovery prospects, with some of them 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. Other participants however were able to harness the negative emotions caused by the life-changing ABI conditions by engaging into a process of self-enhancement and making-sense of their new life.

The experiences of participants regarding their spatial and temporal movement during their rehabilitation was further explored in relation to the changes occurred by their ABI condition. More specifically, the majority of participants expressed a lack of future direction, being unmotivated in making plans for the future, while others felt a strong sense of moving forward, being interested in the future possibilities about their recovery and new life situation. Spatial movement was explored in terms of the process of going back home after in-patient care. Juxtaposed with the hospital experiences, the return at home was felt either as a pleasant or unpleasant transition. Several participants experienced a strong sense of 'feeling at home' when they went back to their familiar surroundings. Other participants however felt a sense of disappointment or ambivalence upon their return at home, considering hospital as a safer and more stable environment for continuing their recovery. This is an interesting finding that reveals the non-mutually exclusive association between the perceived sense of 'feeling at home' and returning back to your own homeplace. Overall, temporal and spatial movement were associated with positive feelings revealing increased levels of well-being.

5.3 Theme 2: Seeking emotional and practical support through social interaction

The second theme indicates the need for emotional and practical support as one of the main facilitators which affect older individuals' sense of well-being and their experiences of rehabilitation care. Participants' experiences have shown that the sense of belonging, the emotional support by family as well as the adoption of specific behaviours such as the image of "good patient" can strengthen their rehabilitation progress and increase the levels of their well-being. This theme pertains to the first objective of the study which aims to explore how older individuals living with ABI sense well-being when undergoing physical rehabilitation.

5.3.1 Category 1: Strengthening the sense of belonging through social interactions

The need for belonging and socialisation refers to their human emotional need to develop a sense of familiarity with members of social groups that they interact with during their rehabilitation. Social interaction and participating in social activities are key processes for participants to strengthen their sense of affiliation and to feel human again, by feeling that they are accepted by their close social environment, the health professionals and their peers. This process involves emotional support along with inspiring and meaningful communication. Consequently, this leads to pleasant relationships and comfortable situations for the participants. Unpleasant situations however were also identified with participants experiencing a sense of loneliness and sadness due to the lack of meaningful social interaction, encouragement and support.

The following quotation, illustrates how the lack of social interaction can adversely impact on participants' felt experiences of well-being:

> *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)***

The participant's ABI condition has affected his social life, as he has lost contact with his friends. The sense being part of a group along with the need to affiliate with others contribute to the enhancement of older individuals' emotional wellness as through the interaction with other people they feel that their human capacity to communicate has remained intact, especially after surviving from a stroke. Social inclusion and social activation are thus considered important drivers for the participant as this can alleviate any sense of loneliness and isolation. The stroke survivor here demonstrates the unpleasant emotion that he experiences due to the lack of this sense of connectedness that he was feeling in the past and which he would have been feeling if he was energetically participating in social activities and interacting with his friends.

In contrast to the previous case, the example below indicates the positive outcomes that have ensued from the successful interaction between health professionals and the participant.

> *The behaviour of the staff was excellent thanks to [doctor's name] he was a former military doctor, you know that, right? It doesn't seem to him. You would think he was a priest, with a smile, with politeness, he is very polite. He inspired me with confidence. That is, even if I said something stupid then, which I definitely did, he would look at me in a serious manner and would say yes, to give you courage.*
>
> ***(Participant J)***

The polite and mild manner of the doctor boosted the confidence of the participant as well as his sense of belonging. In this case, the participant has felt appreciated during the hospitalisation due to the professionalism and familiarity through which the doctor has behaved towards the participant. The overall encounter and particularly the way the doctor was communicating, not only inspired the participant by giving him courage and strength to continue with his rehabilitation, but it also reinforced the participant's social self-perception by easing any sense of low self-confidence or embarrassment.

Similarly, in this case the participant highlights the smooth coexistence and mutual communication that she had with the doctors and the healthcare staff in general.

> *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 approving and admiring communication along the pleasing and hospitable attitude towards the participant made her feel deep satisfaction, contributing to her emotional and physical wellness. She also felt proud of herself from the compliments that the healthcare staff made about her to her husband. The positive feelings that the participant still holds for this relationship indicates the constructive impact that this social interaction had for lifting her spirits and improving her self-perception. Instead of facing a hierarchically dominated interaction and relationship, the participant felt a sense of familiarity and kindness, that enabled her to feel that she is cherished and admired by the healthcare staff and most importantly to feel part of the group.

5.3.1.1 Interpretative Summary of Category

This category illustrates the relation between social interaction and the sense of being human, insofar meaningful communication can impact to the improvement of personal experiences and self-perceptions of older individuals with ABI during their rehabilitation. Participants highlighted 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 of the discussions as a transformative factor that can deeply affect the perception of self and self-esteem of the participants.

Perceiving themselves as active members of a group and feeling able to communicate with others brought a sense of mutual affection and closeness but also a sense of uniqueness to the participants. Many participants highlighted how social interaction made them feel more valued and accepted, thus reinvigorating their sense of being human. At the same time, they felt more secure and confident, as they had the opportunity to share their concerns and struggles with others while also receiving practical advice, inspiration and encouragement by the healthcare staff. It also boosted their morale and motivation to keep up with their rehabilitation. The opportunity to socialise by engaging in ongoing dialogue and participating in social activities satisfied their desire and need to keep in contact with the outside world.

The lack of such meaningful interactions and social engagements led to feelings of isolation and low self-esteem. In such cases, participants expressed their sadness and disappointment when they felt that they had lost contact with their friends or when they were not anymore actively included within social groups. Unsuccessful communication with healthcare staff also affected their sense and perception of human belonging, as they started feeling more vulnerable and insecure.

5.3.2 Category 2: Emotional support and encouragement by family

Family's support has greatly contributed to the improvement of participants' emotional state. More specifically, the presence of family and their involvement in the rehabilitation process, was described by the older individuals as a source of power, hope and courage, that boosted their confidence and enhanced their sense of well-being. Furthermore, the practical assistance provided by the family eased the intimidating early stages of participants' clinical experience, while also reassuring participants' concerns about the continuation of their post-discharge rehabilitation. Overall, family support and involvement in rehabilitation is experienced as a fundamental facilitator for the participants' rehabilitation progress, as it has a positive effect on participants’ adaptation to the new reality and their sense of continuity.

In the following quotation, the participant highlights the emotional contribution of their family to the rehabilitation process:

> *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)***

Although she experiences the strong affection provided by her immediate family, she acknowledges that it is not feasible for them to be fully involved in her healthcare support. According to the participant, her family’s emotional engagement fully exemplifies the vital assistance that she needs. At the same time, she describes the practical ways that her family helps her in everyday activities at home after her discharge. The substantial and continuous help offered by her husband and her children upholds her sense of affinity, while enabling her to feel peaceful and unconcerned about her situation.

In a similar vein, the participant in the example below indicates the crucial role of family support during her rehabilitation in the clinic:

> *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)***

The participant uses a vivid simile (*“locked in the golden cage”*) which reveals her emotional charged state during her hospitalisation. However, the practical support that her family offered diminished the sense of isolation and confinement that she would otherwise feel inside the hospital. The participant further implies the emotional support that she has received by her loved ones (*"also practical help"*) indicating that her family also contributed to her emotional enhancement during her rehabilitation. Overall, the participant appreciates her family's invaluable support and recognises its beneficial effects regarding her experience in the hospital. The clinic was not anymore perceived as a restrictive place; rather it felt like home due to the continuous presence of her family.

5.3.2.1 Interpretative Summary of Category

All participants emphasised how essential family support was during their rehabilitation and healthcare process. The practical but most importantly emotional help that family provided was perceived as the best medicine and therapy that they could have during the hard times they were going through. It was also described as a fundamental requirement for enhancing their well-being as they cope with the life-changing consequences of their condition which have heavily influenced their emotional state but also their spatial and temporal awareness. Participants were particularly appreciative and thankful for the love, care and actions of their family aimed towards their recovery. The supportive and intimate environment that family provided to older individuals instilled them with confidence, boosted them both mentally and physically and encouraged them to carry on with their recovery.

5.3.3 Category 3: Adopting the role of "good patient" as a coping mechanism

This category displays the ways participants have adopted the "good patient" persona as a coping mechanism during their clinical rehabilitation. More specifically, it explores the behaviours and actions that the participants perceive as appropriate in the hospital environment. At the same time, older individuals' perceptions reveal how they feel and relate the particular clinical performance to experiencing a more pleasant rehabilitation experience.

In the following example the participant indicates her good performance during hospitalisation, as an individual that never complained and was always pleasant:

> *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; they even wanted to take a picture of me to have me there...*
>
> ***(Participant B)***

The participant here implies that the sense of enjoyment and the good treatment that she was experiencing by the healthcare staff was bound and related to her appropriate, good performance. In this sense, she has internalised a particular understanding of the "good patient" role, as someone who will receive and experience better healthcare treatment and support because of her calm, polite and uncomplaining manner. This perception largely reflects the socially constructed ideal behaviours that the patients believe they should adopt and also the expectations they believe that the medical establishment has from patients.

In a similar vein, the following quotation highlights the perception that the participant has about how patients should behave in order to be treated well:

> *[The healthcare staff] were very good people. Because they didn't shout... [...] the [other patients] would press the button all the time and shout and sometimes the nurses would shout at them and tell them "What do you want since I just treated you!". I mean, they crucified the guys, you know what I mean? [...] there were many patients who were shouting during the night and were tiring the nurses...*
>
> ***(Participant K)***

The participant sympathises with the nurses, stating that due to the bad behaviour of some patients, who were demanding and shouting, the nurses were suffering, feeling tired and sometimes shouting too. Through this experience, the participant demonstrates her perception that if the patients wish to avoid being treated adversely by the healthcare staff, they should behave appropriately so as to receive an enhanced and more effective healthcare. This is further evident by the description of her own treatment as the nurses did not shout to her nor behaved badly to her, implying that she was treating nurses with politeness and understanding. According to her experience, the healthcare staff "*were very good people*".

5.3.3.1 Interpretative Summary of Category

This category illustrates the views of patients about what their behaviour and clinical performance should be during the rehabilitation. Their perceptions are largely 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. Patients therefore resort to the adoption of this role by not complaining and acting according to expectations, in order to be able to cope with the difficulties of their situation and to secure the full support of the medical staff during the rehabilitation process. However, this attempt to "fit in" poses the question of whether this contributes to a real improvement in their well-being as patients themselves may be oppressed and self-objectified, being forced to adopt a good patient image just to be able to receive the expected support. In reality they may not get the support and help they want in the way they would like - thus experiencing a false sense of well-being and fulfilment.

5.3.4 Summary of Theme 2

The current theme presents the variety of the experiences and perceptions that participants have regarding the emotional and practical support that they have received during their rehabilitation care and how this support has contributed to their overall sense of well-being. The phenomenological analysis of the data in relation to the second theme meets the first objective of this study by demonstrating how older individuals living with ABI experience and realise emotional and physical well-being by seeking social interactions to fulfil their sense of closeness and intimacy, through family support and by adopting a polite and undemanding behaviour during their clinical rehabilitation.

More specifically, participants highlighted the significance of meaningful interactions in preserving and even strengthening their sense of humanity and socialisation, by illustrating how these can lead to the improvement of their self-realisation as well as to their experiences of rehabilitation progress. 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. 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 that their family was providing to them, by acknowledging the positive effects this had to their emotional state during their rehabilitation. Lastly, the adoption of the “good patient” role by many older individuals serves as a means to secure the full support of the healthcare staff during the rehabilitation. However, this traditional understanding of what constitutes an appropriate patient behaviour in the clinical setting poses many questions about the actual essence of the well-being that they experience.

Overall, the experiences of older individuals living with ABI illustrate that the process of seeking support is perceived by them as fundamental for increasing the levels of their well-being and for strengthening their rehabilitation progress.

5.4 Theme 3: Identifying contextual processes of rehabilitation

The third theme focuses specifically on the interpretations and conceptions of older individuals regarding the contextual processes and factors of their rehabilitation. In particular, this theme examines participants' feelings and experiences regarding the impact that the overall hospital environment and their in-patient care had on their recovery process. Rehabilitation interventions are also explored from the perspective of participants’ lived experiences, looking at how they assess their overall process and outcomes. Lastly, the theme presents participants’ opinions and experiences regarding particular organisational and structural issues that influence their care provision and by extension their well-being during rehabilitation.

This theme is related with the fourth and fifth objectives of the study which aim to examine and understand how older individuals living with an ABI experience on the one hand their interaction with health professionals when undergoing physical rehabilitation and on the other hand the overall impact of Greece’s healthcare and rehabilitation system on their sense of well-being.

5.4.1 Category 1: Impact of clinical environment on rehabilitation process

This category deals with the impact of clinical contextual factors on the rehabilitation and recovery process of participants as felt and experienced by them. These external factors correspond to the clinical environment and the overall care services provided by the healthcare staff during the in-patient hospitalisation. In this theme the focus is placed exclusively on participants' lived experiences regarding the overall clinical context (in which rehabilitation took place) and how these have influenced their sentiments about their recovery progress as well as their perceptions about the range, availability and delivery of healthcare services. The communication and relationship with the healthcare staff was the most important factor that influenced their felt experiences of the overall care they received as well as their sense of well-being. The following quotations indicate the good relationship that participants had with the doctors and nurses in the rehabilitation clinic and the positive experiences they felt as a result of this:

> *Easy, yes, it was easy. I tell you they were impeccable there. The nurses and the doctors and all. There was also [doctor's name] over there; He was the best, the best! His jest was, wow! I mean, [...] he used to call me rascal. "Hey, you rascal!" he was shouting from afar. That's how he was calling me. <laughing>. I also liked the teasing. I was a teaser too.*
>
> ***(Participant M)***

> *At the rehabilitation clinic, I had excellent impressions from everyone and from [...] 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)***

The pleasant memories that participants hold from their communication with the healthcare staff indicate their satisfaction during their physical rehabilitation in the clinic. The "impeccable" behavior and pleasant attitude of the nurses and doctors is reflected in their attempts to offer a familiar and enjoyable environment to older individuals. The very good relationship between the participants, the nurses and doctors had a positive impact on older individuals' sense of well-being, making them feel more comfortable during their hospitalisation, and facilitating their recovery process as well as their adjusting to their new reality. At the same time, the above examples indicate a positive evaluation of the overall services and facilities within the clinic. The participants seem to have no complaints, feeling very satisfied about their overall in-patient rehabilitation experience.

In addition, the following quotation explicates the positive effects that contextual factors had on the rehabilitation experiences and emotional state of the participant after the felt changes following the stroke incident:

> *From 2011 onwards there was a big difference because the stroke immobilised me. I could not walk. It upset my balance. My body swayed sometimes to the right and sometimes to the left. [...] 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. If I were abandoned in such a place I don't know how I would feel... This sympathy from all the staff inside, made me not think about my condition. Psychology plays a big role and played a big role in my recovery.*
>
> ***(Participant D)***

In the example above, the participant highlights the pleasant experience and feelings he felt during his in-patient rehabilitation, expressing his satisfaction with the treatment he received from the healthcare staff. In this case the healthcare context and the delivered rehabilitation services had a direct positive effect on the way the participant experienced the changes caused by the stroke, without being affected by any negative preconceptions that he might have regarding the clinical environment. According to his narrative, the trust and love received by the healthcare staff resulted in a satisfying lived experience, as it formed a familiar and friendly hospital environment for patients. The participant further illustrates how significant the effect of these contextual factors was on boosting his morale and well-being and consequently on his overall rehabilitation experience.

Contrary to the previous example, the following quotations demonstrate the unpleasant sentiments and perceptions that participants held regarding the hospital setting, regardless of the actual positive assessment of the overall treatment they had received by 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)***

In the first example above, the participant acknowledges her negative experience regarding the speech and mobility limitations that were caused by the ABI incident, which made her feel sad and frustrated. While the participant states that she was satisfied with the health care treatment delivered by the healthcare staff, it seems that the clinical setting per se was experienced by the participant as an unattractive and restrictive environment contributing to her uncomfortable emotional state during her in-patient rehabilitation. This experience probably stems from her pre-existing perceptions about the hospital setting which were reinforced in combination with the fear and uncertainty she felt about the future due to the changes brought about by the stroke. Similar to the first quotation, participant J expresses a positive experience regarding the healthcare delivery. However, the experience he had of the hospital environment was not a satisfactory one, considering the rehabilitation environment unattractive and dull and expressing his desire to leave. This influenced his rehabilitation and emotional state making feel less enthusiastic and idle.

5.4.1.1 Interpretative Summary of Category

The current category presents the experiences and perceptions of participants regarding the impact of contextual factors on their rehabilitation. In particular, the focus lies on participants' construal about the hospital setting and the rehabilitation care they received. Consequently, the category explores the extent to which participants' lived experiences of these factors indicate a satisfactory effect on their recovery process. The analysis of the data reveals mostly positive perceptions and experiences of the rehabilitation care which older individuals received from the healthcare staff, focusing on the effective communication and overall pleasant relationship that they developed with the healthcare staff during their physical rehabilitation. The friendly atmosphere and positive attitude of the nurses and doctors along with the exceptional services provided within the clinic, were identified as important facilitators for participants' rehabilitation progress. As a result, older individuals achieved an increased sense of well-being, as indicated by the optimism, joyfulness and familiarity that they felt during their hospitalisation. However, this was not judged in the same way by all participants. Paradoxically, while several participants reported that they were satisfied with the care they received, they developed a sense of dislocation which was characterised by a judgmental perception of the hospital environment. In this case their sense of place seems to be obscured by the internalised negative preconceptions regarding the medical environment or even by the negative emotions they have developed (such as frustration and disappointment) due to their functional limitations and lifestyle changes. On the other hand, several participants recognise the positive impact that these relationships within the clinical environment have had on their recovery. The sense of place felt by those older individuals contributed to their well-being during physical rehabilitation, helping them to overcome any unpleasant sentiments that they might have been experiencing.

5.4.2 Category 2: Identifying structural issues in relation to care provision

The second category examines the older individuals' experiences regarding various structural issues that they have identified in relation to their care provision. Their sense of well-being during their rehabilitation was adversely affected with participants expressing unpleasant feelings and complaints about various structural and organisational burdens and hindrances that they faced within the healthcare setting as well as after their discharge. One major issue that was mentioned by many participants relates to the low staffing levels in the rehabilitation department which seems to affect their overall rehabilitation experience:

> *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. I also pooped my pants. Well, first they were holding their nose, then they were doing this and that... I didn't like it. 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... because of the smell... 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)***

According to the participant, the lack of assistance that his wife experienced in the rehabilitation clinic seems to be associated with the short number of nursing staff in the clinic. This is evident by the concerns that he expresses regarding the burden that the lack of healthcare staff puts on patients who do not have their relatives by their side and cannot afford to pay a carer. The unprofessional behaviour that the participant felt by the nurses, also made him feel embarrassed of his condition but also increased his frustration that his wife did not receive any help with his hygiene needs. The whole incident also affected his rehabilitation process and sense of well-being, as he was feeling sad and to an extent guilty about his wife's fatigue instead of focusing exclusively on his recovery plan. While the participant's experience is centered around his disappointment regarding the behaviour of the nurses, he implicitly acknowledges that this negative situation was due to the issue of not having enough staff to complete the daily tasks in the rehabilitation department.

Another salient issue recognised by several participants relates to the high costs of continuing rehabilitation after their discharge:

> *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 gymnast and he helps me a lot...*
>
> ***(Participant K)***

> *I wanted to have a carer to... But how can I have one, this requires money. I'm getting a low pension now. My expenses are many. Having a woman requires money.*
>
> ***(Participant L)***

In both cases the participants expressed their concerns about the high costs of their home rehabilitation. In the first example, the participant faced many challenges regarding her continuation of rehabilitation at home. Living in a rural area has limited her access to affordable formalised rehabilitation services. Private rehabilitation services were very expensive for her to afford, forcing her to stop the specialized physiotherapy sessions. In the second example, the low pension that the participant was receiving made it difficult for her to afford a carer. In both cases the participants are forced to fit into a standardised framework of healthcare provision which is characterised by an unequal distribution of treatment opportunities. In their attempt to rationalise their condition and convince themselves that they are not disconnected from the reality that they live in, they seem to accept this situation as an inevitable and sometimes reasonable state of affairs.

5.4.2.1 Interpretative Summary of Category

The current category explores the felt experiences of participants in relation to the structural and organisational issues that they have identified throughout their in-patient or home rehabilitation. These range from specific organisational deficiencies to broader socio-economic factors that characterise Greece's healthcare system. Participants have identified the lack of adequate healthcare staff in rehabilitation clinics as a fundamental issue that adversely impact on their overall rehabilitation experience as well as on their sense of well-being. This leads to insufficient support which affects their rehabilitation programme both in terms of their recovery progress but also in terms of their emotional state, as they feel neglected and helpless. In addition, the high costs of home rehabilitation in conjunction with the limited access to affordable rehabilitation services especially in rural areas (where many of the participants of this study resided) has increased their treatment burdens, forcing them to give up on their rehabilitation programmes. The participants seem to accept these circumstances as unavoidable in their attempt to make meaning of their new life situation.

5.4.3 Summary of Theme 3

Overall, the third theme presents the interpretations, perceptions and felt experiences of participants about the impact that contextual factors, organisational issues and structural healthcare deficiencies have on their rehabilitation and sense of their well-being. The consequences of these processes are evaluated by the participants in different ways according to their lived experiences and felt emotions. The phenomenological analysis of the data in relation to the third theme meets the fourth objective of this study by demonstrating how older individuals living with an ABI experience their interaction with health professionals within the broader context of in-patient rehabilitation as an important factor that can contribute to their sense of well-being. Finally, the analysis also meets the fifth objective of the study, as it explores the way participants assess the overall impact of Greece's healthcare and rehabilitation system on their rehabilitation through their lived experiences.

The impact of the hospital environment and of the provided care on older individuals' rehabilitation was either positively or negatively assessed by the participants, indicating both pleasant and unpleasant experiences. More specifically, the majority of participants felt a sense of place and familiarity within the hospital setting highlighting the positive impact that these contextual factors had on their recovery. Some participants, however, were more detached and judgmental about the clinical environment displaying a sense of alienation. Regardless, the vast majority of the participants have appreciated the support and encouragement that they received from the healthcare staff. Their felt experiences about the relationship with the nurses and doctors during their in-patient rehabilitation was filled with liveliness, hopefulness and a strong sense of familiarity, leading to a greater sense of well-being. In contrast, the felt experiences of participants in relation to the structural and organisational issues that they identified throughout their rehabilitation process have unfavourably affected older individuals' 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.

5.5 Theme 4: The felt sense of self in the aftermath of ABI

The last theme presents the experiences and feelings of the participants regarding the perceptions they hold about their self-identity following their diagnosis with ABI as well as their self-awareness during their rehabilitation. More specifically, the analysis identifies a distinction between a sense of dependency and passivity and a sense of self-reliance and involvement that participants experience as in-patients but also after their hospital discharge. In their attempt to adapt to the new reality and the challenging process of their rehabilitation, participants strive to make sense of their self, bringing to the surface a multitude of conflicting emotions and experiences. This theme is related with the first and second objectives of the study which aim to explore how older individuals living with ABI sense their well-being when undergoing physical rehabilitation as well as how they feel about themselves in the context within which they exist.

5.5.1 Category 1: Passivity and sense of dependency

Many participants experienced a sense of dependency and passivity during their rehabilitation, either in terms of being passively dependent on healthcare professionals or on their family. This sense of dependency was realised as a result of being unable to perform activities as before due to their ABI condition. In the following quotation the participant describes his dependency on his wife for attending the rehabilitation sessions due to his inability to communicate effectively:

> *No. At first no. My wife was telling me today we were going to do speech therapy to do physiotherapy and I was going wherever I was told I was going. I couldn't react.*
>
> ***(Participant H)***

In the above example, the participant experiences his passivity as an inescapable condition since he was not able to react in the early days of his hospitalisation. Therefore, the reliance on his wife even though not pleasant it was not necessarily felt as dehumanising. In a similar vein, the following quotation illustrates how the participant perceives patients as being passively subjected to the external forces of the rehabilitation process:

> *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)***

In the above case the participant is so eager to recover that he complies with the idea of excessive passivity during his rehabilitation, believing that this is the only way that his rehabilitation will be successful. Therefore, he preferred not to express any complaints that he might have (*"I had put these things in second place"*) and to react with a smile in case he was insulted – although he did not experience any insults according to his account. The participant construes the acceptance of his passivity as a means to an end, that would enable him to focus on his target to recover and to move on.

However, most participants experienced their dependency and passivity during their rehabilitation as a dehumanising condition that leads to unpleasant feelings:

> *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, cooks... I get sad. I would like to do these things myself. I used to do everything myself... Now that's how it is, whether I like it or not...*
>
> ***(Participant K)***

> *[…] the children get tired. I wake them up at night - I happen to go to the bathroom at night [and] they [also] bring the bedpan. It's awful, awful.*
>
> ***(Participant L)***

In the above quotations, participant K feels sad that she is not able to do things by herself, as she used to do before the incident. Also, she does not feel comfortable for having to rely on other persons for her care. She seems to have accepted her situation even though she wishes to somehow regain control of her own health and self. Similarly, for participant L the dependence on her children for doing simple, everyday activities (such as going to the bathroom) has affected very negatively her emotional state.

5.4.1.1 Interpretative Summary of Category

This category illustrates the effects that passivity can have on the emotional state of older individuals living with ABI. The majority of participants who were feeling inactive during rehabilitation expressed intense unpleasant feelings and low levels of wellbeing. This experience rendered them passive recipients of healthcare support and increased their sense of dependency. In some cases, however, participants seem to have acknowledged their passivity as an unavoidable situation, whereas others 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 in relation to how their passiveness can eventually lead to achieving a sense of well-being, illuminates the complexity of the human experience when faced with such challenging situations.

5.5.2 Category 2: Self-reliance and involvement as a means for independence

As indicated in the previous category, the sense of dependency and passivity that was expressed in many of the participants' narratives has generated feelings of sadness and embarrassment. In essence, when in passivity participants are stripped of their self-reliance and dignity. The desire and need to regain their independence and autonomy was noticeable throughout the discussions with all the participants who had experienced the dehumanising sense of dependency after their ABI diagnosis and during their rehabilitation. The following quotations illustrate the change of mood of participants when they managed to regain their sense of autonomy:

> *But I don't have to be [monitored that much now] – and my wife now... I feel a little better now. I feel very well.*
>
> ***(Participant C)***

> *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 two 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)***

Although not fully recovered, both participants felt emotionally and physically well when they managed to regain their ability to act and live independently. This situation revived their morale and enhanced their sense of well-being. The dehumanising conditions that they were experiencing were replaced by a restored sense of personhood and self-efficacy.

The need and aspiration to gain a more active participation and to know more about their rehabilitation was also expressed by many participants. This was further perceived as a means to sustain or regain their independence. In the following quotation the participant had a more active involvement in the decision-making process regarding her transfer from the neurological clinic to the rehabilitation department and the continuation of her rehabilitation. When asked if she was informed about her transfer, the participant answered:

> *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)

The participant expressed openly her opinion and wish about how she wanted to continue her rehabilitation in the clinic, thus asserting her presence and maintaining her self-reliance. User involvement thus appears to be very closely linked to a sense of autonomy which by extension can lead to the improvement of well-being.

5.5.2.1 Interpretative Summary of Category

This category reflects the need and desire of older individuals living with ABI to feel independent and maintain a sense of self-reliance throughout 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. In addition, participants' desire of being 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) highlights their effort to become more autonomous and restore their ability to make their own decisions. Feeling a sense of self-preservation had a positive effect on the experiences of older individuals and increased their sense of well-being. More specifically, participants felt reinvigorated and more comfortable with themselves hence facilitating their adaptation to the new reality.

5.5.3 Category 3: Making sense of the new identity

The last category of the fourth theme reflects on the ways in which older individuals living with ABI strive to make sense and realise the new changes that have occurred in their lives after their diagnosis. Participants reported a variety of concerns and desires about their self-awareness throughout their rehabilitation process. Many participants expressed their uneasiness about the way they have changed as individuals, experiencing displeasing changes in their character. More specifically, they felt that they have become more sensitive and vulnerable as indicated in the following quotation:

> *I cannot do the things I did before. […] I feel weaker. […] I cry more easily; I get sad more easily...*
>
> ***(Participant E)***

In the above example, the participant highlights his inability to do things as he used to before his ABI diagnosis. The awareness of his new condition has a negative effect on his psychological state by discouraging and reducing his energy and motivation. His weakness has clearly overwhelmed him, as he realises that he has become a more sensitive and vulnerable person, who is unable to easily contain his unpleasant feelings. The felt physical inability transmutes into a sense of dullness and an inability to move forward. Likewise, the next participant highlights his emotional concerns that have resulted from the physical and bodily changes after his diagnosis:

> *I'm having a hard time. Not just some hard 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)***

The participant focuses on the differences between his previous robust physical condition and the mobility difficulties he faces at present. He is fully aware of the negative impact that this condition has on his psychology and overall well-being. The way he makes sense of himself indicates the unpleasant experience that he has throughout his rehabilitation. This realisation confines him, leading him to remember his past self while evading to think about how he could move forward.

In contrast, the following quotation shows how the participant accepts and faces her situation more optimistically:

> *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 neighbor 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)***

In this case the participant welcomes and appreciates the feelings of joy in her life. She describes herself as an optimist and self-sufficient person. These personal traits and her attitude towards life has helped her overcome the difficulties of her condition. Her experience of wellbeing emphasises a high-spirited mood that has a meaningful quality of buoyancy and a welcome desire to move forward. Laughing and smiling against the struggles of her life constitutes a coping mechanism that positively impacts on her emotional state.

5.5.3.1 Interpretative Summary of Category

This category emphasises the different ways that participants were making sense of their everyday life after their ABI diagnosis and throughout their rehabilitation. There is a variety of experiences in the narratives of older individuals regarding the ways they are trying to cope with their new life situation. The physical changes that have occurred due to the ABI have affected many participants emotionally, as they realise the noticeable changes in their self and the difficulties and struggles that they are facing. This self-awareness intensifies their unpleasant feelings, bringing about a strong sense of disappointment and pessimism which does not allow them to move forward. Some participants, however, develop a more optimistic attitude towards their new life, by realising their self as a horizon that is 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.

5.5.4 Summary of Theme 4

The current theme demonstrates the different experiences and feelings which the participants have sensed during the process of realising their self after their diagnosis with ABI and during their rehabilitation. The phenomenological analysis of the data in relation to the fourth theme meets the first and second objectives of this study by demonstrating how older individuals living with ABI experience and conceptualise emotional and physical well-being through the different perceptions, feelings and experiences of their personhood in relation to the context within which they exist throughout their rehabilitation process.

The felt sense of passivity and its ensuing lack of independence is juxtaposed with the felt or desired sense of self-sufficiency and independence. The former is linked with unpleasant experiences and emotions bringing about a loss of meaning in their lives. In some instances, however, embracing passivity during rehabilitation is recognised as a defense mechanism and as a motivator for achieving recovery. Developing a sense of self-efficacy and agency constituted a desired process by the participants. It was mainly associated with pleasant emotions and experiences and pertained not only to the ability of acting and living independently but also to their need of being more actively involved in their rehabilitation process. Lastly, the analysis indicated the different experiences of participants regarding the process of making meaning of their new reality throughout the challenging stages of their rehabilitation. Several participants developed a pessimistic attitude towards their new life as they have been negatively affected by the changes that have occurred, whereas other participants had adopted a more hopeful and optimistic attitude that motivated them to move forward, thus contributing positively to their well-being.

CHAPTER 6: TENTATIVE FRAMEWORK

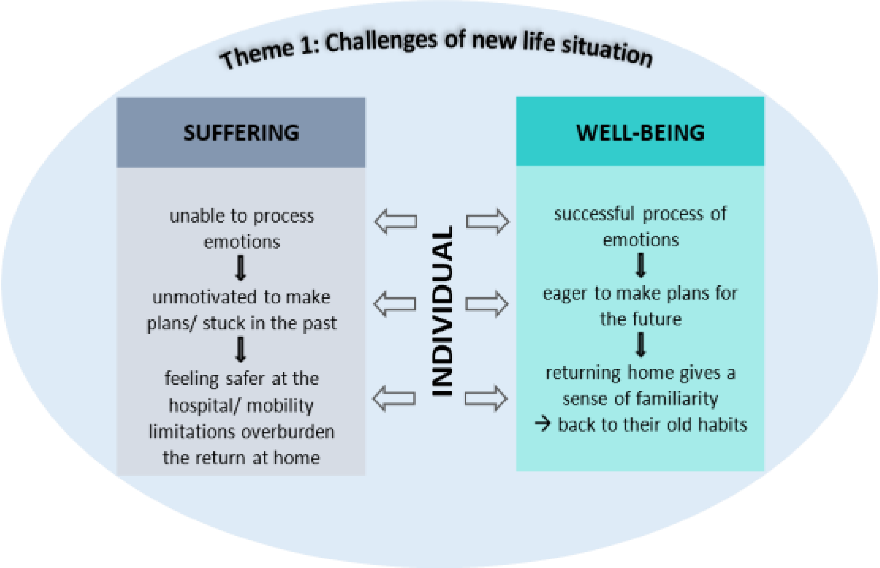
6.1 Introduction

This chapter reveals the relationship between the themes as developed in the analysis chapter with the aim to generate a tentative framework. The interpretation and synthesis of the findings revealed three dimensions (subjective, inter-subjective and contextual) which served as conceptual lenses for elucidating the various links and patterns between the themes and categories. In the following sections, each theme is revisited, by conceptually linking and connecting individuals' experiences and feelings during ABI rehabilitation to their sense of well-being and their sense of suffering respectively. The focus on both concepts of well-being and suffering will contribute to the understanding of older individuals' needs regarding their ABI rehabilitation. The different subjective experiences, intersubjective relations and contextual conditions influence and determine older individuals' experiences of their well-being as well as the realisation of their new reality. The chapter concludes by identifying and explicating the framework for exploring the impact of ABI rehabilitation on older individuals' experiences and sense of well-being.

6.2 Challenges of new life situation

The challenges of new life situation refer to the conditions that older individuals subjectively experience regarding their new way of living. The various considerations that older individuals living with ABI face are related either to their sese of well-being or their sense of suffering (Figure 6.1).

Figure 6.2 *Theme 1: Challenges of new life situation*



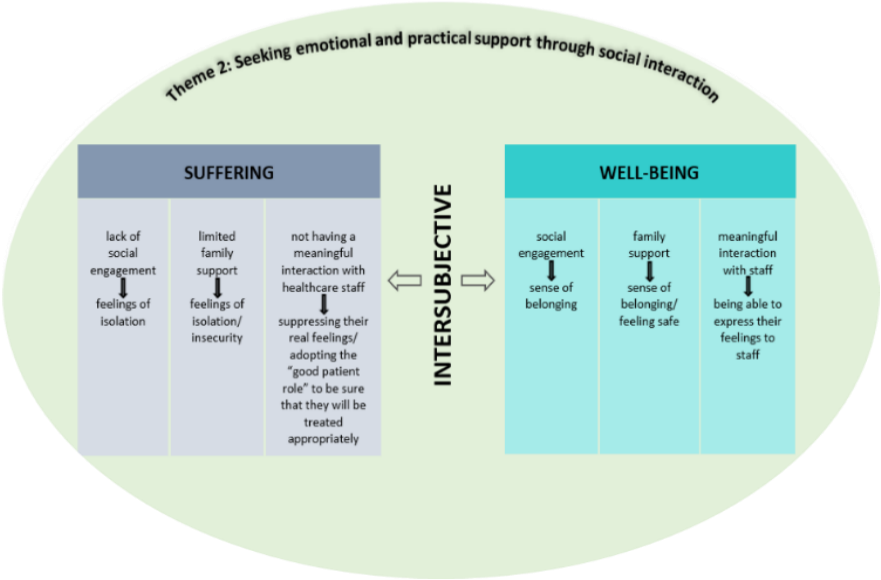
As it is reflected in the findings, older individuals who are able to successfully process their emotions experience a sense of well-being. In particular, when older individuals are able to embrace their new way of life and deal productively with the new reality are more willing to make future plans. At the same time, older individuals that have already accepted the new life situation are more enthusiastic and prepared for their return at home after the inpatient rehabilitation. In this case, returning home offers a sense of familiarity to older individuals, thus making them feel human beings again. This further enables them to return to their old habits but also to pursue new activities for the future.

On the other hand, a sense of suffering is experienced when older individuals are not able to process their emotions and feelings. This happens if they remain trapped in the past and they are not eager to make plans for their future. When older individuals return home, they may feel different compared to their old selves, and home (contrary to their expectations) is not felt as a safe and familiar place anymore. These feelings are related to mobility limitations as well as people being unable to recognise and accept their new life situation. In this case, they do not manage to retrieve their human identity developing instead a sense of displacement.

6.3 Seeking emotional and practical support through social interaction

Older individuals living with ABI and undergoing physical rehabilitation seek for emotional and practical support through their social interactions. Older individuals' intersubjective experiences of social engagement or marginalisation leads to a felt sense of well-being or suffering respectively (Figure 6.2).

Figure 6.2 *Theme 2: Seeking emotional and practical support through*



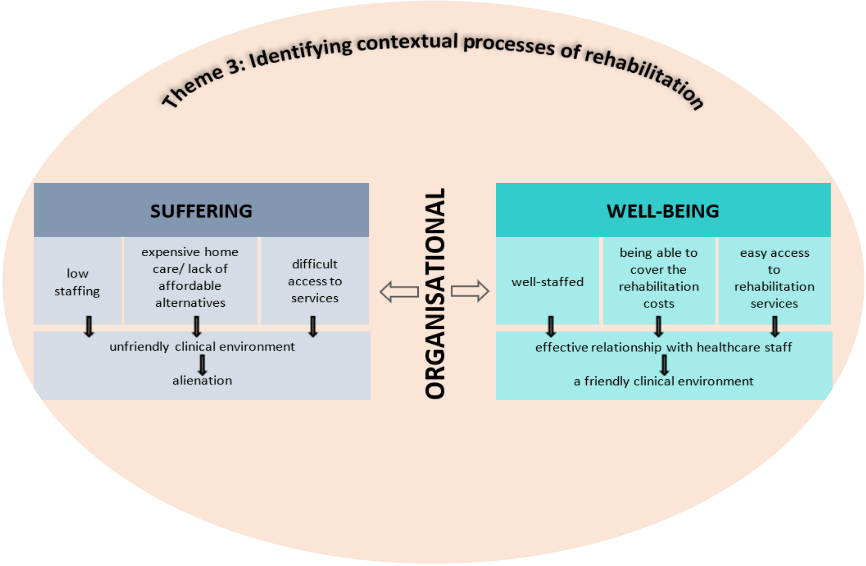
Based on individuals' narratives, social interactions may refer to those with their families, the health professionals who are responsible for their care and treatment and/or their friends. Through social engagement and involvement in activities older individuals enhance their sense of belonging, helping them feel as accepted members of a group or active members of the society. In the same vein, being part of a family is a crucial aspect of older individuals' sense of well-being. Older individuals who receive family support, feel a strong sense of belonging and thus enhance their sense of well-being. Family offers encouragement, hope and motivation to continue with their rehabilitation and to keep being optimistic for their future. Lastly, during ABI rehabilitation older individuals seek meaningful interaction with healthcare staff as this makes them feel not only engaged and accepted but also empowers them to convey their real emotions and thoughts.

There are also suffering experiences which result from the lack of social engagement. In these cases, older individuals do not feel as actively involved members of the society and as a result they experience feelings of isolation. In addition, feelings of insecurity are also observed through the limited family support that older individuals may receive. Lastly, there is a lack of felt sense of well-being for older individuals when meaningful interaction with healthcare staff is not achieved. When older individuals experience such a situation, they adjust their attitude and behaviour during rehabilitation in such a manner so as to receive the expected care and attention from the healthcare staff (e.g. by not complaining even though they are not satisfied with the healthcare received).

6.4 Identifying contextual processes of rehabilitation

Various organisational and contextual aspects have also been identified as key factors for determining the felt sense of well-being or suffering that older individuals living with ABI might experience (Figure 6.3).

Figure 6.3 *Theme 3: Identifying contextual processes of rehabilitation*



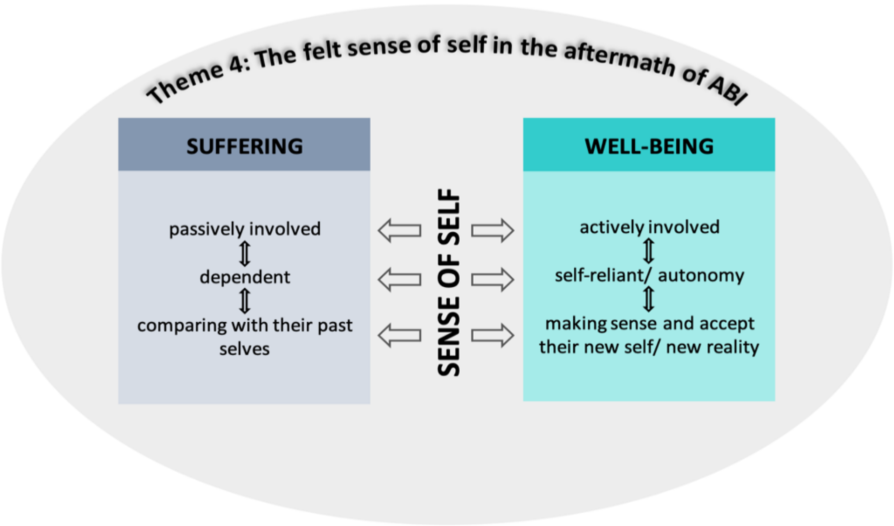
In particular, older individuals have associated the organisational conditions related to the clinical environment with the attainment of a sense of well-being. The adequate staffing of the rehabilitation department facilitates the process of healthcare provision and sustains the quality of delivery, ensuring that the process of rehabilitation for older individuals runs smoothly and their needs are effectively and fully accommodated by the healthcare staff. Moreover, the ability to cover rehabilitation costs along with the opportunity to easily access the rehabilitation services alleviates any potential financial and movement challenges that might disrupt their rehabilitation after being an inpatient, leading to a better emotional state with less stress and concerns. Overall, these parameters maintain an effective and fruitful relationship between older individuals and healthcare professionals, creating a friendly and familiar rehabilitation environment that enhances the felt sense of well-being.

In contrast, those older individuals who have unfavourable experiences in relation to these organisational issues in the clinical environment develop a sense of suffering during their rehabilitation. Specifically, the understaffing of departments can largely disrupt the process of rehabilitation and also adversely affect the quality of care delivery, leading to unpleasant feelings and a felt sense of suffering. In addition, the issue of unaffordable care alternatives especially after inpatient rehabilitation and the difficult access to rehabilitation services (especially in rural areas) impact adversely on their rehabilitation, generating a sense of insecurity and precariousness regarding their future progress. This leads to an unfriendly and insecure rehabilitation environment, leading to the alienation of older individuals.

6.5 The felt sense of self in the aftermath of ABI

The most important parameter for older individuals to achieve a sense of well-being is to accept and become aware of the new changes in their lives after the ABI incident. In cases where people are unable to embrace their new reality, individuals are faced with a sense of suffering (Figure 6.4).

Figure 6.4 *Theme 4: The felt sense of self in the aftermath of ABI*



Although the ABI incident entails life changing consequences, individuals can evolve and adapt to the new conditions by making sense of and accepting their new reality. In this case older individuals are actively involved in their rehabilitation procedures which augments their sense of independence. Their sense of autonomy is further increased if they feel more empowered and are able to perform daily activities by themselves without having to rely to the help of others. Through these interrelated processes, individuals develop a felt sense of well-being that empowers them to move forward with their life and redefine their self in view of their new reality.

On the other hand, in their attempt to regain their identity, some individuals do not manage to appreciate and accept their new reality. People can become overwhelmed with sentiments of passivity if they do not feel empowered to engage dynamically with their rehabilitation and recovery process. A sense of dependency on others can increase their sense of suffering. In this situation, individuals are unable to fully realise their future prospects; instead, they compare their new challenging condition with their past selves, by recalling the time before the incident as a state of normalcy that they would like to return.

6.6 A framework for the impact of ABI rehabilitation on older individuals' sense of well-being

This section explicates the framework of well-being for older individuals living with ABI, presenting its contribution to the analysis of the impact of rehabilitation on older individuals' sense of well-being. The Framework consists of four components that relate to the themes developed in the previous sections:

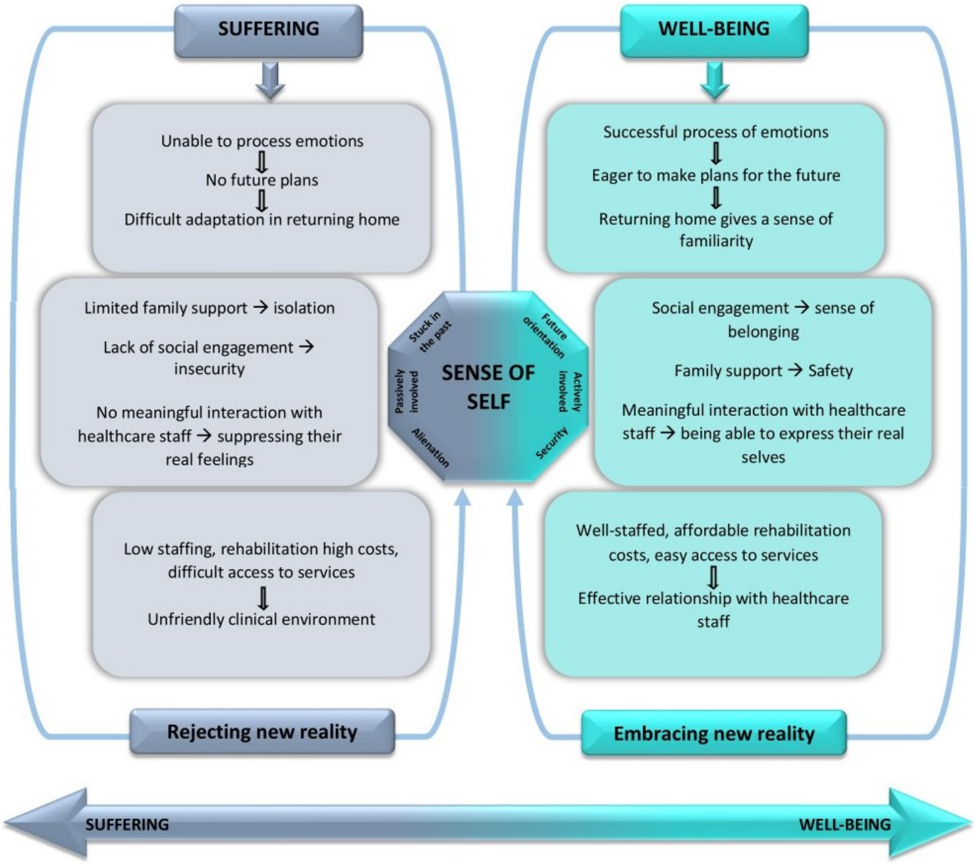
i. Challenges of new life situation
ii. Seeking emotional and practical support through social interaction
iii. Identifying contextual processes of rehabilitation
iv. The felt sense of self in the aftermath of ABI

The framework is developed around the felt sense of self which highlights older individuals' adaptation or not to their new life after the ABI incident. Their felt emotional and physical state as well as their conceptualisations regarding their new reality, are influenced and experienced as an interrelation of different subjective experiences, intersubjective relations and contextual conditions.

The framework develops specific patterns drawing on the interrelation between the first three themes/components, which indicate the personal and interpersonal parameters as well as contextual aspects that lead either to a felt sense of well-being or suffering. The different states of well-being and suffering are then contrasted, signifying their diverse impact on older individuals' realisation of their new reality. In this sense, the fourth theme comprises the core component of the framework, by representing a mixture of the other three themes/ constructs. The components identified in the fourth theme correspond to particular features and aspects of the other three themes.

The relationships within and across the four components identified and established in this framework are visually represented in the form of a cyclical diagram to provide comprehensive explications and explanations of the well-being experiences and conceptualisations of older individuals with ABI during rehabilitation (Figure 6.5).

Figure 6.5 *A tentative framework for the impact of ABI rehabilitation on older individuals' sense of well-being*



When older individuals achieve a felt sense of well-being, they manage to accept and embrace their new reality. Well-being is achieved when older individuals manage to successfully process their emotions during their rehabilitation. Their return at home further enhances their emotional state, as this marks the return to a calm and familiar environment. In this situation, older individuals may also experience a sense of continuity and purpose, that motivates them to make plans for the future. Older individuals can also attain an increased sense of well-being through their social engagement and active involvement in their rehabilitation. Successful interpersonal relations with the healthcare staff can reinforce their sense of belonging while also enabling them to express their real selves. Furthermore, the full support that they experience from their family establishes a sense of safety and stability. Organisational and structural aspects related to the clinical environment and rehabilitation services (i.e., well-staffed departments, easy and affordable access to rehabilitation and friendly clinical environment) contribute to the overall improvement of older individuals' emotional and physical state. Overall, the achievement of well-being reflects an optimistic self-realisation, characterised by a sense of independence, feelings of security and familiarity, active involvement in various activities, and a positive future orientation.

On the other hand, older individuals may hold a pessimistic conception of their new life as a result of a sense of suffering that they may experience during rehabilitation. This felt sense of suffering is experienced by older individuals when they are unable to process their emotions successfully. Thus, they remain trapped in a nostalgic reminiscence of the past, without anticipating about their future possibilities. At the same time, a sense of displacement is created as due to the emotional and physical challenges that they encounter, they find it difficult to adapt easily upon their return at home. As regards their interpersonal experiences, older individuals may receive limited help and support from their family, they do not develop a meaningful interaction with the health staff, while also not being able (or eager) to actively engage into their rehabilitation process. The limited and non-meaningful social interactions create a sense of isolation, insecurity and dependency, which leads older individuals to suppress their emotions. Finally, the sense of suffering is also greatly influenced by organisational and contextual clinical aspects. The low staffing of departments, the high costs and the difficult access to rehabilitation services create an unfriendly clinical experience, which further intensifies the feeling of suffering. In short, older individuals seem to feel a sense of dependency and alienation, as they remain passively involved during the rehabilitation process, while at the same time they seem to remain stuck in the past without any expectations for the future. In this state of suffering, the process of self-realisation becomes unfruitful, resulting in older individuals rejecting their new reality.

This relationship however is not causal/ exclusive. There are many variations regarding the sense of well-being or suffering that older individuals may experience during ABI rehabilitation, indicating more complex experiences and feelings. A person may experience circumstances which can lead to a sense of wellbeing but also some aspects leading to suffering. At the same time, individuals may vary over time in how they see themselves and their lives. For example, there were cases of older individuals who were in a better position physically during their recovery enabling them to feel a sense of independence. However, when asked about their future plans they expressed more unpleasant feelings and views, thus indicating a lack of future orientation. For this reason, the different features presented in this framework are not separate nor indicate a clearcut juxtaposition but imply a continuum within which more nuanced experiences can be identified.

6.7 Conclusion

According to the above tentative framework, older individuals' sense of well-being and realisation of the new changes in their lives after the ABI is experienced as an interrelation of different subjective experiences, intersubjective relations and contextual conditions. The framework is based on the acknowledgement that the well-being possibilities of older individuals who live with ABI and undergo physical rehabilitation intertwines with their realisation or rejection of the new reality after the ABI diagnosis. Older individuals may thus develop a sense of well-being when they are able to accept and regain their sense of self. In this case, they manage to successfully process their emotions, they are eager to engage in social interactions, and they have an effective relationship with the healthcare staff, which strengthens their sense of future orientation. In addition, older individuals may experience a sense of suffering when they do not manage to come into terms with their new situation after the ABI. They usually remain stuck in their past feeling a sense of helplessness about their current situation. Their social interactions are also limited as they feel isolated within an unfriendly clinical environment. It should be noted however that these observations do not constitute absolute values; they rather function as points of emphasis for revealing older individuals’ needs, feelings and difficulties during ABI rehabilitation. Taken together, the findings of this study and the resulting tentative framework put forward an existential and phenomenologically informed approach that could be used for interpreting older people's experiences of well-being, while also providing a guiding framework for healthcare professionals as they seek to improve the quality of care through the delivery of dignified and humanising care.

CHAPTER 7: DISCUSSION OF THE FINDINGS

7.1 Introduction

This thesis aims to explore and acquire an in-depth understanding of older individuals' experiences of their lifeworld when undergoing physical rehabilitation, following ABI diagnosis, in relation to their sense of well-being during care provision within the Greek Healthcare System. The current chapter aims to relate the findings of this study to the existing literature, while also showing the ways that it moves beyond it. The critical interpretation and discussion of the findings (as these were analysed and sorted out in chapters 5 and 6) will be compared and contrasted to other research studies that focus on rehabilitation and healthcare interventions related to chronic and life changing conditions. Furthermore, the discussion will provide novel understandings on older individuals' lifeworld experiences when living with ABI, focusing on their felt emotions during rehabilitation. The lifeworld approach and theoretical model of existential well-being (as described in Chapter 3) by Galvin and Todres (2013) will be utilised for the discussion of well-being conceptualisations and experiences, focusing specifically on the dwelling-mobility dimensions of well-being. The chapter is structured according to the key thematic axes that were identified in the proposed tentative framework (Chapter 6).

7.2 Subjective experiences and emotions: Challenges of new life situation

The findings of the current study indicate a variety of lifeworld experiences that older individuals living with ABI deal with during the overall process of their rehabilitation. In many cases, older individuals expressed several existential concerns in their narratives about their new life situation as a result of the new life-changing conditions and limitations that their ABI imposed upon them. In this sense, the diagnosis of ABI was a major turning point in their lifeworld, in that it was an event that substantially changed their life bringing up new thoughts, emotions, experiences as well as possibilities of learning and understanding their new life situation. By examining the movement towards a new life with a chronic condition from a phenomenological perspective, Berglund

(2014) highlights the possibilities for self-reflection and the pursuit of balance for the individuals within their lifeworld. In the current study, participants described both the ABI diagnosis and the rehabilitation process as difficult and distressing and a time that negatively affected their sense of self-esteem and self-reliance. Such negative existential reconsiderations and thoughts have been also highlighted in relevant research, in that from the point of diagnosis of severe or chronic illnesses and onwards, individuals develop a sense of suffering in relation to their worsening quality of life and the burdens that their condition brings to their daily routines (Nilsson, Jansson and Norberg, 1999; Schroevers, Kraaij and Garnefski, 2011; Benkel *et al.*, 2019). Moreover, in line with the findings in earlier studies looking at stroke patients' rehabilitation experiences (Löfmark and Hammarström, 2005; Olofsson, Andersson and Carlberg, 2005; Tholin and Forsberg, 2014; Loft *et al.*, 2017), older individuals in this research expressed how the inpatient rehabilitation and hospitalisation experiences in a clinical setting have made them feel trapped and restricted, thus overwhelming them with existential concerns and sentiments of docility, subordination and dependency.

The negative thoughts and unpleasant feelings that participants expressed evoked a number of variations. In their most intense form, participants were contemplating the idea of dying as a solution to their condition which was mostly viewed as an inescapable illness. This signifies a suffering mobility experience, which is characterised by a depressive existential mood. Galvin and Todres (2013) describe the felt depression as being constituted by a deficit of "mood mobility", that is a felt inability to move forward, which further involves a pessimistic attitude, a lack of energy and motivation and feelings of voidness and meaningless regarding their future life. The participants that expressed negative existential thoughts and feelings signified a strong sense of suffering thus suppressing or neglecting any pleasant experiences or learning possibilities that they might have had during rehabilitation.

Nevertheless, some participants in this study also expressed mixed feelings, as they were able to harness the negative emotions caused by the life-changing ABI conditions by engaging into a process of self-enhancement and making-sense of their new life. In this way they managed to adapt effectively to the new changes in their life. This indicates a move from the dwelling suffering dimension to a sense of well-being that emphasises a process of dwelling towards a mood of "peacefulness" (Galvin and Todres, 2013). This process reflects a direction towards the acceptance of their ABI condition, which involves patience and a harmony of mind that can lead to further emotional, physical and behavioural improvement. As such, some participants in this study managed to reconsider their life-changing conditions and improve themselves, developing a strong desire to find meaning in their new life situations. However, this process still included the challenges and concerns that one would inevitably experience about their ABI situation as well as the future outcome of their recovery.

This variation also appears in other studies, indicating how individuals may feel positively about the turning point that occurs in their life, by leveraging the possibilities this can offer on learning about their new situation (Rise *et al.*, 2013; Berglund, 2014; Nyvang, Hedström and Gleissman, 2016). In their study about older individuals' experiences regarding stroke and their inpatient rehabilitation, Loft *et al.* (2017) highlight the uneasy feelings and thoughts that older individuals experience specifically about how stroke has altered their understanding of their bodies and self-awareness. However, they also indicate the mixed feelings that many participants expressed, feeling grateful and fortunate for having survived from the stroke and for being able to undertake rehabilitation (Loft *et al.*, 2017). In this sense, their experiences are ambivalent as they find themselves in a peculiar stage of their recovery process.

The various difficulties and adversities induced by the ABI diagnosis and the intensive physical rehabilitation process, aggravated older individuals' negative lifeworld experiences, increasing their existential anxiety. Many participants expressed a sense of self-perceived burden and guilt in relation to the support and care that they were receiving from their close others. This emerged as a major concern for older individuals indicating the existential unease, frustration and discomfort that they were experiencing when receiving familial support, as they felt that they were currently imposing (or are going to impose) physical and emotional burdens to others, especially to their family. Similar findings have been reported by other studies where stroke survivors felt that they were a burden for their closed ones either due to the consequences of their stroke (Dalvandi *et al.*, 2010) or because of the full caregiving responsibilities that family members were loaded with as a result of the insufficient support that stroke survivors received from formal health care services (Simeone *et al.*, 2015). McPherson, Wilson and Murray (2007) have also found a strong sense of self-perceived burden reported by individuals with severe illness, such as advanced cancer. For them it goes beyond benefitting from their family's support; instead, they were considering themselves and the whole process of their rehabilitation as causing hardships and suffering to their loved ones (McPherson, Wilson and Murray, 2007). In the current study, older individuals' perception of self-worth was significantly impacted by perceiving themselves as a burden, leading to a range of unpleasant emotions, such as regret, exasperation and worry about how their excessive care needs affected others. Worry, guilt, and frustration have been particularly recognised as some of the main traits related to the felt sense of being a burden to others (Cousineau *et al.*, 2003).

Together with the self-perceived feeling of being a burden to their family members older individuals in this study have also expressed a felt sense of dependency and the strong desire to die. More specifically, the physical limitations that many of this study's participants experienced as a result of their ABI condition as well as the need for physical assistance increases their feelings of uncertainty and unworthiness and by extension their worries that their current situation will impose difficulties to others. As a result, the only solution according to some of this study's participants for relieving their family of the care burdens is to die. This view is supported by other studies which have discovered a strong association between self-perceived burden, a felt sense of dependency and psychological concerns such as depression, unworthiness and guilt (Chio *et al.*, 2005; Wilson, Curran and McPherson, 2005; McPherson, Wilson and Murray, 2007; Galvin and Todres, 2013).

The concerns that older individuals expressed in this study related to their unpleasant perceptions that they hold about their future orientation. Many participants indicated in their narratives how the impact of ABI and its long-term consequences had affected their lifeworld perceptions, causing them feelings of uncertainty and meaninglessness about their future. Uncertainly can be experienced as a form of anxiety about the unpredictability of poststroke physical and bodily capacities, which is often caused by periods of slowed or halted recovery or due to physical or emotional burdens that might be experienced during rehabilitation (Lou *et al.*, 2017; Dongen *et al.*, 2020). These feelings can disappoint individuals and make them feel uncertain about what the future might hold or even whether they would ever "get back to normal." (Salter *et al.*, 2008; Lou *et al.*, 2017). In the same vein, many older individuals in this study express a lack of interest in making future plans as they do not believe that their ABI condition nor their recovery prospects can provide any meaningful purpose for moving forward.

This further indicates their struggle and vulnerability in effectively adapting to and accepting their changed life. On the one hand they do strive to carry on, wishing that they will be healthy and independent. However, their efforts are undermined by negative feelings that they develop regarding their age and the unpredictability of their condition status, thus making them feel unmotivated to carry on. For them, the ABI condition is felt as a breakdown in their lives, setting a new reality that blocks any future expectations.

Following Galvin and Todres (2013) framework, this study has found that the temporal perceptions of participants have been largely affected by the ABI condition and its consequences. Participants expressed a sense of temporal stagnation during their rehabilitation, feeling that their recovery and in general their future orientation has been blocked without having any opportunity to move forward (Galvin and Todres, 2013). This form of suffering was further associated with recollections of their past self, as participants were juxtaposing their past more active and energetic self to the uncertain, unsafe and in some cases intolerable present circumstances that they were experiencing - what Galvin and Todres, (2013) describe as the felt sense of an “elusive present”. The intense form of present unsettledness was often coappearing with a felt sense of depression. In some cases, the emphases of dwelling and mobility were intertwined leading to a sense of what Galvin and Todres (2013) describe as ‘no respite’. As such, participants felt that the continuity between the past, the present and the future has been disrupted. Participants felt their past life along with the unpleasant feelings that they were experiencing due to their condition was pulling them back, not allowing them to embrace and find peace in their present situation, while further deepening their anguish and despair leading to a self-perceived lack of future mobility.

Nevertheless, some participants illustrated a strong will to continue living and making future plans despite their condition and the difficulties of their rehabilitation. These participants manage to find a positive outlook towards a welcoming future, by accepting and overcoming their present adversities and being ambitious about getting better in the future. This gradual acceptance of their ABI condition indicated a strong sense of “present centeredness”, where individuals are absorbed by their present situation, accentuating what is happening in their lives in ways that are valued and wanted (Galvin and Todres, 2013). Within this variation of “present-centeredness”, the presence of their family or a caring health care professional was experienced as an anchor to their reality that would motivate them to move forwards. This is also highlighted by Berntzen *et al.*

(2020) and Flinterud *et al.* (2021) who describe how caring and social aspects, such as the presence of family or healthcare professionals during the participants' recovery process, serve as a means of moving from an "elusive present" to "present-centeredness". In the current study, the recalling of past-self provided an additional driving force for those participants who developed a sense of "present-centeredness" to further carry on, as their perception of recovery was based on retrieving their past self and capabilities in the future.

Simultaneously, the temporal dwelling of "present-centeredness" that individuals in this study have expressed fostered a felt sense of temporal mobility, that is a sense of "future orientation". During their rehabilitation participants developed a future orientation, which further led them to the temporal dwelling-mobility dimension of well-being, called "renewal" (Galvin and Todres, 2013). "Renewal" encompasses how the participants felt and described embracing their ABI experiences, either by accepting or taking their ABI condition for granted as an unavoidable step towards their future recovery, while integrating their rehabilitation experiences with the desire of leading a different and improved life after their recovery. In this study, participants' sense of their present but also their past life stories set the ground for movement towards a future that opens up (Galvin and Todres, 2013). In line with the findings of this study, Synnes *et al.* (2020) show how their participants redefined their various abilities, struggles and challenges in living with chronic illness as new resources and ways for carrying on, thus energising them to continue living meaningful lives. Flinterud *et al.* (2021) also indicate a process of moving towards a felt sense of "reneweal", as participants sought to integrate their critical illness experiences into their new everyday life, subsequently redefining their identity and creating a new normality and strived to move towards a hopeful and possible future.

Despite the fact that some participants manage to find a positive future orientation in their various ways, the fragility and vulnerability that is still displayed in all their narratives should remind us how fragile the balance is between moving from a felt sense of well-being to a felt state of suffering and vice versa (Synnes *et al.*, 2020; Flinterud *et al.*, 2021). Surviving and living with a chronic and life-changing condition such ABI is more than just recovering. It can challenge the perceptions of one's identity, by giving rise to newfound understandings of life. These can lead to either negative experiences of the present situation and a lack of future orientation or provide a new positive awareness of what one still has as well as of the new opportunities that lie ahead (Frank, 2013; Synnes *et al.*, 2020).

The process of returning home after inpatient rehabilitation was also described as a major transition for older individuals in this study. For many participants their return at home was experienced as a positive spatial movement from the alienated and unfamiliar hospital environment to a place that was felt secure and familiar. Despite the challenges of adjusting to this new reality, their return at home generated a sense of well-being. In the same vein with other research, participants in this study expressed feelings of relief, calmness and comfort, as they felt that their home was providing them a feeling of strength, independence and usefulness as well as protection to their privacy and identity (Gillsjo and Schwartz-Barcott, 2011; Silverglow *et al.*, 2020). In line with Molony (2010), home enabled the participants of this study to further develop a strong sense of social connection with their family and friends.

In these cases, going back home strengthened their sense of well-being providing a strong positive sense of 'being and feeling at home'. Being at home was perceived as an experience of welcome 'dwelling' offering a sense of peaceful settling and stillness. In some cases, however, this sense of 'settled at homeness' offered possibilities for more adventures and journeys (either metaphorical or literal). This unity of spatial mobility and dwelling in well-being provides a felt sense of 'abiding expanse', indicating both the safety and settledness of home but also the movement possibilities that familiar surroundings can provide to individuals. For example, looking at her garden from her window one participant could feel both the calmness but also the joy that she would feel by playing with her grandchildren when they would come to visit. The stillness of the grass was complemented with the spatial movement and energy of playing with her children on it. This reconnection with her own place offered a sense of familiarity, while also making her feel alive again - by opening up the possibility for embodied and emotional mobility.

Many participants, however, experienced difficulties or disappointment upon or after their return at home. The realisation of the difficult new conditions at home that stems from their mobility limitations aggravated these participants' view of their residence as an unpleasant environment. The findings of this study are in line with the results presented in the relevant literature regarding the changed perceptions that older individuals experience about their self and spatial mobility when returning home - as they are not able undertake the same activities as prior to the stroke incident (Olofsson, Andersson and Carlberg, 2005; Wottrich, Åström and Löfgren, 2012; Nordin, Sunnerhagen and Axelsson, 2015; Hartigan *et al.*, 2011; Simeone *et al.*, 2015; Hestevik *et al.*, 2019).

As Nordin, Sunnerhagen and Axelsson (2015) claim, for individuals who have suffered a stroke coming home is ultimately a difficult situation as their abilities and capacities have changed compared to before stroke. In their study, Nordin, Sunnerhagen and Axelsson (2015) indicate how individuals experience mixed expectations when returning home, which reveals their ambivalence about being discharged from hospital. The initial sense of joy for coming home thus turns into an illusion of returning to normality for stroke survivors as most of them quickly realise that their old habits and routines no longer apply in their situation - or at least not in the same way as they thought it would be since they are no longer the same person due to their limited mobility.

The unrealistic expectations that individuals often have about their return and continuation of rehabilitation at home (either as a consequence of their ABI or other limitation) may lead to a felt experience of one’s home as an unknown place in contrast to the home as a familiar setting that would facilitate recovery and the rehabilitation process (Nordin, Sunnerhagen and Axelsson, 2015). As a result, the variety of distressing emotions that usually occurs to patients after stroke such as anxiety, fear and insecurity may worsen, causing disappointment about their return at home and further compromising their home adaption as well as their recovery process (Hartigan *et al.*, 2011; Nordin, Sunnerhagen and Axelsson, 2015).

However, it should be pointed out that feelings of anxiety, uncertainty and fear about their limitations and the way these would affect their home integration were expressed by the majority of this study’s participants - which is a normal reaction considering the life-changing consequences that older individuals have experienced due to ABI. Similarly, to the findings in Hartigan *et al.* (2011), despite being anxious older individuals in this study were determined to return home with the hope to regain their autonomy and return back to normality. Hartigan *et al.* (2011) further present how their participants’ optimism overshadowed their limitations and distressing feelings, by considering their home as a familiar and safe place and their return as an important step in recovery that would enable them to regain control and become self-reliant. According to Nordin, Sunnerhagen and Axelsson (2015) hope as well as the (sometimes unrealistic) expectations that individuals develop about returning home can be an important boost for their emotional well-being, positively affecting their recovery.

The distressing feelings that older individuals have experienced with regards to their return at home have been also associated with the positive experiences that some participants expressed about their inpatient rehabilitation. They perceived the hospital environment as a safer and more secure place for pursuing their successful recovery, while feeling uncertain about the continuation of their rehabilitation at home. This felt sense of familiarity that these individuals experienced within the clinical environment, led them to develop a series of unpleasant feelings about their homeplace, which negatively affected their emotional state as well as their motivation for further rehabilitation upon their return at home.

Similar findings have been presented by Wottrich, Åström and Löfgren (2012) who indicated that participants were feeling ambivalent about the unknown environment that they will meet at home in contrast to the safety they were feeling in the hospital ward. Moreover, their participants described the lack of confidence they felt regarding their own abilities after their discharge, indicating the unmet expectations that they experienced regarding their recovery. For them physical training was mainly associated with the physiotherapy sessions they were receiving in inpatient rehabilitation. As a result, their rehabilitation at home as well as their social interactions were compromised as they were worried about not receiving the same professional rehabilitation support as before while also experiencing less improvement than expected (Wottrich, Åström and Löfgren, 2012). However, no study has been found that indicates participants' clear preference for the hospital environment in comparison with a distressing spatial experience of returning home.

In the current study, participants described divided feelings about what life would look like after coming home. These pertain to a combination of positive expectations about their return and continuation of their life at home but also fear about the impact that the new changes would have on their future prospects, abilities and routine. Olofsson, Andersson and Carlberg (2005) have also indicated the different feelings that older individuals with ABI might experience upon their return at home. One the one hand, older individuals' have expectations about 'coming home'. These are partly fulfilled by the felt familiar social environment and the closeness of their family members, while also re-establishing their self-esteem by managing to feel oneself again (Olofsson, Andersson and Carlberg, 2005). At the same time, when returning home, older individuals experience a significant change with regards to their sense of self and their daily routines. They feel that they are not the same people as before, since now they perceive themselves dependent on others and unable to perform tasks as before – making them feel insecure and anxious about becoming ill again (Olofsson, Andersson and Carlberg, 2005).

7.3 Intersubjective relations: Emotional and practical support through social interaction

This study has highlighted the significance that social connectedness and meaningful social interactions have for the rehabilitation of older individuals living with ABI as well as its contribution to the overall sense of self and wellbeing, supporting the work of Martin, Levack and Sinnott (2014). Social interactions are associated with a wide and diverse network of social ties and activities, including interactions with close family and friends as well as with more peripheral encounters (i.e., individuals or groups outside the network of close social ties) (Fingerman *et al.*, 2019). Peripheral encounters in the current study refer to participants being involved in community or leisure activities or interacting with the healthcare staff in the clinical environment. Based on participants' narratives, this study demonstrates the strong beneficial effects that social relationships can have on older individuals' well-being.

Focusing on the social lives of older adults whose health status varied, Fingerman *et al.* (2019) have confirmed the contribution of socially engaging with close and peripheral social ties in improving older individuals' health and well-being. More specifically, there has been evidence that older individuals living with ABI who have developed close personal relationships further experience a strong support system which can improve well-being after their diagnosis (Elloker and Rhoda, 2018). This can reinforce older individuals' socialisation and participation in activities as well as their return to their work or hobbies, thus increasing their functional and psychosocial recovery prospects (Wang, Kapellusch and Garg, 2014; Norlander *et al.*, 2016; Elloker and Rhoda, 2018). As participants in this study reported, experiencing meaningful social interactions had positive effects to their sense of self-esteem, making them feel unique, valued and accepted.

The intent for “meaningful” interactions as expressed by the participants needs to be taken into consideration as an important parameter for understanding the type of social encounters and the quality of support that participants experienced during their ABI rehabilitation. Older individuals focus on establishing social interactions that would feel meaningful to them and by extension benefit their well-being, according to their social needs, personal interests and perceptions of what they believe is meaningful for their life (Söderberg and Emilsson, 2021). Based on Söderberg and Emilsson’s (2021) research, older individuals employ various strategies for strengthening the conditions of meaningful social interactions in the context of eldercare services based on personal choices and initiatives. These strategies range from socialising with people who share common interests (for stimulation or fun) or participating in activities for the sake of companionship, to interacting with the healthcare staff (e.g. by having some small talk with them in order to feel better or when in need of social support in difficult times) (Söderberg and Emilsson, 2021).

The need for mutual affection and closeness expressed by many participants in the current study further relates to the functional and emotional vulnerability that they were feeling due to their condition. In addition, the factor of aging and the marginalisation that some of them have experienced after their diagnosis can also be part of the cause for their pursuit for external and self-validation through social encounters. Research has shown how individuals with ABI often experience misunderstanding, stigmatisation and negative attitudes due to their condition (McLellan, Bishop and McKinlay, 2010; Wilkie *et al.,* 2021). The impact of these negative attitudes to older individuals living with ABI can become more intense, considering the discrimination that these persons may also experience on the basis of their age (Kydd *et al.*, 2018).

Overall, social interactions for older individuals in this study were viewed as an important driver to socialise, that is to engage in ongoing dialogue and participate in social activities. This correlates to a well-being experience that emphasises what Galvin and Todres (2013) have defined as ‘mysterious interpersonal attractiveness’. This experiential state involves a desire or attraction towards the interpersonal possibilities that offer a sense of movement. In this sense, older individuals are intrigued by the opportunities of interpersonal interactions that lie ahead, which motivates them to socialise and keep in contact with the outside world. Their capacity to engage in a diverse array of social ties, becomes stronger especially when effective and meaningful communication is achieved.

Family interaction and support were also described by the participants of this study as a significant well-being experience. The meaningful social ties that most of the participants maintained with their closed ones contributed to the improvement of their physical rehabilitation and well-being outcomes, as the care assistance and emotional support provided by their family instilled older individuals with self-confidence and encouragement to carry on with their rehabilitation. The findings of this study are further corroborated by relevant research which also highlights the vital role that family emotional and practical support can play in improving the rehabilitation experiences, emotional state and recovery prospects of older individuals with ABI (Galvin, Cusack and Stokes, 2009; Galvin *et al.*, 2011; Lawler, Taylor and Shields, 2015; Bennett *et al.*, 2016; Loft *et al.*, 2017). Family support can further contribute to older individuals' interaction with peripheral social ties, fostering their re-integration back into the community and empowering them to participate more actively in leisure activities (Beckley, 2007; Elloker and Rhoda, 2018).

Family's involvement in older individuals' care constitutes a distinctive feature of the Greek society, which is generally characterised by strong family support networks. This is further linked to the central role of the family which can be generally observed in Mediterranean countries in terms of welfare provision, where family usually functions as an alternative to state services and benefits intended for the provision of elderly care (Gal, 2010). In Greece, as in other Mediterranean countries, caring for older individuals is still very much perceived as a family obligation and responsibility. This stems from the enduring sense of family solidarity and acceptance of care responsibilities by family members (Grasselli, Montesi and Iannone, 2008; Gal, 2010; Naldini, 2016).

The present study also reveals a strong manifestation of intergenerational family care. On the one hand, this is determined by the lack of adequate family-friendly social services and benefits that could offer alternative care solutions (Gal, 2010). At the same time, it is also largely associated with the dominant social norm of strong family ties and relations that can be observed within the Greek society (Gal, 2010; Dagkouli–

Kyriakoglou, 2021). Support received and provided within family networks further imply a sense of reciprocity, where receivers are expected to be givers in the future (Dagkouli–Kyriakoglou, 2021). This phenomenon is driven by the fact that in Mediterranean countries, and especially in Greece, children remain in their parents' household even when they have reached an advanced age (Vogel, 2003; Gal, 2010; Dagkouli–Kyriakoglou, 2021). During the financial crisis in Greece, the practice of extended intergenerational cohabitation increased even more due to high youth unemployment figures and the lack of welfare support for housing by the state (Dagkouli–Kyriakoglou, 2021).

According to the narratives of older individuals in this study, the emotional and practical support that they receive from their family during their rehabilitation, has led to a positive interpersonal well-being experience characterised by a sense of ‘kinship and belonging’ (Galvin and Todres, 2013). Participants value the strong interpersonal family connections, as they feel comfortable with their kins while also experiencing a sense of confidence in themselves turning into active members of the family network. In this form of intersubjective dwelling, there is a sense of “we” which creates a relaxed situation and environment, whether this refers to the clinical setting or home. This further fosters a sense of familiar security, inclusion and togetherness that functions therapeutically for the participants. When this experiential state occurs, older individuals perceive and feel family support and involvement as a pillar where they can rely on in difficult situations and get the strength and courage to carry on and follow their rehabilitation.

The reverse situation was also expressed by some participants in this study. As a result of their condition, some older individuals did not experience meaningful interactions or were unable to engage in the same interactions and socialise as before. These cases pertained mostly to unsuccessful encounters with peripheral social ties, that is lack of meaningful communication with the healthcare staff in the clinical environment or lack of social engagement with friends and community groups after their return at home.

Participants described a sense of alienation and isolation which aggravated their interpersonal suffering experiences (Galvin and Todres, 2013). In this kind of intersubjective suffering, older individuals’ sense of interpersonal belonging and kinship is disrupted, feeling an existential loneliness. They perceive themselves as outsiders who have be cut off from meaningful social engagements. While still yearning for some kind of familiar interpersonal connection (which in most cases related to a desire of ‘returning back to normalcy’) the participants who expressed this kind of suffering experience an intense existential disorientation, revealing the significant impact that ABI had on their sense and perception of their humanity and self-efficacy. Although there were external factors that influenced their intersubjective experiences (e.g. cases where the clinical or home environment was unwelcoming or desentisised to older individuals’ need and desire for interpersonal belonging), it seems that older individuals have internalised a sense of despair, perceiving themselves as frail and powerless to pursue social participation. This in turn aggravates their felt sense of isolation and insecurity, making them to assume that due to their condition their desire to ‘return back to normalcy’ will never be satisfied.

Difficulties with social participation have also been reported in relevant studies when individuals with ABI experience limited support from their family (Sumathipala *et al.*, 2011; Elloker and Rhoda, 2018). Nevertheless, with regards to family interactions, these were painted in a positive light by almost all participants of this study. This probably relates to their perception on always pursuing and maintaining strong family ties – a social norm deeply ingrained in the Greek society – or it perhaps they were not feeling comfortable to share any unpleasant experiences. Some participants however expressed their fear and guilt on becoming a burden to their families. As mentioned above, this self-perceived guilt yielded unpleasant emotions to the participants, making their re-integration in the family environment more difficult.

Another interesting finding of this study relates to the ways participants perceive, understand and respond to representations of “a good patient”. While invoked in various studies regarding the notion of patient compliance and adherence, the construction and adoption of the so-called “good patient persona” and the way this kind of behaviour affects the interpersonal interactions of patients as well as their treatment outcomes has been limited (Campbell *et al.*, 2015). Older research has described the role of “good patient” as being silent, passive and accepting (Wortman and Dunkel-Schetter, 1979; Taylor, 1979). Patients may adopt the perceived role of “good patient” under the concern that it might be inappropriate to express their feelings to the doctors (despite their need and interest in doing so) or because they feel that doctors may react negatively (Wortman and Dunkel-Schetter, 1979). McCreaddie and Wiggins (2009) have found that compliance is basic tenet of the “good patient” role in terms of being willing or agreeing to do what is expected by them without complaining. Sycophancy is also another feature that patients may also express in terms of demonstrating an overstated gratitude and appreciation regardless of the level of services' quality provided by the healthcare staff or even by employing self-depreciating humour to ensure their acceptance by the healthcare staff (McCreaddie and Wiggins, 2009). Although these behavioural strategies imply some sort of emotional inhibition or suppression, McCreaddie and Wiggins' (2009) study seem to experience the "good patient" role both positively and as a coping mechanism.

Campbell *et al.* (2015) demonstrate the positive effects that the notion of a "good patient" can have on the health outcomes of people living with HIV. They however point out the potential detrimental effects that the non-conformance with the "good patient persona" can have on the patient-nurse relationship, as they might experience an indifferent stance by the healthcare staff (Campbell *et al.*, 2015). The characteristics of the "good patient persona" identified by the participants in Campbell *et al.*'s (2015) study concur with those reported in the relevant literature. These include among others being polite, obedient and patient, demonstrating enthusiasm for treatment and adhering to the medication schedule (Campbell *et al.*, 2015).

One significant parameter that determines the perception of the "good patient" role and the responses to it pertains to the perceived hierarchical system that dominates the healthcare system. Patients seem to feel inferior in relation to the healthcare staff, given the authority and power that the latter hold during the healthcare process (Löfmark and Hammarström, 2005). Such perceptions and experiences are also evident in this study. The findings identify a link between the adoption of the "good patient" persona by the patients and their perceptions of a hierarchic medical structure. Participants feel that their behaviour should conform to a good, uncomplaining and polite behaviour during their inpatient rehabilitation in order to guarantee the full support and assistance of the medical staff and receive proper care. In this way they try to cope with the difficulties of the rehabilitation process. Many participants in this study believe that by acting according to the expectations of the healthcare staff (which they view as being superior to them) they will achieve more pleasant treatment experiences. The traditional understanding of the good patient that they seem to hold is thus reinforced by their socially constructed perception of a hierarchically structured clinical environment.

On the one hand performing within the 'good patient persona' may signify their appreciation or respect for the medical establishment and the treatment they receive by the nurses and other healthcare givers. This is evident in narratives of this study's participants where older individuals legitimise their "good" conduct as the proper way to behave in the clinical environment, while also condemning poor behaviour of other patients as causing problems and suffering to the nurses. On the other hand, it may also indicate their reluctance or even fear to express freely their feelings and concerns to the healthcare staff. In the current study, some participants felt obliged to adopt a good patient image - by suppressing their real needs, accepting bad behaviours or by objectifying themselves - just to be able to receive the expected support. Lastly, it could also be the case that by demonstrating a "good" behaviour they try to satisfy their desire and need for interpersonal belonging. The lack of confidence, insecurity or vulnerability that they might feel leads them to consider the "good patient" role as a means for successfully becoming active members of the group. However, the pursuit of pleasing others along with the desire to be included in the group suggests a process of homogenisation, where people get involved in practices in which their own uniqueness and individuality is de-emphasised (Galvin and Todres, 2013). As such, it is important to consider whether this attempt to "fit in" leads to a real improvement in their well-being or conversely heightens their existential concerns and suffering experiences – leading to sense of depersonalization and a false sense of fulfillment regarding their interpersonal needs.

7.4 Contextual processes: The impact of structural and organisational issues on the sense of well-being

Findings from this study suggest that the design and organisation of the built environment of the hospital can have a major effect on the degree of 'social interaction' that takes place. Previous studies have indicated how important the environmental surroundings and organisational culture of the clinical setting can be for the well-being of individuals, in terms of influencing their attitudes and experiences in relation to their rehabilitation care (Fowler *et al.*, 1999; Douglas and Douglas, 2004; Braithwaite *et al.*, 2017). In their systematic review Braithwaite *et al.* (2017) found that there is strong association between healthcare organisational cultures and patient outcomes, with positive healthcare workplace cultures being linked to better patient outcomes. Douglas and Douglas (2004) underscore the importance of critically recognising the vital link that exists between the organisational climate (i.e., the values and cultural norms that characterise the various clinical levels) and the built environment of the hospital setting. In their research they have found that patients had positive experiences viewing the built hospital environment as encouraging and reassuring (Douglas and Douglas, 2004). Fowler *et al.* (1999) further demonstrate how the built environment of a healthcare facility can positively or negatively impact on the wellbeing of both patients and clinicians, which by extension can facilitate or hinder their recovery progress. They highlight the importance of involving patients in the design and planning of clinical institutions, by fostering their sense of control and autonomy (Fowler *et al.*, 1999).

In this study, participants felt that the clinical environment led to positive experiences, perceiving the setting of their inpatient rehabilitation as a supportive and friendly health environment. According to the majority of the narratives, participants' perceptions of a pleasant clinical environment were linked to their need of establishing access and a meaningful connection with the healthcare staff. The findings further illustrate the emphasis that older individuals placed on the positive attitude and behaviour of the healthcare staff that they experienced during their rehabilitation. This further links to their need for social engagement and effective communication discussed in the previous section. The positive attitude of the nurses and doctors created a welcoming atmosphere – with many individuals considering staff as their "second family" – which further facilitated the provision of high quality services within the clinic. In line with relevant studies, the pleasant experiences of the clinical environment reported in this study, boosted older individuals' morale and confidence for carrying on with their recovery, while also providing a sense of safety and security that alleviated any emotions of vulnerability (Douglas and Douglas, 2004; Braithwaite *et al.*, 2017).

The sense of optimism and familiarity that older individuals expressed in this study regarding the organisation and built environment of the hospital indicates the positive impact that the broader context of the clinical setting had on their rehabilitation process. As such the contextual clinical factors are not perceived merely in terms of physical qualities or measurements but can also constitute a felt sense of place, where individuals feel at home. This refers not only to the physical environment of the healthcare institution but also to the practices and routines that occur within that setting (Galvin and Todres, 2013). A felt sense of place can be conducive to pleasant feelings, helping older individuals with ABI to deal with any suffering experiences that they might have due to their condition. In this study, this felt sense of place within the hospital environment was instantiated by the comfort, familiarity and accessibility to healthcare staff that older individuals experienced during their inpatient rehabilitation.

On the other hand, a felt sense of "dislocation" can be experienced when individuals are unable to find or develop a sense of place (Galvin and Todres, 2013). This creates a confusion and a sense of strangeness as individuals try to acclimatise themselves within the new and unknown organisational culture and environment of the hospital setting (Galvin and Todres, 2013). In this study, there were cases where participants reported on the one hand a sense of satisfaction with regards to the care they were receiving while also experiencing a felt sense of dislocation during their hospital rehabilitation. This probably relates to the unpleasant feelings that they were experiencing due the challenges and changes elicited by their condition, which led many of them to develop a disapproving and pessimistic perception of the hospital setting. Furthermore, the negative preconceptions and stereotypes commonly associated with the hospital environment, particularly in Greece (Goula *et al.*, 2021), may have also played an important role in the adoption of such negative views about the clinical rehabilitation environment by some participants.

Participants in this study have further acknowledged the impact of various exogenous factors throughout their rehabilitation (whether inpatient or at home) which relate to organisational deficiencies but also to broader structural issues that characterise Greece's healthcare system. One of the most significant organisational issues identified by older individuals was the lack of adequate healthcare staff in rehabilitation clinics. Shortages of healthcare staff and especially of nurses can be observed worldwide, creating various challenges and problems for healthcare services and health policies on both the local and global levels (Oulton, 2006; Marć *et al.*, 2019; WHO, 2022). The causes of nursing shortages are multifaceted pertaining mostly to the increasing gap in the supply and demand of well-prepared and qualified nurses but also to the global demographic pressures that appear in the recent years (i.e., the systematic increase in elderly population and decreasing number of births) (Marć *et al.*, 2019). Focusing on the perceptions of healthcare workers and hospital executives in the United States, Buerhaus *et al.* (2007) provide an indication of the negative consequences that nursing staff shortages can elicit on care processes, hospital capacity and nursing practice. Concerns were expressed about nursing shortages leading to poor quality patient care, negative impacts on the quality of work life for nurses as well as to ineffective collaboration between healthcare professionals (Buerhaus *et al.*, 2007). Patient safety in terms of the amount of time nurses can spend with patients was further identified (mainly by nurses) as being negatively impacted by shortages in healthcare staff (Buerhaus *et al.*, 2007).

In Greece, there is a significant undersupply of nurses in public hospitals. A key reason seems to be the effect of the financial crisis and its ensuing economic recession that hit Greece in the previous decade. The strict control of public spending and its further reduction due to the austerity measures adopted in the country led to workforce and equipment shortages in the healthcare sector (Economou *et al.*, 2017; Ziomas *et al.*, 2018). More specifically, there was a freeze and, by extension, a substantial reduction in the recruitment of new nursing staff (Zikos *et al.*, 2019). As a result, the ratio of nurses per 1,000 population has remained almost the same (3.37% in 2008 and 3.38 in 2019) during the financial crisis period (OECD and European Union, 2020). Other factors that influence the undersupply and low retention numbers of nursing staff relate to the job dissatisfaction that many nurses in Greece have been experiencing over the last decade (Zikos *et. al.*, 2019). Some of the main factors that Greek nurses identify relate to the difficult economic and working conditions that characterise Greek hospitals, including heavy workloads due to inadequate staffing levels, the lack of teamwork between nurses and other health professionals, inadequate supply of equipment and technical infrastructure, and issues related to ineffective administration and nursing leadership of the profession (RN4CAST, 2009; Economou *et al.*, 2017; Zikos *et al.*, 2019). Chronic problems of the Greek healthcare sector such as low pay for nurses, issues of meritocracy and recognition of personal achievements, and the lack of clarity about the tasks and competencies involved in the nursing role further explicate the low retention numbers as well as the unpopularity of nursing profession as a career choice in Greece (Sapountzi-Krepia *et al.*, 2008; Zikos *et al.*, 2019). According to Zikos *et. al.* (2019), the large number of nurses who have left Greece seeking better work conditions in other countries since the beginning of the crisis may cause additional nursing shortages in the near future.

In the future, recruitment needs will be significantly affected by the expected increase in the number of older people and in how their general health condition develops. Given the current trends, the number of new nurses may not be sufficient to replace the increasing numbers of older individuals in need of care, posing significant challenges and pressures not only to the general organisation and operation of public health services in Greece but also to the provision of dignified care services for older individuals. It should be noted, however, that during the COVID-19 pandemic there was a significant increase of 81% in the absolute number of practising nurses in Primary Health Care Units in Greece (from 2,747 in 2019 to 5,004 in 2022) (Hellenic Statistical Authority, 2020; 2022). The sudden increase in the recruitment of new nurses was probably due to the high demand for additional health personnel and for filling the gaps to effectively manage the increased coronavirus cases. It remains to be seen whether these additions will be permanent or temporary.

Participants in this study perceived the lack of adequate healthcare staff in rehabilitation clinics as a disruptive factor that impacted on their recovery progress, leading to insufficient support and care. At the same time, this situation intensified their suffering experiences, making them feel unsafe, helpless or that their needs or expectations are neglected. This form of suffering also emphasises a felt sense of “agitation” which is characterised by irritation and disturbance that things are going wrong (Galvin and Todres, 2013). Older individuals reflect this sense of agitation when citing the shortcomings of the Greek healthcare sector as the main causes for the clinical underperformance they may have experienced during their inpatient rehabilitation. In other words, they seem to sympathise with the nursing staff – even in cases where they have reported disappointing experiences regarding nurses’ behaviour – attributing this negative situation to the lack of nursing staff in the rehabilitation department or to the difficult professional conditions that prevail in Greek hospitals (such as low wages, plethora of patient/workload and demanding work hours). This translates into a strong sense of persistent interference from outside, which in these cases relates to the pressures that older individuals feel and experience due to the perceived organisational and structural healthcare deficiencies.

The high costs of home or private rehabilitation after their hospital discharge along with the limited access to sufficient rehabilitation services especially in rural areas (where many of the participants of this study resided) have been also highlighted by many participants as fundamental structural issues that negatively impact on the continuation of their rehabilitation.

While in theory all older individuals in Greece have unrestricted access to long-term care services, in practice there are various barriers that hinder their access to care services. A significant issue is the limited access and service provision in rural areas - where there is a lack of special institutions, such as rehabilitation centres - in contrast to the main urban areas which concentrate the best availability of services (OECD, 2011; Economou *et al.*, 2017). The uneven distribution of nurses by geographical region further highlights the geographical inequities and disparities observed in the Greek context, with many hospital units in rural areas of the country facing significant understaffing problems (Economou *et al.*, 2017; Zikos *et al.*, 2019).

At the same time, as rehabilitation and physiotherapy services (both inpatient and outpatient) for older individuals in Greece are mainly provided by the private sector (Economou *et al.*, 2017), the range of choices regarding the rehabilitation services that older individuals receive is limited to a large extent from the respective socio-economic conditions. In this sense, individuals are not always able to control and/or make decisions about rehabilitation services and processes, unless if they have the financial ability to afford to buy private services (Putman *et al.*, 2007; Hakkennes *et al.*, 2011; Magdon-Ismail *et al.*, 2016). Therefore, the efficacy of rehabilitation services provided to older people with ABI depends not only on their health needs but also to a large extent on socio-economic discrepancies, with poorer people and those living in rural areas facing greater limitations of choice and therefore greater dissatisfaction with the rehabilitation process.

The high costs associated with private or home rehabilitation services along with the insufficient formal long-term care services especially in Greek rural areas often lead to the increased involvement of family in the provision of informal care to the elderly (OECD, 2011). Nevertheless, it should be noted that in recent years there seems to be an increase of Greek households' use of formal long-term care services to allow more women to join the labor force (World Bank, 2020).

Many of the participants in this study reported that due to the high cost of home or private rehabilitation after discharge, they were forced to not continue their rehabilitation program fully or even to abandon it altogether. At the same time, they expressed their regret about the burden put on their families, who undertake the responsibility of care provision, essentially covering for the lack of affordable private health care options and the limited access to care services in rural areas.

This unequal access to care services and distribution of treatment opportunities caused by geographical and socioeconomic divergences that exist in Greek older population, has elicited unpleasant feelings to the participants of this study. Older individuals experience feelings of isolation and marginalisation as well as a sense of oppression as they feel "imprisoned" and unable to overcome the consequences caused by the structural healthcare insufficiencies that determine their rehabilitation (Galvin and Todres, 2013). Nevertheless, they seem to accept and embrace this situation by rationalising it as an inevitable state of affairs that cannot be changed. This internalizing practice probably functions as a coping mechanism to alleviate the sense of disconnection and imprisonment they may feel and by extension to facilitate their adjustment to their new demanding and challenging reality.

7.5 Striving for autonomy: The felt sense of self in the aftermath of ABI

The narratives of older individuals in this study illustrate a variety of experiences regarding the changes that occurred in their lives and how these impacted on their attempt to make sense of their self-identity after the onset of their ABI condition and throughout their rehabilitation. The redefinition and negotiation of a person's self-identity has recently become quite central in ABI rehabilitation research (Martin, Levack and Sinnott, 2014). The struggles that older individuals with ABI often experience due to the various changes in their physical, cognitive, social and emotional functioning, can have a profound impact on their ability to reclaim and make sense of their self-identity after the brain injury (Ellis-Hill and Horn, 2000; Ellis-Hill, Payne and Ward, 2000; Martin, Levack and Sinnott, 2014; Pallesen, 2014).

This process is often associated with a loss of continuity, as individuals with ABI often compare their current situation with their former life, with the hope to restore their ability to act and make decisions as they did before the brain injury (Pallesen, 2014). Pallesen (2014) further highlights the challenges and difficulties that stroke survivors experience in their attempt to come into terms with their situation after stroke, which is often coupled with a loss of confidence, frustration and exhaustion since they feel that they have been stuck into an unpredictable and never ending process of change. Martin, Levack and Sinnott (2014) illustrate the changed view of self that individuals with ABI developed as a result of the changes occurred after their brain injury. In particular, participants were concerned about not being able to return to their life before ABI, as they felt dependent and reliant on others for assisting them in undertaking daily tasks and sustaining social interactions (Martin, Levack and Sinnott, 2014). Similarly, studies that focus on the rehabilitation of older individuals with ABI highlight the struggles and concerns that participants experience in their attempt to regain a sense of self-awareness and independence (Tholin and Forsberg, 2014; Loft *et al.*, 2017). Many older individuals reported being overwhelmed with sentiments of passivity, subordination and dependency that made feel "imprisoned" and motionlessness (Löfmark and Hammarström, 2005; Olofsson, Andersson and Carlberg, 2005; Loft *et al.*, 2017). Last but not least, organisational and structural factors of health provision can also affect individuals' autonomy. The various deficiencies and disparities discussed above contribute to the limitations in older individuals' decision-making capacities and choices regarding their rehabilitation.

In their attempt to make sense of the changes in their lives after their diagnosis, some participants in this study highlighted the sense of passivity and docility they felt during their inpatient rehabilitation or at home after their discharge. The lack of personal agency that older individuals felt was closely related to a sense of incompetence and a lack of confidence. Following Galvin and Todres' (2013) framework, this suffering experience emphasises a sense of personal identity as "lacking ability", that is a felt sense that one is not able to make meaningful changes and achieve aspirations in their life nor that they can act autonomously as they did before. Indeed, those participants who expressed a sense "of not being able to" held a pessimistic view of their present and future self, enclosing themselves into a labyrinth of inactiveness and dependency during their hospitalisation as well as at home. As a consequence, many older individuals reported being passively dependent on health professionals and their knowledge, due to the insecurity and impotence they were feeling. This relates to the view of oneself as a passive recipient of medical decisions and interventions, a view emphasised by the traditional medical model and which many patients have further internalised, by adopting a passive approach to their condition and treatment without interfering or actively engaging in their recovery process (Galvin and Todres, 2013; Raina and Thawani, 2016; Mishra *et al.*, 2016).

The self-perception of inability and lack of energy was further aggravated by the physical limitations and cognitive struggles that they were facing due to their brain injury. In many cases the realisation of the noticeable changes in their self-identity had a negative effect on the emotional state of the participants intensifying their suffering and unpleasant experiences during the process of rehabilitation. As a result, participants expressed feeling weaker and more sensitive due to their ABI. Some also felt a sense of disappointment and pessimism about their recovery outcomes as well as a strong sense of blocked future (Galvin and Todres, 2013). At the same time, the experience of bodily changes yielded a physical suffering experience of "stasis and exhaustion" which was characterised by a lack of energy, a lack of desire to move and a felt withdrawal of their bodily powers and vitalities (Glavin and Todres, 2013). The felt bodily sense of 'not being able to go forward' was redeveloped into a lethargic state that demotivated them to pursue their recovery aspirations and to carry on with their rehabilitation.

In this study however there was a conscious acceptance of passivity and dependency by some participants with regards to their role during inpatient rehabilitation. Passivity and dependency on healthcare professionals was accepted and embraced as an unavoidable situation or even valued by some as a coping mechanism that would help them navigate throughout their rehabilitation and achieve a successful recovery. The way that these participants normalised their passiveness reflects a wellbeing experience of "layered continuity", where older individuals experience a layered sense of identity that foregrounds both a sense of 'being able to' and a strong sense of 'just being' (Galvin and Todres, 2013). The combination of these two identity resources provides both a unity and multiplicity to one's identity, a complex inclusive state that gives an ambiguous experience where one feels a general sense of achievement about who they are and a sense of confidence about what they are able to do but also relaxed and unconcerned about any definition themselves (Galvin and Todres, 2013). In this study, participants experienced a sense of "layered continuity" by self-consciously letting themselves into the need of simply being cared for, without being concerned about their felt sense as passive recipients of care, while at the same time preserving a latent sense of capableness and optimism about their recovery outcomes.

The majority of participants expressed the need and desire to feel independent and a sense of self-efficacy throughout their rehabilitation. Self-efficacy reflects individuals' convictions or confidence in their capacity to succeed, carry out tasks, achieve specific goals and control their social environment (Neils-Strunjas *et al.*, 2017). Its beneficial influence on individuals' behaviour, motivation and approach to challenges has been highlighted by the relevant literature, in terms of improving older individuals' overall well-being and quality of their life, as well as supporting and maintaining positive outcomes for rehabilitation of ABI specifically (Moller, Ryan and Deci, 2006; Welford *et al.*, 2010; Neils-Strunjas *et al.*, 2017; Vaghela, Santoro and Braham, 2021). Self-efficacy is further closely linked to self-management, which involves individuals making decisions autonomously and dealing appropriately with the routine of home rehabilitation after leaving the hospital setting (Pollack *et al.*, 2016). Neils-Strunjas *et al.* (2017) correlate high self-efficacy with high levels of resilience, that is the ability of a person to successfully adapt or recover faced with adversity, significant stress or serious injury such as ABI. Resilience has been tied to better quality of life, lower distress and lower rates of depression (Neils-Strunjas *et al.*, 2017).

Patient engagement in decision-making and goal setting about their care is an essential component of maintaining self-efficacy especially throughout inpatient rehabilitation. Engaged patients usually receive improved health outcomes and better experiences of health care (Mishra *et al.*, 2016). However, as Mishra *et al.* (2016) further illustrate in their study, existing patient engagement systems in hospital settings do not fully allow for the active involvement and contribution of patients in their care, hence maintaining the traditional view of patients as passive recipients of care. This can lead to a sense of diminished autonomy and personhood, as older individuals do not receive adequate information or even the opportunity to understand fully their diagnosis and also to make informed choices about their rehabilitation.

Many participants, in the current study, reported an increased sense of self-efficacy, which relates to the well-being experience that emphasises a sense of their new personal identity as "I can" (Galvin and Todres, 2013). When such an emphasis is experienced individuals feel confident about their capacity of acting independently in their daily lives and taking care of themselves without depending on the others. A sense of optimism towards their new life was often observed in tandem with their felt experiences of autonomy, perceiving themselves as being 'on the move', that is moving into a future and its expanding horizons that are full of open possibilities. Galvin and Todres (2013) further highlight the close relationship between ‘I can’ identity-mobility and a sense of personal agency, which in this study was mainly associated with participants’ desire of being actively engaged in their rehabilitation process by obtaining sufficient information and making their own decisions about their care. Some older individuals also developed a sense of personal identity as “I am” which emphasised a sense of self-preservation. This was experienced as a familiar continuity that made them feel reinvigorated, more engaged with and more comfortable about themselves.

Such well-being experiences contributes to an increased sense of well-being, facilitating their bodily awareness and personhood, and by extension their adaptation to the new reality. Their effort to become more autonomous helps them to put aside any unpleasant experiences of suffering, motivating them to pursue their future aspirations and empowering them to face the new challenges with a sense of confidence.

CHAPTER 8: CONCLUSION

8.1 Research Aim - Research Question - Research Objectives

The purpose of this study was to capture the lived experiences of older individuals living with ABI and undergoing physical rehabilitation. Thus, it provides an interpretive exposition illustrating the impact of the Greek healthcare and rehabilitation system on their felt sense of well-being. Drawing on the aim and findings of the literature review, the thesis was guided by the following research question:

> *What are the lived experiences of older individuals undergoing physical rehabilitation after an acquired brain injury (ABI) in relation to their sense of well-being within the Greek formalised healthcare system?*

Through this phenomenological investigation, the study sought to interpret and understand what it means for older people to live with a form of ABI and their felt sense of well-being when in physical rehabilitation. Thus, the analysis and the interpretation of the research data answered the following five objectives:

- Objective 1: To explore how older individuals living with an ABI sense well-being when undergoing physical rehabilitation.
- Objective 2: To explore how older individuals living with an ABI undergoing physical rehabilitation feel about themselves and the context within which they exist.
- Objective 3: To explore how older individuals living with an ABI undergoing physical rehabilitation experience the life changes that may occur after the injury.
- Objective 4: To understand the felt experiences of older individuals living with an ABI undergoing physical rehabilitation of their interaction with health professionals.
- Objective 5: To examine the impact of Greece’s healthcare and rehabilitation system on the felt experiences of the well-being of older individuals undergoing physical rehabilitation.

The data analysis was phenomenologically guided, focusing on interpreting the participants' subjective experiences, conceptions and assumptions concerning the topic under investigation. The study of the data generated four overarching interpretive themes which addressed the research objectives. The first research objective is met in the second and fourth themes by demonstrating how older individuals living with ABI experience and realise emotional and physical well-being by seeking social interactions to fulfil their sense of closeness and intimacy, through family support and by adopting a polite and undemanding behaviour during their clinical rehabilitation. Meaningful interactions strengthen older individuals' sense of humanity and lead to the improvement of their self-realisation. In addition, being dependent on others led older individuals to develop a pessimistic attitude towards their new life.

The fourth theme of this study answers the second research objective by demonstrating how older individuals living with ABI experience their sense of well-being through the different feelings and experiences of their personhood in relation to the rehabilitation context within which they are embedded. The felt sense of passivity and its ensuing lack of independence is linked with unpleasant experiences bringing about a loss of meaning. In some instances, however, embracing passivity during rehabilitation is valued and used as a defence mechanism that motivates them towards achieving recovery.

The third research objective is met in the first theme by demonstrating how older individuals living with ABI cope with the life changes that may occur after the injury throughout their physical rehabilitation. In many cases, older individuals' new reality made them experience a mood of depression as well as feelings of guilt and sadness related to their thoughts of being a burden to their families. Thus, many expressed a lack of movement, being unmotivated to make plans for the future. Nevertheless, the participants who were able to harness such negative emotions caused by the life-changing ABI conditions engaged in a process of self-enhancement and making sense of their new life with the result of experiencing increased levels of personal well-being.

The fourth and fifth objectives of this study are answered in the third theme, which indicates how older individuals living with an ABI experience their interaction with health professionals within the broader context of in-patient rehabilitation. This constitutes an essential contributing factor to their sense of well-being as well as to the way participants assess the overall impact of Greece's healthcare and rehabilitation system through their lived experiences. On the one hand, a sense of place and familiarity within the hospital setting highlighted the positive impact that these contextual factors had on their recovery, leading to a greater sense of well-being. However, on the other hand, understaffing issues and the lack of affordable alternatives in rehabilitation can essentially disrupt rehabilitation experiences as well as the improvement of older individuals' well-being.

8.2 Limitations

During the research process, various limitations were identified. One limitation of the study pertains to the specific movement restrictions set in the country due to the COVID-19 pandemic. As such, the entire effort to gain access to potential participants was complex since access to hospital visitors was restricted for an extended period. Another limitation of this study concerns the representativeness of the sample. Due to the focus on older individuals and the fact that the overall rates of TBI are generally higher in younger individuals, most of the selected participants were diagnosed with stroke (a non-TBI). In contrast, only two participants had suffered a TBI. This may have affected the balance of the sample, as there was no opportunity to include a comprehensive sample of older individuals' experiences living with TBI. At the same time, however, it corroborates the correlation between age and the occurrence of TBI and non-TBI incidents suggested by the literature (Lui and Nguyen, 2018; Centers for Disease Control and Prevention, 2019).

Furthermore, the sample's representativeness might have been affected by the fact that all participants reside in a specific geographical region of Greece. This promotes the question of whether the lived experiences of older individuals living with ABI might differ if they reside in another area of the country. Nevertheless, as this thesis provides a case study, offering such a broad account would not be possible. A more comprehensive examination incorporating a broader sample with participants from other regions in the country would have exceeded this research project's time and space limitations.

Lastly, another possible limitation is that even though I became aware of my pre-conceptions before the beginning of this thesis by reflecting on my personal and professional background, my pre-understandings might have unavoidably influenced the data analysis and interpretations of the findings. Therefore, to minimise any potential risks of bias, reductionism and partiality, I have ensured that an explicit reflective account of my research journey has been provided in the thesis by making my position and values as explicit and transparent as possible.

8.3 Recommendations for future research

Although the present study provides valuable insights into the well-being experiences of older individuals during physical rehabilitation, there is always room for further research to enhance knowledge in this field. Firstly, more qualitative research focusing on the well-being experiences of older individuals with other chronic illnesses are required to comprehend their conditions and compare them with those who have suffered from ABI. This will help in interpreting well-being experiences and identifying any similarities or differences in relation to ABI incidents.

Moreover, incorporating non-phenomenological qualitative approaches or mixed methodologies, could provide richer insights into the perspectives and experiences of older individuals' felt sense of well-being and the quality of their rehabilitation. Future research could also examine the views of healthcare professionals responsible for the care of older individuals with ABI. In particular, it would be valuable to explore the possible impact of organisational issues on healthcare professionals' performance in delivering rehabilitation care to older adults.

Lastly, the findings of this study demonstrate the need for more qualitative research on older individuals' experiences living with TBI, given that the study sample primarily consisted of participants who had suffered nTBIs. Therefore, further research is needed to provide a more comprehensive understanding of the well-being experiences of older individuals living with TBI.

8.4 Study's implications

This research study offers significant theoretical and practical implications for clinical practice. Older individuals who have suffered an ABI and undergo physical rehabilitation face various changes and existential concerns in their lives. Therefore, when designing clinical approaches, health professionals must consider the way older individuals perceive and deal with their new condition.

The study’s findings highlight three essential dimensions that health professionals can focus on during the physical rehabilitation of older individuals with ABI. These dimensions, as outlined in the study's tentative framework, include how older individuals embrace their personal feelings, the effectiveness of their interpersonal relationships, and how contextual processes impact their physical rehabilitation. These factors influence individuals' experiential possibilities to achieve a robust sense of well-being and to accept their new reality.

By incorporating these variables into clinical practice, healthcare professionals can evaluate more effectively the complex conditions that patients experience when dealing with health-related issues. This can lead to a more comprehensive approach to rehabilitation that encompasses the values of dignity and humanisation rather than relying solely on impersonal and technology-guided clinical practices. Thus, the proposed tentative framework can serve as a guide to help health professionals assess challenges in clinical practice and improve care delivery by achieving more humanising and effective care.

Moreover, the research findings could have significant implications for healthcare policies by underscoring the necessity and benefits of integrating humanising practices into care provision. Structural and organisational inadequacies and distortions observed in the Greek health system highlight the need for improvement, with particular attention to the difficulties patients face during hospitalisation. In light of the deleterious effects of the COVID-19 pandemic, policymakers must prioritise positive policy directions that preserve the dignity of care and give greater consideration to patients’ existential concerns. A more humanising approach in relevant policies will thus emphasise the importance of acknowledging patients’ intricate experiential circumstances and how these can be effectively considered so that people feel more appreciated and dignified human beings during healthcare. Ultimately, this can enable patients to attain a more holistic and enriching sense of well-being.

8.5 Personal reflections

As I approached the conclusion of my doctoral journey, there are several aspects upon which I would like to reflect. Initially, I did not anticipate the breadth of directions that this voyage would take me. The present study has widened my understanding of the human experience and its significance to comprehending the emotional and physical hurdles that individuals encounter. While healthcare delivery has long been dominated by technological and medical interventions, these measures would be futile without considering the human element, including human emotions and each person's distinct needs. Consequently, I opted to employ phenomenology as a research methodology to explore the lived experiences of older individuals, enabling their voices to be heard and their concerns, needs, and aspirations to be revealed - as these are consciously apprehended and felt by individuals. As Martin Heidegger (Heidegger, 1962, p. 58) indicates: “phenomenology" means ἀποφαίνεσθαι, τὰ φαίνομενα — to let that which shows itself be seen from itself in the very way in which it shows itself from itself”. Although I was not particularly acquainted with this research approach, I became engrossed in the philosophical foundations of phenomenology, recognising its focus on unravelling the diverse experiential possibilities of individuals.

Engaging in the interviewing process and connecting with vulnerable individuals presented both challenging and stimulating experiences. During the initial interviews with participants, I recall feeling anxious as I thought I was intruding into their innermost thoughts and emotions. This apprehension prompted me to reflect on my own reservations. Indeed, the fieldwork experience enabled me to confront and acknowledge my concerns and biases and to open up about my feelings. This process proved to be a potent and cathartic experience that heightened my sensitivity to my preconceptions and how these might affect the research process. Although it was not feasible to entirely suppress my personal feelings and reservations, I endeavored to bridle them to ensure that they would not pose substantial challenges to the analysis of the data and interpretation of the findings. It is my belief that I made every effort to foster an environment of comfort and familiarity for the participants while maintaining adherence to the research protocol and ethical principles that undergirded the study.

This research journey has fortified my reflexive abilities and research ethos, making me a more competent scholar and, more importantly, a better person. As a researcher, my goal is to persist in investigating individuals' personal experiences and beliefs, in addition to comprehending the intricate process of achieving well-being. In the field of healthcare, I am of the opinion that we must prioritise humanising and dignified care as a significant factor in enhancing the quality of clinical practices.

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APPENDICES

Appendix A

Search strategies used in the electronic databases

CINAHL Plus

#	Query	Limiters/Expanders	Results
S5	"(older individuals OR older people OR older adults OR elderly OR aged) AND (acquired brain injury OR traumatic brain injury OR brain injury OR tbi OR abi OR stroke) AND (physical rehabilitation OR physical therapy OR geriatric rehabilitation OR hospital rehabilitation OR community rehabilitation OR elderly care) AND (experiences of well-being OR perceptions of well-being OR sense of well-being OR well-being) AND (qualitative research OR qualitative study)"	Limiters - Publication Year: 2005-2020 Expanders - Apply equivalent subjects Narrow by Language: - english Narrow by SubjectAge: - aged: 65+ years Search modes - SmartText Searching	**389**
S4	"(older individuals OR older people OR older adults OR elderly OR aged) AND (acquired brain injury OR traumatic brain injury OR brain injury OR tbi OR abi OR stroke) AND (physical rehabilitation OR physical therapy OR geriatric rehabilitation OR hospital rehabilitation OR community rehabilitation OR elderly care) AND (experiences of well-being OR perceptions of well-being OR sense of well-being OR well-being) AND (qualitative research OR qualitative study)"	Limiters - Publication Year: 2005-2020 Expanders - Apply equivalent subjects Narrow by SubjectAge: - aged: 65+ years Search modes - SmartText Searching	391
S3	"(older individuals OR older people OR older adults OR elderly OR aged) AND (acquired brain injury OR traumatic brain injury OR brain injury OR tbi OR abi OR stroke) AND (physical rehabilitation OR physical therapy OR geriatric rehabilitation OR hospital rehabilitation OR community rehabilitation OR elderly care) AND (experiences of well-being OR perceptions of well-being OR sense of well-being OR well-being) AND (qualitative research OR qualitative study)"	Limiters - Publication Year: 2005-2020 Expanders - Apply equivalent subjects Search modes - SmartText Searching	1,464
S2	"(older individuals OR older people OR older adults OR elderly OR aged) AND (acquired brain injury OR traumatic brain injury OR brain injury OR tbi OR abi OR stroke) AND (physical rehabilitation OR physical therapy OR geriatric rehabilitation OR hospital rehabilitation OR community rehabilitation OR elderly care) AND (experiences of well-being OR perceptions of well-being OR sense of well-being OR well-being) AND (qualitative research OR qualitative study)"	Expanders - Apply equivalent subjects Search modes - SmartText Searching	1,582
S1	"(older individuals OR older people OR older adults OR elderly OR aged) AND (acquired brain injury OR traumatic brain injury OR brain injury OR tbi OR abi OR stroke) AND (physical rehabilitation OR physical therapy OR geriatric rehabilitation OR hospital rehabilitation OR community rehabilitation OR elderly care) AND (experiences of well-being OR perceptions of well-being OR sense of well-being OR well-being) AND (qualitative research OR qualitative study)"	Expanders - Apply equivalent subjects Search modes - Find all my search terms	

APA PsycInfo

#	Searches	Results
1	(older individual* or older people or older adult* or elderly or aged).af.	730477
2	(acquired brain injury or traumatic brain injury or brain injury or tbi or abi or stroke).af.	189280
3	(physical rehabilitation or physical therapy or hospital rehabilitation or community rehabilitation or geriatric rehabilitation or elderly care).af.	31232
4	(experienc* of well-being or perception* of well-being or well-being).af.	282850
5	(qualitative research or qualitative stud*).af.	339459
6	1 and 2 and 3 and 4 and 5	270
7	1 and 2 and 3 and 4 and 5	270
8	limit 7 to (english language and yr="2005 - 2020")	**253**

PUBMED

Search number	Query	Filters	Results	Time
21	((((((((older individual*) OR (older people)) OR (older adult*)) OR (elderly)) OR (aged)) AND ((((((acquired brain injury) OR (traumatic brain injur*)) OR (brain injur*)) OR (TBI)) OR (ABI)) OR (stroke))) AND ((((((physical rehabilitation) OR (physical therapy)) OR (geriatric rehabilitation)) OR (hospital rehabilitation)) OR (community rehabilitation)) OR (elderly care))) AND (((experience* of well-being) OR (perception* of well-being)) OR (sense of well-being))) AND ((qualitative research) OR (qualitative stud*))	English, Aged: 65+ years, from 2005 - 2020	**218**	18:32:25
20	((((((((older individual*) OR (older people)) OR (older adult*)) OR (elderly)) OR (aged)) AND ((((((acquired brain injury) OR (traumatic brain injur*)) OR (brain injur*)) OR (TBI)) OR (ABI)) OR (stroke))) AND ((((((physical rehabilitation) OR (physical therapy)) OR (geriatric rehabilitation)) OR (hospital rehabilitation)) OR (community rehabilitation)) OR (elderly care))) AND (((experience* of well-being) OR (perception* of well-being)) OR (sense of well-being))) AND ((qualitative research) OR (qualitative stud*))	English, from 2005 - 2020	327	18:32:18
19	((((((((older individual*) OR (older people)) OR (older adult*)) OR (elderly)) OR (aged)) AND ((((((acquired brain injury) OR (traumatic brain injur*)) OR (brain injur*)) OR (TBI)) OR (ABI)) OR (stroke))) AND ((((((physical rehabilitation) OR (physical therapy)) OR (geriatric rehabilitation)) OR (hospital rehabilitation)) OR (community rehabilitation)) OR (elderly care))) AND (((experience* of well-being) OR (perception* of well-being)) OR (sense of well-being))) AND ((qualitative research) OR (qualitative stud*))	from 2005 - 2020	330	18:32:10
18	((((((((older individual*) OR (older people)) OR (older adult*)) OR (elderly)) OR (aged)) AND ((((((acquired brain injury) OR (traumatic brain injur*)) OR (brain injur*)) OR (TBI)) OR (ABI)) OR (stroke))) AND ((((((physical rehabilitation) OR (physical therapy)) OR (geriatric rehabilitation)) OR (hospital rehabilitation)) OR (community rehabilitation)) OR (elderly care))) AND (((experience* of well-being) OR (perception* of well-being)) OR (sense of well-being))) AND ((qualitative research) OR (qualitative stud*))		355	18:31:10
17	(qualitative research) OR (qualitative stud*)		248,744	18:30:12
16	((experience* of well-being) OR (perception* of well-being)) OR (sense of well-being)		720,494	18:29:36
15	(((((physical rehabilitation) OR (physical therapy)) OR (geriatric rehabilitation)) OR (hospital rehabilitation)) OR (community rehabilitation)) OR (elderly care)		578,162	18:29:20
14	(((((acquired brain injury) OR (traumatic brain injur*)) OR (brain injur*)) OR (TBI)) OR (ABI)) OR (stroke)		505,104	18:29:01
13	((((older individual*) OR (older people)) OR (older adult*)) OR (elderly)) OR (aged)		5,473,918	18:28:09

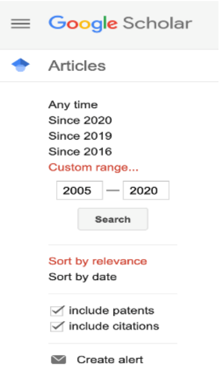
ASSIA

(older individuals OR older people OR older adults OR elderly OR aged) AND (acquired brain injury OR traumatic brain injury OR brain injury OR tbi OR abi OR stroke) AND (physical rehabilitation OR physical therapy OR hospital rehabilitation OR community rehabilitation OR geriatric rehabilitation OR elderly care) AND (experiences of well-being OR perceptions of well-being OR sense of well being OR well-being) AND (qualitative research OR qualitative study)

Applied filters: 2005-2020 | English = **1,062** results

SCOPUS

History Count	Search Terms	Results
4	(ALL ("older individuals" OR "older people" OR "older adults" OR elderly OR aged) AND ALL ("acquired brain injury" OR "traumatic brain injury" OR "brain injury" OR tbi OR abi OR stroke) AND ALL ("physical rehabilitation" OR "physical therapy" OR "geriatric rehabilitation" OR "hospital rehabilitation" OR "community rehabilitation" OR "elderly care") AND ALL ("experiences of well-being" OR "perceptions of well-being" OR "sense of well being" OR well-being) AND ALL ("qualitative research" OR "qualitative study")) AND (LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2005)) AND (LIMIT-TO (LANGUAGE , "English")) ...View More	**824** document results
3	(ALL ("older individuals" OR "older people" OR "older adults" OR elderly OR aged) AND ALL ("acquired brain injury" OR "traumatic brain injury" OR "brain injury" OR tbi OR abi OR stroke) AND ALL ("physical rehabilitation" OR "physical therapy" OR "geriatric rehabilitation" OR "hospital rehabilitation" OR "community rehabilitation" OR "elderly care") AND ALL ("experiences of well-being" OR "perceptions of well-being" OR "sense of well being" OR well-being) AND ALL ("qualitative research" OR "qualitative study")) AND (LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2005)) AND (LIMIT-TO (LANGUAGE , "English")) ...View More	824 document results
2	(ALL ("older individuals" OR "older adults" OR elderly OR aged) AND ALL ("acquired brain injury" OR "traumatic brain injury" OR "brain injury" OR tbi OR abi OR stroke) AND ALL ("physical rehabilitation" OR "physical therapy" OR "geriatric rehabilitation" OR "hospital rehabilitation" OR "community rehabilitation" OR "elderly care") AND ALL ("experiences of well-being" OR "perceptions of well-being" OR "sense of well being" OR well-being) AND ALL ("qualitative research" OR "qualitative study")) AND (LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2005)) ...View More	836 document results
1	(ALL ("older individuals" OR "older people" OR "older adults" OR elderly OR aged) AND ALL ("acquired brain injury" OR "traumatic brain injury" OR "brain injury" OR tbi OR abi OR stroke) AND ALL ("physical rehabilitation" OR "physical therapy" OR "geriatric rehabilitation" OR "hospital rehabilitation" OR "community rehabilitation" OR "elderly care") AND ALL ("experiences of well-being" OR "perceptions of well-being" OR "sense of well being" OR well-being) AND ALL ("qualitative research" OR "qualitative study")) ...View More	864 document results

Google Scholar	
	Search: Well-being in older individuals diagnosed with Acquired Brain Injury (ABI) or stroke when receiving rehabilitation care

Appendix B

Data extraction - Characteristics of included studies

#	Reference details (author(s), year, country)	Study design/ Methodological Approach	Purpose/ Aim of study	Study setting	Population characteristics (sample size, age, sex, type of disease)	Data collection methods & data analysis techniques	Outcomes/ Findings relevant to older individuals with ABI
[1]	**Andersson and Hansebo (2009), Sweden**	Qualitative study	To explore, from a gender perspective, older people's experiences of nursing care after a stroke	Hospital environment (stroke rehabilitation ward)	5 women & 5 men with stroke; between 66 and 75 years old	Individual interviews Qualitative content analysis	- A main theme ('to promote recovery of the body') and five categories were identified: bodily nursing care, support in reclaiming functions, lack of participation in care, supportive relationships and seeking consolation in sorrow. - The main theme reflects how women's and men's experiences of nursing care after a stroke are intertwined with the unexpected changes in the body that affect the whole of life. - In the light of the body being-in-the-world, the findings of the study indicate that men felt more vulnerable when they need bodily care as their identity as a man was threatened. Women seemed more comfortable with bodily care and described unemotionally, in specific and matter-of-fact terms, the help they needed. - There was a wish to get back to life as it was before the stroke. Men and women had different goals, apparently as a result of older women and men having different traditional roles in the home (e.g. older women as housewives and mothers which manifest links to their bodies prior to the stroke; men focused on outdoor activities as they struggled to regain their male role). - Both men and women in the study seemed to hide their sorrow about the illness from healthcare professionals while neither the women nor men communicated their goals to the nurses, physiotherapists or occupational therapists concerning the outcome of their rehabilitation. This corresponds with the finding that they were not able to participate in their care. - Overall, the differences in older patients' experiences of nursing care may be based on their gender. Their perceptions are linked with their lives as women and men before they had their stroke. Both men

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							and women will reclaim former abilities but what they perceive to be the goals of nursing care and rehabilitation may differ.
[2]	**Bennett *et al.* (2016), Australia**	Qualitative descriptive approach	To explore stroke survivors' perspectives of novel models of inpatient physiotherapy, which provide an increased amount of therapy	Participants' usual place of residence	10 stroke survivors; mean age = 71 years	Face to face, semi-structured interviews Thematic analysis	- Three main themes emerged from the data: Too much, too little or just right; My experience – alone and together; and Meeting my needs. More specifically: - While more therapy time was favoured by several participants, the same people also indicated that there was an upper limit to the amount of therapy time they could cope with, with many reporting issues with fatigue. Moreover, while some participants were appreciative of the opportunity to rest within therapy sessions, others strongly indicated that they disliked having to wait for staff assistance between exercises - participants spent more than one-third of their therapy time inactive. Lastly, Seven days per week physiotherapy was preferred by some, but not all participants. For some, the break meant not improving, difficulty restarting and having nothing to do. Conversely, a break was highly valued by other, in order to rest and spend time with significant others. - Personal achievement and success during therapy sessions were reported by participants. Several participants also valued the opportunity to observe the progress of others and reported that it provided them with hope and motivation for their own recovery. - Sharing staff with other participants was an acceptable format for some circuit group participants; however, others indicated that the group format was unable to meet their individual needs optimally. Subsequently, several participants in this study highlighted the need for individualised or tailored content. - Overall, findings revealed a wide variety of beliefs, priorities and preferences regarding how intensely they could work during their physiotherapy; their individual and group experiences of success and challenge; and their need to have their own specific needs met.

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							- There was a sense that participants often did not have the opportunity to know or influence other options or could not access them when they did exist – this lack of choice seemed to be a linking concept between the themes.
[3]	**Ellis-Hill *et al.*** **(2009), UK**	Qualitative Study	To understand what constitutes a 'good' or 'poor' experience in relation to the transition from hospital to home following a stroke	Home environment	20 stroke patients; mean age = 70 years 13 carers	Semi-structured interviews Framework analysis was used for systematically analysing the transcripts	- Focusing on the experiences of patients and their relatives, three key interlinked tensions were identified which applied to all of the participants in the study: (1) Continuity in recovery versus loss of momentum; (2) Being supported versus being abandoned; (3) Being in the picture versus being in the dark. These tensions involve the relationships between the person, and their body, service providers, and family and friends. - Patients described their own models of recovery, which involved a sense of momentum and getting on with their life. These models although different for each individual were based on the following common aspects: (a) their own life situation and their understanding of themselves; (b) their current bodily experience, and (c) understandings developed through interactions with healthcare professionals. - Discharge was successful if: (i) This sense of momentum was maintained, (ii) they felt supported, and (iii) they felt informed about what was happening. - Discharge was seen as difficult when: (a) Momentum was perceived to be lost, (b) people did not feel supported, or (c) they felt in the dark about the plans or their recovery. - The discharge experience could be improved by healthcare professionals by understanding and exploring patients' individual models of recovery. This would enable healthcare professionals to: (a) gain access to patients' concerns, (b) develop programmes

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							addressing these, (c) correct misinterpretations about recovery and discharge, (d) keep people fully informed about the work they are carrying out regarding discharge, and (e) share and validate the experience of patients, to reduce their sense of isolation.
[4]	**Gallacher *et al.* (2018), Scotland, UK**	Qualitative Study	To expand and verify the taxonomy of treatment burden through interviews with stroke survivors; to explore the factors that influence capacity in stroke survivors; to create a conceptual model of treatment burden and stroke patient capacity	Home environment.	29 participants who had a stroke; mean age 68 years	Semi-structured interviews. Data from the first 15 interviews were analysed using a Coding framework informed by Normalisation Process Theory (NPT) Thematic analysis was used to code data for the remaining 14 interviews	- This study uncovers the considerable treatment burden experienced by those with stroke, shown to be heavily influenced by the quality and configuration of health and social care. - The following broad areas of treatment burden were identified: (i) making sense of stroke management and planning care; (ii) interacting with others including health professionals, family and other stroke patients; (iii) enacting management strategies; (iv) reflecting on management. - Participants described six factors that influence patient capacity: personal attributes and skills; physical and cognitive abilities; support network; financial status; life workload; and environment. Patient capacity was found to be a dynamic entity, one that is ever changing depending on circumstances at any one point in time. Moreover, many aspects of capacity are amenable to change depending on the availability of health and social care services. - The study highlighted some important causal pathways between treatment burden and patient capacity: (i) treatment burden is identified as arising from healthcare workload and/or the endurance of care deficiencies; (ii) both healthcare workload and care deficiencies can influence and be influenced by patient capacity; (iii) the quality and configuration of health and social care services can influence the presence of care deficiencies, the magnitude of healthcare workload (and hence the treatment burden) as well as the capacity of patients to manage their health; lastly, patients' capacity

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							can also be influenced by factors external to healthcare systems such as the presence of dependents.
[5]	**Galvin, Cusack and Stokes (2009), Ireland**	Qualitative study (Grounded theory)	To examine the experiences of inpatient physiotherapy rehabilitation delivered after stroke (and the involvement of the family) from the perspectives of stroke survivors and physiotherapists	Acute stroke inpatient hospitals	10 individuals with stroke (4 male & 6 female); mean age = 73 years 10 senior physiotherapists (9 female & 1 male)	Semi-structured interviews with people with stroke & Focus groups with senior physiotherapists (n=2) Transcripts were analysed using the grounded theory approach	There are several concordant opinions and similarities – but also dissimilarities - between the perspectives of people with stroke and physiotherapists. The results show that both patients' and physiotherapists' experiences of physiotherapy are generally quite positive. Physiotherapists need to be cognizant of the elements of rehabilitation that are important to people with stroke and to find out ways of encouraging realistic goals and expectations of physiotherapy without affecting the process of active rehabilitation and skill acquisition. All participants identified areas where the quality of physiotherapy care could be improved such as more involvement of families in the delivery of exercises and the need for additional physiotherapy in the inpatient and outpatient settings. - Duration of physiotherapy – more physiotherapy should be provided (from what is routinely given) during the inpatient stay: Both groups agreed that people with stroke could benefit from more physiotherapy than they routinely receive, which according to the therapists varied from 30 to 60 min a day five times per week. However, physiotherapists suggested that additional therapy would be most beneficial on discharge from hospital, whereas nine of the 10 participants with stroke reported that they could benefit from more additional physiotherapy during their inpatient stay. - Importance of mobility therapy – walking: Participants also reported that the component of their physiotherapy programme they liked the most was walking (n=6) followed by lower-extremity exercises (n=4). - Lacking involvement of family members in physiotherapy:

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							All physiotherapists reported that they 'routinely' involved families in the inpatient treatment programme. Contrary to this, seven participants with stroke reported that their family members had not been invited to attend physiotherapy sessions even though this was acceptable to the person with stroke and the family were happy to do so. - Positive role of families in rehabilitation process – families' participation in physiotherapy can be advantageous both physically and emotionally: People with stroke identified several potential benefits to themselves and their families, should their families become involved in their rehabilitation process. Therapists reported that younger and more motivated patients benefit most from physiotherapy after stroke. Physiotherapists also reported that cognitive impairment could impede recovery because of limited carryover by the patient. Finally, both therapists and people with stroke reported that families are eager and motivated to participate in the physiotherapy and that their involvement can be advantageous both physically and emotionally. - Views on physiotherapists – patients identified encouragement and honesty as important attributes of physiotherapists: People with stroke also identified encouragement and honesty as two important characteristics in a physiotherapist involved in the rehabilitation of a person with stroke.
[6]	**Krishnan *et al.* (2019), USA**	Qualitative Study	To explore stroke survivors' perspectives and experiences in post-acute care (PAC) and understand their involvement and satisfaction in choosing their PAC	Individuals' homes/ Location where support group meeting was held/ Health care facility where some	18 stroke survivors; mean age = 68 years	Semi-structured interviews. Thematic content analysis	Most of the participants reported that they were not involved in selecting their PAC setting and that others (mainly doctors but also family members and clinicians) did that for them. While few participants did mention some involvement, the level and extent of their involvement was not indicative of shared decision making; for these reasons most participants were not satisfied. When asked about the process of rehabilitation goal setting, some participants mentioned that they were involved, some mentioned they

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			provider and with regards to rehabilitation goal setting; and to examine their discharge recommendations for stroke survivors	individuals were residing			were not involved, and others did not talk about their involvement during rehabilitation goal setting. Among the participants involved in goal setting, some mentioned that they were asked to contribute only by way of asking questions or raising concerns. Many participants revealed the need for specific information during their stay at the acute hospital or PAC before being discharged from the acute hospital or PAC. More specifically, stroke survivors expressed the need for information and to know more on - rehabilitation services following discharge to home, - medical interventions such as Botox for spasticity, medications and equipment, - timely diagnosis, - their health, - the insurance coverage (services covered by their insurance plan), - what to expect following discharge, - the availability of resources such as support groups, - various psychological changes poststroke such as depression. Moreover, most participants were enthusiastic to give recommendations to peers based on their experiences. These recommendations were categorized into 3 major areas: - Participants stressed the importance of self-motivation and self-advocacy. More specifically they advised their peers to be involved, work as hard as they could, cooperate with their family and therapists, modify their lifestyle to control their blood pressure and improve nutrition, and pay attention to psychological health (eg, depression). participation in services, and coping strategies.

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							- They also encouraged other stroke survivors to participate in services, such as rehabilitation and support groups. - Participants finally suggested some coping startegies by encouraged other stroke survivors to accept their condition and have hope, faith, and patience. In sum, there was more patient involvement in goal setting during rehabilitation compared to selecting PAC setting. In general, the study concludes that many former IRF (inpatient rehabilitation facility) and SNF (skilled nursing facility) stroke survivors report not being involved in either aspect of care. On the other hand, the majority reported that were mostly satisfied with their rehabilitation experience.
[7]	**Löfmark and Hammarström (2005), Sweden**	Qualitative follow-up study.	To analyse from a gender perspective how older women and men responded to treatment after stroke in the acute care setting, characterized by a medical hierarchic structure	1st interview: Hospital setting (stroke ward) 2nd interview: Home environment - 4 to 6 weeks later	12 stroke patients; between 75 and 83 years old	Semi-structured interviews Participants were interviewed twice. Regarding the second interview, 2 participants refused to be interviewed again Grounded theory analysis	- Four subcategories identified as negotiations grounded in the responses of stroke patients to the treatment and care after stroke: (i) striving for autonomy, (ii) following the rules, (iii) building alliances, and (iv) criticizing the care. The subcategories were related to each other, resulting in a core category labeled Negotiations Within the Medical Context. - The participants used various ways of negotiating with the health care staff in their subordinate position to influence their situation on the medical hierarchic context of the ward. Overall, no major differences were found within the group of women and within the group of men in relation to marital status, social class, or level of disability concerning how they negotiated within the medical context. - According to the findings, the elderly stroke patients can increase their power from below by performing resistant negotiations. In this way, they are actively striving toward a decrease in the staff's power over them. The study hypothesises that the health care staff in the specific ward held negative attitudes toward the elderly women and

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							men and that these attitudes intensified the participants' experience of subordination - The participants also wanted to picture themselves as capable and assertive individuals and express their independence of others before and after the stroke. The patients had a strong desire to be seen as individuals in their total life situation. - The older stroke patients in this study can be seen as temporary visitors in the acute care setting. Because of their relatively short stay on the ward, as well as their situation as severely diseased stroke patients, the health care staff assumed that these patients would adjust to the rules in the ward. In this study, the participants' wish to follow the rules was the most evident example of their subordination and adjustment within the hierarchic medical context. - The participants tried to build alliances with the staff but also criticized the care. We interpreted these two ways of negotiating as being gendered: it is hypothesised than women chose to negotiate with the nurse assistants, as they also were in a subordinate position within the medical context, while men turned to nurses, physiotherapists, or occupational therapists, as they perceived themselves to be on the same level as the medical staff in the hierarchic medical context. Authors also hypothesize that because of the medical hierarchical structure, it was hard for both the women and the men to negotiate with the physician in charge. - In the acute care setting, there is a risk that elderly, severely diseased patients will be seen as passive victims and not as active agents who are able to take part in the care and rehabilitation. The study points to the need to make the health care staff more aware of older women's and men's actions and strengths. A focus needs to be put on how power relations in the medical context affect women's and men's experiences and negotiations in the hospital.

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[8]	**Loft *et al.* (2017), Denmark**	Qualitative Study	To describe patients' experiences with inpatient stroke rehabilitation and their perception of health professionals' roles and functions	University hospital / Stroke unit in the Capital Region of Denmark.	10 stroke patients; mean age = 68	Qualitative Study	The patients' experiences with inpatient stroke rehabilitation and their perception of nurses' and nurse assistants' roles and functions during hospitalisation were found to be related to one overall motif which derived from 10 categories and was recurring in the patients' interviews Patients struggled with existential thoughts and concerns about the future and these thoughts unquestionably affected their experiences within the rehabilitation unit. These experiences called for human contact and support from the nursing staff when these thoughts and concerns arose. The patients had a strong desire to talk about their thoughts and concerns about the future and did not feel that these needs had been recognised or addressed by the nursing staff. The patients perceived nursing staff as mostly polite and helpful but did not see them as therapeutic and active stakeholders. Overall, they perceived that the nursing staff's function and role in relation to their rehabilitation was unclear. They have also given the impression of rarely being aware of the goals set for the week - and if they were aware of these goals, they still found it difficult to work towards them while their participation proved challenging. This was due to the patients lacking knowledge about their own body's capacity. Their motivation to work towards goals was further hampered by the nursing staff's lack of involvement and support.
[9]	**Mangset *et al.*** **(2008), Norway**	Qualitative study Grounded theory approach	To identify factors contributing to elderly stroke patients' satisfaction with post-stroke rehabilitation	Initially stroke rehabilitation unit at a university hospital followed by home	12 stroke patients; mean age = 77 years	Semi-structured interviews Analysis was based on Giorgi's (1985)	- Being treated with respect and dignity is the core factor influencing elderly stroke patients' satisfaction and perception of the quality of their rehabilitation process. This need seemed to be strongly related to stroke patients' feelings of vulnerability and dependence. - The core category was further divided into five subcategories emerging out of the patients' descriptions of daily care experiences and their reflections on the rehabilitation process. These are:

#	Reference details (author(s), year, country)	Study design/ Methodological Approach	Purpose/ Aim of study	Study setting	Population characteristics (sample size, age, sex, type of disease)	Data collection methods & data analysis techniques	Outcomes/ Findings relevant to older individuals with ABI
				environment, nursing home environment, or at the outpatient clinic of the hospital		phenomenological method	• 'Being treated with humanity', • 'Being acknowledged as individuals', • 'Having their autonomy respected', - 'Having confidence and trust in professionals' • 'Dialogue and exchange of information' - The statements covered a continuum from satisfaction via indifference to dissatisfaction. Expressions of satisfaction emerged mainly as general statements while expressions of dissatisfaction described situations in greater detail. In general, patients seemed to perceive subtle signals that made a significant contribution to their evaluation and emotional responses. - Satisfaction was merely connected to daily care experiences and fulfilment of basic needs. Trust in providers, patients' positive evaluation of services and being dignified seemed more closely associated with satisfaction than being involved in treatment decisions. - The findings demonstrate how the quality of patient–professional interaction influences patients' satisfaction with stroke rehabilitation.
[10]	**Morris *et al.* (2015), Scotland, UK**	Exploratory Qualitative Approach	To explore stroke survivors' and artists' beliefs about participating to visual arts programme during in-patient rehabilitation and identify potential benefits and mechanisms of action	Individuals' homes or a place of their choosing Artists were interviewed in their workplace or the local university	11 stroke survivors; mean age = 73 years 3 artists	In-depth semi structured Interviews Framework approach was used to identify themes and develop conceptual schemes	Findings suggest that art participation may influence important psychosocial outcomes that other rehabilitation approaches do not address and can overall lead to benefits for stroke survivors that may enhance their experiences of rehabilitation. Specifically: The non-medical, social context of art facilitated social interaction, provided enjoyment and distraction from stroke and re-established social identity thereby improving mood. The processes of art making generated confidence and self-efficacy, setting and achievement of creative, communication and physical recovery goals that provided control over survivors' situation and hope for recovery. Creative output involved completion of artwork and display for viewing which enhanced self-esteem and improved mood, providing

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							survivors with new identities through positive appraisal of the work by others. Lastly, self-efficacy, hope and control appeared to mediate benefits. The study paves the way for a future effectiveness trial.
[11]	**Morris, Payne and Lambert** **(2007), UK**	Qualitative Study Grounded theory approach	To study the experiences of patients, carers, and staff throughout a specialist hospital stroke care pathway and to make links between their experiences	Hospital setting	10 stroke patients (8 female & 2 male); mean age = 67 years. 5 carers (3 female & 2 male) 6 rehabilitation therapists (5 female & 1 male) 5 female acute unit staff 4 rehabilitation doctors and nurses	Qualitative focus groups of patients, carers and staff following a semi-structured format Qualitative data analysis/ thematic analysis	- Patients needed more individual information about stroke and their care as well as more information about their discharge. - The lack of information produced anxiety and problems with adjustment post-discharge. This shortfall is explained by both the patients and staff as a result of limited medical knowledge and poor communication between staff and older individuals. - Interactions and relationships with staff were seen as vital in providing emotional support and encouragement as well as care. Patients maintained a positive view of individual staff by pointing to service deficits (e.g. low staffing levels, pressures on staff and problems in staff management) which led to insufficient therapy and lack of attention to unpredictable events. - Incongruence between patients' expectations and the services provided. More specifically, the patients found carers focused on issues such as: (i) the shortage of nursing staff; (ii) an organisational orientation that did not include individuality and which has a narrow focus of care and an emphasis on physical needs to the exclusion of broader (non-physical) human needs (e.g. stimulation, variety and family contact). Nevertheless, carers and patients were not generally critical of the philosophy and rationale of care.

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[12]	**Nimrod and Hutchinson (2010), Canada**	Qualitative study Grounded theory approach	To examine older adults' response to activity restrictions or constraints by understanding the role of innovation in adapting to disability and loss in later life	At home (except for two interviews that were conducted in the second author's office)	17 participants; mean age = 72 years 7 participants were stroke survivors 4 lived with some form of arthritis 2 were cancer survivors 2 were living with Parkinson's disease (one of whom had also had a stroke) 2 had Fibromyalgia	In-depth interviews The interview transcripts were scrutinised through qualitative analysis techniques – implementing within and cross-case analysis as well as comparison strategies	The findings of this study suggest the following: 1. Similar to innovation among healthy older adults, innovation among older adults with chronic health conditions may result from various triggers. While some of them are internal, others are external or instrumental; 2. Changes in health may serve as precursors for innovation, having either a direct or indirect influence; Especially with regards to stroke survivors that were interviewed the decision to take up a new activity had a direct association with their health condition: as a way to continue their recovery (e.g., following formal stroke rehabilitation) or to improve or maintain physical health or emotional well-being. This was the case of all stroke survivors who joined a "stroke club" which provided both an exercise program led by a volunteer physiotherapist and social activity. 3. Innovation in declining health may involve various inconveniencies, however people find ways to adjust; 4. While innovation among healthy older adults may be either self-preservation innovation or self-reinvention innovation, the main role of innovation among older adults with chronic health condition is preserving a sense of continuity. Overall, innovation activities seem to have a positive impact on elders' well-being. More specifically, it seems that innovation may take an integral part in the process of coping with declined health and physical impairments.
[13]	**Olofsson, Andersson and Carlberg** **(2005), Sweden**	Qualitative Study	To explore the experiences of stroke patients concerning their falling ill; their stay in hospital; their discharge; and their healthcare needs	Home environment	9 stroke patients; mean age = 72 years	In-depth interviews Qualitative data analysis	Three categories that mirror the patients' experience of the process after a stroke – i.e., the process of the illness. the crisis that falling ill entails and the process that the patients went through when they regained control of their lives - were: * 'Responsible and implicated',

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			after their stay in hospital				* 'Depersonalized object for caring measures' and * 'The striving for repersonalization and autonomy'. - The passive acceptance by the patients of what was offered to them and their uncertainty regarding the function of care can be partly explained from the limitations and dominance of the traditional medical model. The patient is placed in a passive, dependent position, becoming an object for the caring measures. Their role is to seek the health care service's competent advice, to adapt to this and obey orders. Also, due to brain damage, stroke patients can find it difficult to grasp their situation and take reponsibility, especially in the initial stages of the process. - The patients demanded information on their illness, recovery, prognosis and medication. At the same time they experienced difficulty in knowing what they should ask about at the acute stage. The majority wanted advice, support and information about their state of health after discharge. - On discharge from hospital they return to their own social environment, but they are no longer the people that they were before: they now know themselves as someone who has had a stroke, which has changed them and there is also anxiety about becoming ill again. For the patients the meaning of "discharge' was 'coming home'. - The relief and joy the patients felt at coming home overshadowed their fear of a new stroke. The homecoming is a confirmation of once again being in control of one's life and being a person. - When they came home the patients got new insights about their state which were important for recovery and rehabilitation. The results highlight the importance of the possibilities that coming home brings as it re-establishes self-esteem, increases responsibility and understanding of the illness and its consequences in relation to the patient's concrete situation.

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[14]	**Poltawski *et al.* (2015), UK**	Synthesis of qualitative data and findings of two studies: 1) a focus group consultation; 2) a small-scale feasibility study of the intervention.	To identify factors that influence the motivation of long-term stroke survivors to engage and maintain involvement in physical exercise, and their implications for programme design.	1) Not clear – probably public spaces/ centres 2) Home environment	1) 5 stroke survivors in group 1 (4 females & 1 male); Median (range) age = 67 (53-77) 6 stroke survivors in group 2 (2 females & 4 male); Median (range) age = 68 (42–74) (+ 2 partners) 2) 6 stroke survivors (and 1 partner) 1 female & 5 males; Median (range) age = 67 (57–72)	1) Focus groups 2) Semi-structure interviews Thematic analysis of transcribed discussions and interviews. ↓ Extraction and synthesis of themes (thematic descriptive approach)	The synthesis of study findings generated four themes indicating factors that can influence motivation to exercise and maintenance for long-term stroke survivors: a desire to move away from a medicalised approach to exercise, beliefs about stroke recovery, and on-going support to sustain commitment. a) The emotional and psychological benefits of the motivation to exercise (wherever this was evident) were particularly valued by the informants. This has implications for the way programmes are promoted, as many stroke survivors may not be motivated to exercise by physical goals. Ensuring that programme content and delivery style reflect these priorities may help sustain participants' commitment. b) The theme about de-medicalising exercise addresses related concepts of perceptions of exercise. Long-term stroke survivors may be more inclined to exercise if they see it as a healthy leisure activity. Participants preferred that programmes should not take place in clinical settings, and some felt that they should not be led by clinicians due to their perceived risk-aversion and low expectations. The use of suitably trained exercise professionals could be considered to promote the positive connotations of exercise as a healthy and enjoyable lifestyle choice. c) Different beliefs were expressed about the capacity to recover from stroke and the value of exercise. Some thought exercise could facilitate physical improvement and functional recovery, while others were sceptical. Through education and the gradual introduction of more demanding activities, physical improvements may build openness and motivation to exercise closer to levels recommended in stroke guidelines. d) The theme of sustaining commitment suggests that motivation to exercise may diminish without external facilitation. Social support is seen as important, but some people are put off by group classes. On-going support is also seen as an external aid to sustaining motivation. Overall, the study suggests that personal and environmental factors can influence motivation to exercise, and that enjoyment and

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							psychological benefits may be more effective motivators than increased fitness or functional benefits. It also emphasises the attractiveness of a de-medicalised, lifestyle-focussed approach in exercise programmes, and the need for on-going advice and support. These strategies may help increase uptake and maintenance of physical exercise, and enhance quality of life in stroke survivors.
[15]	**Tholin and Forsberg (2018), Sweden**	Qualitative study	To investigate how people with stroke experienced their care, rehabilitation, support, and participation in the hospital, primary health care, and the community.	Participants' homes (nursing home & ordinary housing).	11 participants (5 females & 6 males); Mean age = 73 years (range 49-90).	Semi-structured interviews. Content analysis.	Four analytical domains were produced (experience of healthcare, participation, rehabilitation and support) with each domain including various sub-domains and themes in relation to older individuals' experiences regarding their overall rehabilitation and care. - All the interviewees expressed positive experiences (satisfaction) with regards to their in-patient care. Most of them appreciated intense, specific, and professional rehabilitation, having experienced these qualities during most parts of their overall stroke care. - However, they further reported both positive and negative experiences of the continuing care. - Those who received support from the community services expressed satisfaction with the staff, but also felt a lack of autonomy and participation. In particular, several participants felt that they were not involved in the health care planning, but instead relied on the judgement of the staff. - The study emphasises the significance of inviting people with stroke to participate in the planning of care in order to ensure high quality throughout the whole stroke rehabilitation process. - Reconsidering patient's autonomy is a crucial process that needs to be developed and initiated by both the staff and residents in residential community services. - Furthermore, providing specific, intense and professional rehabilitation is considered important for delivering the evidence-based stroke rehabilitation.

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[16]	**White *et al.* (2015), Australia**	Qualitative study	To qualitatively explore stroke survivors' experiences of participation in an enriched environment (EE) within a typical stroke rehabilitation setting and to identify benefits and limitations to implementation	Not explicitly mentioned (probably hospital setting)	10 stroke survivors; mean age = 70.5 years	Semi-structured interviews Inductive thematic approach was utilised to collect and analyse data	Three primary themes emerged from the data: (1) ''It got me moving.'' – Perceived benefits of participation in an EE (2) ''You can be bored or you can be busy.'' – Attenuating factors influencing participation in EE and routine rehabilitation. (3) ''I don't like to make the staff busier:'' – Limitations to use of the EE. - A number of specific and generalised benefits of enriching the environment were perceived by participants. Access to EE activities and participation in both individual and communal forms of EE provided increased opportunities for stimulation and interrupted the ongoing cycle of boredom and inactivity experienced by many participants. Communal EE was found to provide a means for enhanced social interaction among participants whereas individual EE activities promoted increased activity levels at patient's bedside. - However, participants also experienced barriers towards accessing the EE which often led to lower levels of participation and greater time spent at the bedside. Access and frequency of use of the EE was linked to participants' preferences, motivation, ward restrictions, and the availability of staff to assist with mobility. Redistribution of existing resources, the provision of a greater variety of resources and flexibility of ward routines could accommodate the variety of patient preferences, values and comorbidities and thus increase patients' interest and motivation levels - Overall, findings revealed that access to an EE has the potential to improve activity levels in stroke survivors undergoing stroke rehabilitation.

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[17]	**Wray, Clarke and Forster (2019), UK**	Cross-sectional qualitative study	To explore how stroke survivors with communication difficulties and their family members manage life in the first year after stroke including: - the process of adaptation and adjustment to poststroke life; - strategies used to facilitate participation in poststroke life; and - the needs of this population in relation to self-management support.	Home environment.	14 stroke survivors (3 females & 11 males) with communication difficulties; Mean age = 69,3 years. The carers/ family members of 7 participants were also interviewed.	Semi-structured interviews. Thematic analysis.	Six themes were identified: strategies to manage changes to communication, testing communication outside of the home, balancing support and independence, hope for recovery, obtaining support from healthcare professionals, and adapting activities and keeping busy. Despite the work, many expressed a lack of confidence in their ability and feelings of powerlessness and abandonment. The interview findings suggest that managing life after stroke is a complex process, influenced by individual and contextual factors such as time post-stroke, personality, severity of communication difficulty, availability of family support, and age. Level of participation was often associated with the severity of the impairment, but some participants developed strategies to participate in spite of limited expressive language. Another factor influencing participation was the meaning and consequences of the stroke upon participant's lives. Older participants appeared to resume participation sooner than those with pre-existing health conditions. Stroke survivors with communication difficulties and their families undertook active 'work' to manage the consequences of stroke and living with a communication difficulty. This included a trial-and-error process of 'figuring out' which activities could be managed and which would require further support, as well as developing strategies to manage their communication difficulties.

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							Despite the resourcefulness and creativity demonstrated, some expressed a lack of confidence in their ability and feelings of powerlessness and abandonment at the point of discharge from community services. A self-management approach may be useful to smooth this difficult transition, but such an approach must recognize, support and build upon the active work already undertaken by stroke survivors and their families to ensure that interventions are designed to address the specific needs of this population.

Appendix C

List of codes identified in the reviewed studies

1. Art participation enhances experiences of rehabilitation.
2. Art participation facilitates social interaction.
3. Art participation generates confidence and self-efficacy.
4. Confidence and trust in professionals - associated with older individuals' satisfaction and positive evaluation of rehabilitation.
5. De-medicalisation of exercise – i.e., not taking place in clinical settings and not led by clinicians.
6. Dialogue and exchange of information between staff and older individuals - quality of their interaction influences older individuals' satisfaction with stroke rehabilitation.
7. Difficult discharge - did not felt informed about the plans of their recovery.
8. Difficult discharge - people did not feel supported.
9. Duration of physiotherapy - more physiotherapy should be provided (from what is routinely given) during the inpatient stay.
10. Feeling bored due to high amount of waiting and trapped by the hospital setting /framework.
11. Gender perspective - differences in older individuals; experiences of nursing care based on their gender.
12. Gendered negotiations of older individuals with medical staff - difference between men and women
13. Health changes as precursors for innovation.
14. Health services structural deficits lead to insufficient therapy and rehabilitation.
15. Inpatient physiotherapy - more therapy time favoured by participants.
16. Inpatient physiotherapy - more therapy time not favoured by participants.
17. Inpatient physiotherapy - personal and collective achievement, success.
18. Inpatient physiotherapy - rest time favoured by participants.
19. Inpatient physiotherapy - rest time not favoured by participants.
20. Inpatient rehabilitation - satisfaction when rehabilitation was intense, specific and varied.
21. Interactions with rehabilitation professionals influence long-term participation.
22. Lack of psychosocial support, care and contact from health professionals.
23. Lacking involvement of family members in physiotherapy.
24. Limitations and dominance of traditional model of care - leading to the passivation of older individuals.
25. Maintaining a sense of hope and progression towards recovery.
26. Men and women seemed to hide their sorrow about illness.
27. Men and women were not able to participate in their care.
28. Men different goals than women with regards to getting back to life as before stroke
29. Men felt more vulnerable when they need bodily care.
30. Momentum was maintained - successful discharge.
31. Momentum was perceived to be lost leading to difficult discharge.
32. More information needed about rehabilitation services following discharge.
33. More information needed regarding insurance coverage.
34. More information needed regarding medical interventions.
35. Motivation for exercise during rehabilitation linked to the sense of well-being it promotes.
36. Motivation for exercise engagement – following a lifestyle-based approach.
37. Need to be acknowledged as independent individuals – retain a sense of autonomy.
38. Need to be treated with humanity, dignity and respect - associated with older individuals' satisfaction.
39. Negative experience due to lack of information - leading to anxiety and post-discharge problems.
40. New activities as part of the recovery rehabilitation process.
41. New activities can improve and maintain well-being.
42. New activities, innovation as continuity.
43. New activities, innovation may involve inconveniencies.
44. Older individuals adjust to new activities, innovation.
45. Older individuals feeling as passive and subordinate with regards to rehabilitation and care offered to them - hierarchical medical model.
46. Older individuals need to contact and receive support from nursing staff - although this need not recognised by staff.

47. Older individuals not being part in the planning of continued care, both with respect to hospital and community care.
48. Older individuals’ concerns with regards to nursing staff.
49. Older individuals’ experiences of discharge - 'coming home'.
50. Older individuals’ experiences of discharge - homecoming as confirmation of regaining control.
51. Older individuals’ experiences of discharge - homecoming increases self-esteem, important for recovery and rehabilitation.
52. Older individuals’ experiences of discharge - new insights of their state when returning home.
53. Older individuals’ experiences of discharge – relief, joy and happiness for homecoming.
54. Older individuals’ interaction with staff - building alliances.
55. Older individuals’ interaction with staff - criticise care.
56. Older individuals’ negative experiences with structural, health services deficits: shortage of nursing staff.
57. Older individuals’ negative experiences with structural, health services deficits: a narrow focus and an emphasis of care on physical needs to the exclusion of broader (non-physical) human needs.
58. Older individuals’ negotiations and building alliances with the healthcare staff during their stroke rehabilitation - a way of increasing their power from below by performing resistant negotiations but also a sign of adjustment and subordination.
59. Older individuals’ non-involvement in the selection of post-acute setting.
60. Older individuals’ opinions were not considered after discharge.
61. Older individuals’ own models of recovery - a sense of momentum.
62. Older individuals’ participation in their rehabilitation goal-setting - adequate involvement for some, challenging for others - not being aware of goals set for the week and difficult to work towards them.
63. Older individuals’ positive perceptions of nursing staff.
64. Older individuals’ sense of living in a nursing home as losing their autonomy.
65. Older individuals’ struggling with existential thoughts and concerns: negatively affecting their rehabilitation experiences.
66. Participation in enriched environment - barriers and limitations to use EE.
67. Participation in enriched environment - enhancement of social interaction and increased activity levels.
68. Participation in enriched environment - perceived individual and communal benefits.
69. Participation in enriched environment - ways of reducing barriers of EE use.
70. Passive role of older individuals with stroke - seeking advice from staff and obeying orders.
71. Passive role of older individuals with stroke - the staff decided everything about older individuals’ care plan.
72. Poor communication between medical staff and older individuals.
73. Positive role of families in rehabilitation process - families’ participation in physiotherapy can be advantageous both physically and emotionally – satisfaction of older individuals.
74. Striving for autonomy - demanding information on their situation, recovery etc.
75. Striving for independence - Passive role of older individuals with stroke and difficulty to grasp their situation due to brain damage.
76. Successful discharge - when they felt informed.
77. Successful discharge - when they felt supported.
78. Treatment burden - healthcare workload and care deficiencies influence and influenced by older individuals’ capacity.
79. Treatment burden - quality and configuration of health care services can influence care deficiencies, healthcare workload and older individuals’ capacity.
80. Treatment burden arising from healthcare workload and care deficiencies.
81. Views on physiotherapists - older individuals identified encouragement and honesty as important attributes of physiotherapists.
82. Vulnerability and dependence of older individuals due to their condition - the need to be treated with respect and dignity.
83. Women seemed more comfortable with bodily care.
84. Women's and men's experiences of nursing care associated with unexpected changes in the body.

Appendix D

Themes, Categories & Codes

Themes	Categories	Codes	Papers where code appears
Rehabilitation processes and their impact on older individuals' well-being	**Experiences of inpatient rehabilitation and physiotherapy for older individuals living with ABI**	Inpatient physiotherapy - more therapy time not favoured by participants	Bennett *et al.* (2016)
		Inpatient physiotherapy - more therapy time favoured by participants	Bennett *et al.* (2016)
		Inpatient physiotherapy - personal and collective achievement, success	Bennett *et al.* (2016)
		Inpatient physiotherapy - rest time favoured by participants	Bennett *et al.* (2016)
		Inpatient physiotherapy - rest time not favoured by participants	Bennett *et al.* (2016)
		Inpatient rehabilitation - satisfaction when rehabilitation was intense, specific and varied	Tholin and Forsberg (2014)
		Positive role of families in rehabilitation process - families' participation in physiotherapy can be advantageous both physically and emotionally – satisfaction of older individuals	Galvin, Cusack and Stokes (2009); Loft *et al.* (2019); Tholin and Forsberg (2014); Poltawski *et al.* (2015)
		Lacking involvement of family members in physiotherapy	Galvin, Cusack and Stokes (2009)
		Duration of physiotherapy - more physiotherapy should be provided (from what is routinely given) during the inpatient stay.	Galvin, Cusack and Stokes (2009); Bennett *et al.* (2016)
		Motivation for exercise during rehabilitation linked to the sense of well-being it promotes	Poltawski *et al.* (2015)
		De-medicalisation of exercise – i.e., not taking place in clinical settings and not led by clinicians	Poltawski *et al.* (2015)
		Motivation for exercise engagement – following a lifestyle-based approach	Poltawski *et al.* (2015)
	Hospital discharge experiences of older individuals living with ABI	Difficult discharge - did not felt informed about the plans of their recovery	Ellis-Hill *et al.* (2009)
		Difficult discharge - people did not feel supported	Ellis-Hill *et al.* (2009); Wray, Clarke and Forster (2019)
		Negative experience due to lack of information - leading to anxiety and post-discharge problems	Morris, Payne and Lambert (2007)
		More information needed about rehabilitation services following discharge	Krishnan *et al.* (2019)
		More information needed regarding insurance coverage	Krishnan *et al.* (2019)
		More information needed regarding medical interventions	Krishnan *et al.* (2019)
		Older individuals' non-involvement in the selection of post-acute setting	Krishnan *et al.* (2019)
		Older individuals' opinions were not considered after discharge	Tholin and Forsberg (2014)
		Older individuals' experiences of discharge - homecoming as confirmation of regaining control	Olofsson, Andersson and Carlberg (2005)
		Older individuals' experiences of discharge – relief, joy and happiness for homecoming	Olofsson, Andersson and Carlberg (2005); Wray, Clarke and Forster (2019)
		Older individuals' experiences of discharge - homecoming increases self-esteem, important for recovery and rehabilitation	Olofsson, Andersson and Carlberg (2005)
		Older individuals' experiences of discharge - new insights of their state when returning home	Olofsson, Andersson and Carlberg (2005)

		Older individuals’ experiences of discharge - 'coming home'	Olofsson, Andersson and Carlberg (2005)
		Successful discharge - when they felt informed	Ellis-Hill *et al.* (2009)
		Successful discharge - when they felt supported	Ellis-Hill *et al.* (2009)
Identity and embodiment concerns of older individuals during rehabilitation	**The felt need for autonomy, dignity, humanity of older individuals living with ABI**	Need to be acknowledged as independent individuals – retain a sense of autonomy	Mangset *et al.* (2008); Löfmark and Hammarstrom (2005); Wray, Clarke and Forster (2019)
		Older individuals feeling as passive and subordinate with regards to rehabilitation and care offered to them - hierarchical medical model	Löfmark and Hammarstrom (2005); Olofsson, Andersson and Carlberg (2005)
		Feeling bored due to high amount of waiting and trapped by the hospital setting /framework	Loft *et al.* (2019)
		Older individuals’ struggling with existential thoughts and concerns: negatively affecting their rehabilitation experiences	Loft *et al.* (2019)
		Need to be treated with humanity, dignity and respect - associated with older individuals’ satisfaction	Mangset *et al.* (2008); Loft *et al.* (2019)
		Older individuals’ own models of recovery - a sense of momentum	Ellis-Hill *et al.* (2009)
		Momentum was perceived to be lost leading to difficult discharge	Ellis-Hill *et al.* (2009)
		Momentum was maintained - successful discharge	Ellis-Hill *et al.* (2009)
		Striving for autonomy - demanding information on their situation, recovery etc.	Olofsson, Andersson and Carlberg (2005)
		Maintaining a sense of hope and progression towards recovery	Wray, Clarke and Forster (2019)
		Vulnerability and dependence of older individuals due to their condition - the need to be treated with respect and dignity	Mangset *et al.* (2008)
		Striving for independence - Passive role of older individuals with stroke and difficulty to grasp their situation due to brain damage	Olofsson, Andersson and Carlberg (2005)
		Older individuals’ negotiations and building alliances with the healthcare staff during their stroke rehabilitation - a way of increasing their power from below by performing resistant negotiations but also a sign of adjustment and subordination	Löfmark and Hammarstrom (2005)
		Older individuals’ sense of living in a nursing home as losing their autonomy	Tholin and Forsberg (2014)
	Gender influences on older individuals’ conceptualisation of ABI condition and rehabilitation process	Gender perspective - differences in older individuals; experiences of nursing care based on their gender	Andersson and Hansebo (2009)
		Men and women seemed to hide their sorrow about illness	Andersson and Hansebo (2009)
		Men and women were not able to participate in their care	Andersson and Hansebo (2009)
		Men different goals than women with regards to getting back to life as before stroke	Andersson and Hansebo (2009)
		Men felt more vulnerable when they need bodily care	Andersson and Hansebo (2009)

		Women seemed more comfortable with bodily care	Andersson and Hansebo (2009)
		Women's and men's experiences of nursing care associated with unexpected changes in the body	Andersson and Hansebo (2009)
		Gendered negotiations of older individuals with medical staff - difference between men and women	Löfmark and Hammarstrom (2005)
Institutional factors affecting older individuals' experiences of care and well-being	**Treatment burdens and organisational healthcare factors impacting on older ABI survivors' treatment**	Treatment burden - healthcare workload and care deficiencies influence and influenced by older individuals' capacity	Gallacher *et al.* (2018)
		Treatment burden - quality and configuration of health care services can influence care deficiencies, healthcare workload and older individuals' capacity	Gallacher *et al.* (2018)
		Treatment burden arising from healthcare workload and care deficiencies	Gallacher *et al.* (2018)
		Health services structural deficits lead to insufficient therapy and rehabilitation	Morris, Payne and Lambert (2007)
		Older individuals' negative experiences with structural, health services deficits: shortage of nursing staff	Morris, Payne and Lambert (2007); Löfmark and Hammarstrom (2005)
		Older individuals' negative experiences with structural, health services deficits: a narrow focus and an emphasis of care on physical needs to the exclusion of broader (non-physical) human needs	Morris, Payne and Lambert (2007)
		Older individuals' participation in their rehabilitation goal-setting - adequate involvement for some, challenging for others - not being aware of goals set for the week and difficult to work towards them.	Loft *et al.* (2019); Krishnan *et al.* (2019)
		Older individuals not being part in the planning of continued care, both with respect to hospital and community care	Tholin and Forsberg (2014)
		Limitations and dominance of traditional model of care - leading to the passivation of older individuals	Olofsson, Andersson and Carlberg (2005)
	Older individuals' negative perspectives and interactions with healthcare service and medical staff	Older individuals need to contact and receive support from nursing staff - although this need not recognised by staff	Loft *et al.* (2019)
		Older individuals' concerns with regards to nursing staff	Loft *et al.* (2019); Morris, Payne and Lambert (2007)
		Older individuals' interaction with staff - criticise care	Löfmark and Hammarstrom (2005)
		Poor communication between medical staff and older individuals	Morris, Payne and Lambert (2007); Tholin and Forsberg (2014)
		Lack of psychosocial support, care and contact from health professionals	Tholin and Forsberg (2014)
		Passive role of older individuals with stroke - seeking advice from staff and obeying orders	Olofsson, Andersson and Carlberg (2005); Morris, Payne and Lambert (2007); Löfmark and Hammarstrom (2005)
		Passive role of older individuals with stroke - the staff decided everything about older individuals' care plan	Tholin and Forsberg (2014)
		Older individuals' positive perceptions of nursing staff	Loft *et al.* (2019); Morris, Payne and Lambert (2007)
	Older individuals' positive	Views on physiotherapists - older individuals identified encouragement and honesty as important attributes of physiotherapists	Galvin, Cusack and Stokes (2009)

	perspectives and interactions with healthcare service and medical staff	Older individuals’ interaction with staff - building alliances	Löfmark and Hammarstrom (2005)
		Confidence and trust in professionals - associated with older individuals’ satisfaction and positive evaluation of rehabilitation	Mangset *et al.* (2008)
		Dialogue and exchange of information between staff and older individuals - quality of their interaction influences older individuals’ satisfaction with stroke rehabilitation.	Mangset *et al.* (2008)
		Interactions with rehabilitation professionals influence long-term participation	Morris, Payne and Lambert (2007)
Older individuals’ participation in creative activities as part of rehabilitation	**Art participation and rehabilitation of older individuals living with ABI**	Art participation enhances experiences of rehabilitation	Morris *et al.* (2015)
		Art participation facilitates social interaction	Morris *et al.* (2015)
		Art participation generates confidence and self-efficacy	Morris *et al.* (2015)
	Older individuals’ experiences of rehabilitation and participation in innovation and new activities	Health changes as precursors for innovation	Nimrod and Hutchinson (2010)
		New activities as part of the recovery rehabilitation process	Nimrod and Hutchinson (2010)
		New activities can improve and maintain well-being	Nimrod and Hutchinson (2010)
		New activities, innovation as continuity	Nimrod and Hutchinson (2010)
		New activities, innovation may involve inconveniencies	Nimrod and Hutchinson (2010)
		Older individuals adjust to new activities, innovation	Nimrod and Hutchinson (2010)
		Participation in enriched environment - barriers and limitations to use EE	White *et al.* (2015)
		Participation in enriched environment - enhancement of social interaction and increased activity levels	White *et al.* (2015)
		Participation in enriched environment - perceived individual and communal benefits	White *et al.* (2015)
		Participation in enriched environment - ways of reducing barriers of EE use	White *et al.* (2015)

Appendix E

E.1 Interview questions in English and the research objectives to which they correspond (before the pilot interviews):

General/ descriptive questions	**Research Objectives**
1. Please can you tell me about your experiences living with ABI* (during the last year) - Can you tell me how you spend your day in the rehabilitation clinic/ at home? - Can you describe your scheduled rehabilitation exercises?	1, 2, 5
2. 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?	2, 3
3. What professionals are you linked with at the moment (or in the past)? - How is the relationship between you and your health professionals? - Can you tell me more about that relationship? What is it that makes it good/ bad?	1, 4
4. Can you describe how your family is/ has been involved in your rehabilitation programme? *<u>If yes:</u>* - 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?) *<u>If they say that their family are not very involved:</u>* - Why do you feel that might be? - In what ways does that affect your rehabilitation?	1, 2, 3
Knowledge questions	**Research Objectives**
1. 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*)?	1, 4, 5
2. 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?)	2, 3, 4, 5

3. Do you know what your family thinks of your current situation/ current condition? (e.g., they are supportive/ tired/ they cannot understand/ realise your situation...) - 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? - (Can you give an example of family support)	1, 2, 5
4. What is your definition of *well-being*? - (What is *well-being* for you?) - (What do you understand with the word *well-being*/ How do you understand the word *well-being*?)	2, 3
Questions of personal philosophy	**Research Objectives**
Check how they define well-being – and then ask: 1. Do you think that ABI* has affected your overall well-being? - In what ways?	2, 3
2. Do you think that your current situation has changed you as a person? - If yes, in what ways?	2, 3
3. Have you been making plans for your future? - How does your current situation impact on these plans?	2, 3
4. 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?	4, 5
5. We talked about family previously. 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*?	1, 2, 3
Closing question	
1. Is there anything else you would like to add? Is there anything else you think it is important that we haven't talked about?	

* ABI – specific condition, like stroke or any other brain injury

E.2 Interview questions in Greek and the research objectives to which they correspond (before the pilot interviews).

General/ descriptive questions	Research Objectives
1. Παρακαλώ μπορείτε να μου μιλήσετε για τις εμπειρίες σας μετά τη διάγνωσή σας με Επίκτητη Εγκεφαλική Βλάβη (ΕΕΒ) - κατά τη διάρκεια του περασμένου έτους; - Μπορείτε να μου πείτε πώς περνάτε τη μέρα σας στην κλινική αποκατάστασης / στο σπίτι; - Μπορείτε να περιγράψετε τις προγραμματισμένες συνεδρίες αποκατάστασης;	1, 2, 5
2. Τι πιστεύετε ότι έχει αλλάξει περισσότερο μετά τη διάγνωση σας με ΕΕΒ όσον αφορά την καθημερινότητά σας (κατά τη διάρκεια του τελευταίου έτους); - Μπορείτε να δώσετε ένα παράδειγμα;	2, 3
3. Με ποιους επαγγελματίες υγείας έρχεστε σε επαφή αυτόν τον καιρό (ή στο παρελθόν); - Πώς είναι οι σχέσεις σας με αυτούς τους επαγγελματίες υγείας; - Μπορείτε να μου πείτε περισσότερα για αυτήν την συνεργασία/ σχέση; Τι είναι αυτό που την κάνει καλή/ κακή;	1, 4
4. Μπορείτε να μου περιγράψετε πώς η οικογένειά σας έχει συμμετάσχει/ συμμετέχει/ εμπλέκεται στο πρόγραμμα αποκατάστασής σας; *Αν ναι:* - Τι κάνουν για εσάς; - Με ποιους τρόπους η συμμετοχή τους επηρεάζει την αποκατάστασή σας; - (Μπορείτε να μου πείτε πόσο συχνά βλέπετε τους αγαπημένους σας;) *Αν πουν ότι η οικογένειά τους δεν εμπλέκεται πολύ στην αποκατάστασή τους:* - Γιατί νομίζετε ότι μπορεί να συμβαίνει αυτό; - Πώς αυτό επηρεάζει την αποκατάσταση σας;	1, 2, 3

Knowledge questions	Research Objectives
1. Τι γνωρίζετε για την ΕΕΒ και τη διαδικασία αποκατάστασης; - Τι είδους πληροφορίες έχετε λάβει σχετικά με την αποκατάστασή σας μετά τη διάγνωσή σας με ΕΕΒ; - Πιστεύετε ότι έχετε ενεργό συμμετοχή στον σχεδιασμό του προγράμματος αποκατάστασής σας; - Υπάρχει κάτι άλλο που θα θέλατε να μάθετε για την αποκατάστασή σας ή την κατάστασή σας (ΕΕΒ);	1, 4, 5
2. Είστε ικανοποιημένοι με την υποστήριξη που λαμβάνετε; - Πώς σας έχει υποστηρίξει/ τι επίδραση ασκεί η ομάδα επαγγελματιών υγείας κατά τη διάρκεια της αποκατάστασής σας; - Είστε ευχαριστημένοι/ ικανοποιημένοι με τη ζωή σας αυτή τη στιγμή; - (Υπάρχει κάτι άλλο που θα επιθυμούσατε από τους επαγγελματίες υγείας σχετικά με την αποκατάστασή σας;)	2, 3, 4, 5
3. Γνωρίζετε/ μπορείτε να φανταστείτε τι πιστεύει η οικογένειά σας για την τρέχουσα κατάστασή σας; (π.χ. είναι υποστηρικτικοί ή κουρασμένοι ή δεν μπορούν να κατανοήσουν / συνειδητοποιήσουν την κατάστασή σας...) - Θα θέλατε η οικογένειά σας να συμμετέχει περισσότερο ή λιγότερο στις διαδικασίες αποκατάστασής σας; - Τι άλλο νομίζετε θα μπορούσε να κάνει η οικογένειά σας για να σας κάνει να αισθανθείτε καλύτερα / ότι σας υποστηρίζει; - (Θα μπορούσατε να μου δώσετε ένα παράδειγμα για την οικογενειακή υποστήριξη που λαμβάνετε κατά τη διάρκεια της αποκατάστασής σας;)	1, 2, 5
4. Πώς θα ορίζατε τον όρο *ευεξία*; - (Τι σημαίνει *ευεξία* για εσάς) - (Τι καταλαβαίνετε όταν μιλάμε για προσωπική *ευεξία*;)	2, 3

Questions of personal philosophy	Research Objectives
Βάσει του πώς ορίζουν/ έχουν καταλάβει τον όρο ευεξία, θέτω την εξής ερώτηση: 1. Πιστεύετε πως η ΕΕΒ έχει επηρεάσει την ευεξία σας; (την ευτυχία σας – αναλόγως του πώς απαντήσει παραπάνω, εξηγώ τι εννοώ με τον όρο ευεξία) - Με ποιους τρόπους;	2, 3
2. Πιστεύετε πως η τρέχουσα κατάστασή σας, σάς έχει αλλάξει ως άτομο; - Αν ναι, με ποιους τρόπους;	2, 3
3. Κάνετε σχέδια για το μέλλον; - Πώς επηρεάζει η τρέχουσα κατάστασή σας αυτά τα σχέδια;	2, 3
4. Ποιες είναι οι απόψεις σας σχετικά με τη φιλοσοφία που καθοδηγεί/ που διατρέχει το σύστημα υγείας; - Πιστεύετε ότι το περιβάλλον αποκατάστασης και η οργάνωσή του μπορεί να σας υποστηρίξει περαιτέρω; - Αν ναι, με ποιους τρόπους;	4, 5
5. Προηγουμένως μιλήσαμε για την υποστήριξη της οικογένειας. Κατά τη γνώμη σας, ποια θα πρέπει να είναι η συμμετοχή και υποστήριξη της οικογένειας στα άτομα που ζουν με ΕΕΒ; (Ποιες είναι οι απόψεις σας σχετικά με την συμμετοχή της οικογένειας/ συγγενών για τα άτομα που ζουν με ΕΕΒ;)	1, 2, 3

Closing question
1. Υπάρχει κάτι άλλο που θα θέλατε να προσθέσετε; - Υπάρχει κάτι άλλο που νομίζετε ότι είναι σημαντικό και δεν το συζητήσαμε;

Appendix F

F.1 Interview schedule and questions - modified following the pilot interviews (in English).

i. Greeting - Introduce myself

The researcher will meet the participants and will be introduced, saying a few things for herself.

ii. Welcome and build rapport (make the participant feel comfortable)

Before the onset of data collection, the researcher will engage in the process of negotiating and establishing relationships (rapport) with the participants. This will be done in a variety of ways including expressing interest in participants' concerns, expressing humility, expressing interest in participants' conversations before and after the interview.

iii. Provide information about the research, obtain participant's written informed consent and give them the chance to ask for more information.

The researcher will provide any information regarding the research and obtain a written consent form. The researcher will answer any inquiry regarding the interview process.

iv. Sample characteristics

Gather basic information about the participants (name, age, gender, type of ABI).

v. Interview questions (modified after the pilot interviews)

Questions	Type of Question	Research Objectives
1. Please can you tell me about your experiences living with ABI* (during the last year) - Can you tell me how you spend your day in the rehabilitation clinic/ at home? - Can you describe your scheduled rehabilitation exercises?	**General/ Descriptive**	**1, 2, 5**
2. What do you think has changed the most after you were diagnosed with ABI* in terms of your daily routine (during the last year)? - Give an example.	**General/ Descriptive**	**2, 3**

Questions	Type of Question	Research Objectives
3. 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**	**1, 4, 5**
4. What professionals are you linked with at the moment (or in the past)? - How is the relationship between you and your health professionals? - Can you tell me more about that relationship? What is it that makes it good/ bad?	**General/ Descriptive**	**1, 4**
5. 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**	**2, 3, 4, 5**
6. Can you describe how your family is/ has been involved in your rehabilitation programme? *If yes:* - 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?) *If they say that their family are not very involved:* - Why do you feel that might be? - In what ways does that affect your rehabilitation?	**General/ Descriptive**	**1, 2, 3**
7. Do you know what your family thinks of your current situation/ current condition? (e.g. they are supportive or tired, or they cannot understand/ realise your situation...) - 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? - (Example of family support)	**Knowledge**	**1, 2, 5**

Questions	Type of Question	Research Objectives
8. 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**	**1, 2, 3**
9. What is your definition of *well-being*? - (What is *well-being* for you?) - (What do you understand with the word *well-being*/ How do you understand the word *well-being*?)	**Knowledge**	**2, 3**
Check how they define well-being – and then ask: **10. Do you think that ABI* has affected your overall well-being?** - In what ways?	**Personal philosophy**	**2, 3**
11. Do you think that your current situation has changed you as a person? - If yes, in what ways?	**Personal philosophy**	**2, 3**
12. Have you been making plans for your future? - How does your current situation impact on these plans?	**Personal philosophy**	**2, 3**
13. 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**	**4, 5**
14. Is there anything else you would like to add? - Is there anything else you think it is important that we haven't talked about?		

F.2 Interview questions - modified following the pilot interviews (in Greek).

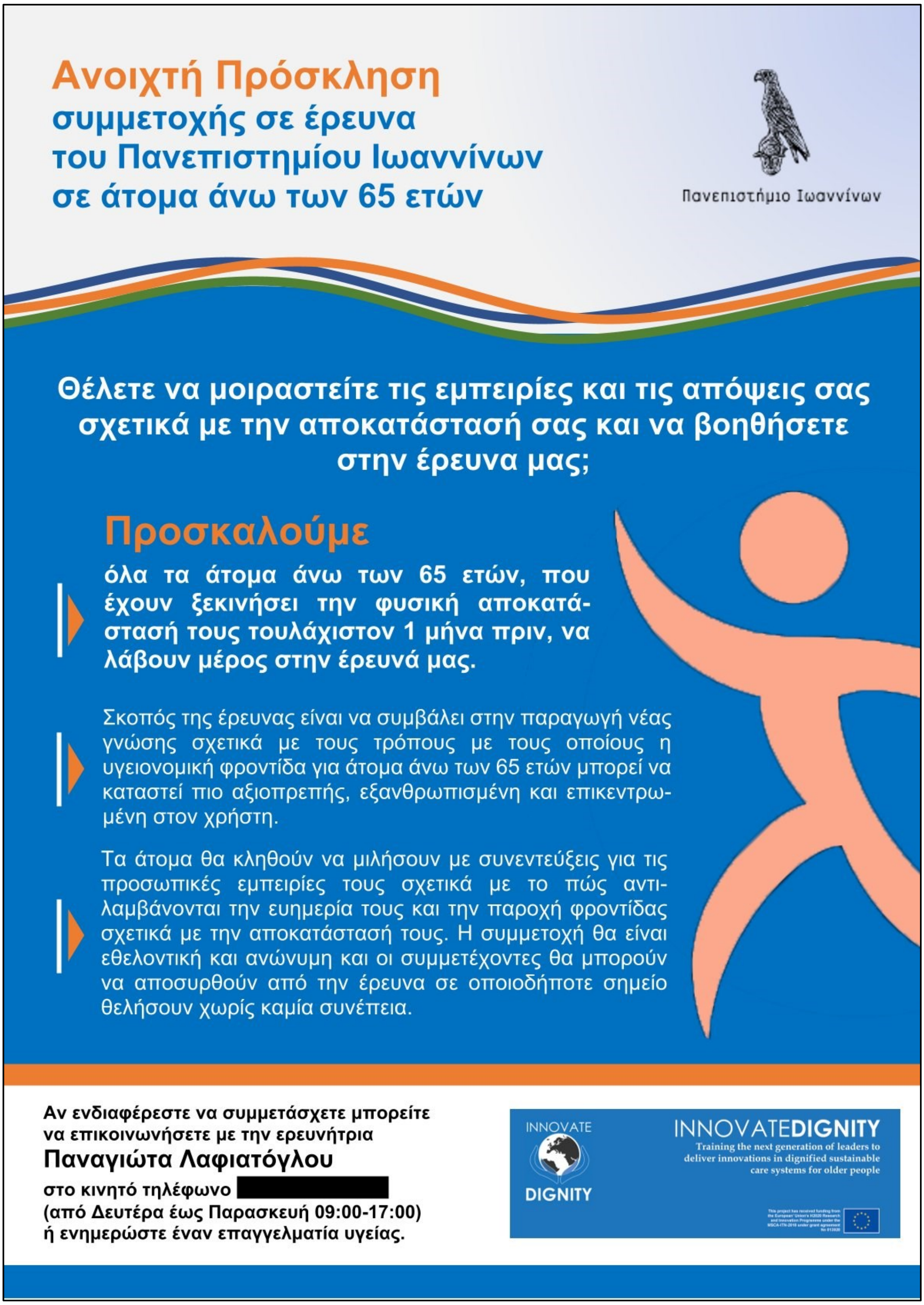
Questions	Type of Question	Research Objectives
1. **Παρακαλώ μπορείτε να μου μιλήσετε για τις εμπειρίες σας μετά τη διάγνωσή σας με Επίκτητη Εγκεφαλική Βλάβη (ΕΕΒ) - κατά τη διάρκεια του περασμένου έτους;** - Μπορείτε να μου πείτε πώς περνάτε τη μέρα σας στην κλινική αποκατάστασης / στο σπίτι; - Μπορείτε να περιγράψετε τις προγραμματισμένες συνεδρίες αποκατάστασης;	**General/ Descriptive**	**1, 2, 5**
2. **Τι πιστεύετε ότι έχει αλλάξει περισσότερο μετά τη διάγνωση σας με ΕΕΒ όσον αφορά την καθημερινότητά σας (κατά τη διάρκεια του τελευταίου έτους);** - Μπορείτε να δώσετε ένα παράδειγμα;	**General/ Descriptive**	**2, 3**
3. **Τι γνωρίζετε για την ΕΕΒ και τη διαδικασία αποκατάστασης;** - Τι είδους πληροφορίες έχετε λάβει σχετικά με την αποκατάστασή σας μετά τη διάγνωσή σας με ΕΕΒ; - Πιστεύετε ότι έχετε ενεργό συμμετοχή στον σχεδιασμό του προγράμματος αποκατάστασής σας; - Υπάρχει κάτι άλλο που θα θέλατε να μάθετε για την αποκατάστασή σας ή την κατάστασή σας (ΕΕΒ);	**Knowledge**	**1, 4, 5**
4. **Με ποιους επαγγελματίες υγείας έρχεστε σε επαφή αυτόν τον καιρό (ή στο παρελθόν);** - Πώς είναι οι σχέσεις σας με αυτούς τους επαγγελματίες υγείας; - Μπορείτε να μου πείτε περισσότερα για αυτήν την συνεργασία/ σχέση; Τι είναι αυτό που την κάνει καλή/ κακή;	**General/ Descriptive**	**1, 4**
5. **Είστε ικανοποιημένοι με την υποστήριξη που λαμβάνετε;** - Πώς σας έχει υποστηρίξει/ τι επίδραση ασκεί η ομάδα επαγγελματιών υγείας κατά τη διάρκεια της αποκατάστασής σας; - Είστε ευχαριστημένοι/ ικανοποιημένοι με τη ζωή σας αυτή τη στιγμή; - (Υπάρχει κάτι άλλο που θα επιθυμούσατε από τους επαγγελματίες υγείας σχετικά με την αποκατάστασή σας;)	**Knowledge**	**2, 3, 4, 5**

Questions	Type of Question	Research Objectives
6. Μπορείτε να μου περιγράψετε πώς η οικογένειά σας έχει συμμετάσχει/ συμμετέχει/ εμπλέκεται στο πρόγραμμα αποκατάστασής σας; *Αν ναι:* - Τι κάνουν για εσάς; - Με ποιους τρόπους η συμμετοχή τους επηρεάζει την αποκατάστασή σας; - (Μπορείτε να μου πείτε πόσο συχνά βλέπετε τους αγαπημένους σας;) *Αν πουν ότι η οικογένειά τους δεν εμπλέκεται πολύ στην αποκατάστασή τους:* - Γιατί νομίζετε ότι μπορεί να συμβαίνει αυτό; - Πώς αυτό επηρεάζει την αποκατάσταση σας;	**General/ Descriptive**	**1, 2, 3**
7. Γνωρίζετε/ μπορείτε να φανταστείτε τι πιστεύει η οικογένειά σας για την τρέχουσα κατάστασή σας; (π.χ. είναι υποστηρικτικοί ή κουρασμένοι ή δεν μπορούν να κατανοήσουν / συνειδητοποιήσουν την κατάστασή σας...) - Θα θέλατε η οικογένειά σας να συμμετέχει περισσότερο ή λιγότερο στις διαδικασίες αποκατάστασής σας; - Τι άλλο νομίζετε θα μπορούσε να κάνει η οικογένειά σας για να σας κάνει να αισθανθείτε καλύτερα / ότι σας υποστηρίζει; - (Θα μπορούσατε να μου δώσετε ένα παράδειγμα για την οικογενειακή υποστήριξη που λαμβάνετε κατά τη διάρκεια της αποκατάστασής σας;)	**Knowledge**	**1, 2, 5**
8. Κατά τη γνώμη σας, ποια θα πρέπει να είναι η συμμετοχή και υποστήριξη της οικογένειας στα άτομα που ζουν με ΕΕΒ; (Ποιες είναι οι απόψεις σας σχετικά με την συμμετοχή της οικογένειας/ συγγενών για τα άτομα που ζουν με ΕΕΒ;)	**Personal philosophy**	**1, 2, 3**
9. Πώς θα ορίζατε τον όρο *ευεξία*; - (Τι σημαίνει *ευεξία* για εσάς) - (Τι καταλαβαίνετε όταν μιλάμε για προσωπική *ευεξία*;)	**Knowledge**	**2, 3**

Questions	Type of Question	Research Objectives
Βάσει του πώς ορίζουν/ έχουν καταλάβει τον όρο ευεξία, θέτω την εξής ερώτηση: **10. Πιστεύετε πως η ΕΕΒ έχει επηρεάσει την ευεξία σας; (την ευτυχία σας – αναλόγως του πώς απαντήσει παραπάνω, εξηγώ τι εννοώ με τον όρο ευεξία)** - Με ποιους τρόπους;	**Personal philosophy**	**2, 3**
11. Πιστεύετε πως η τρέχουσα κατάστασή σας, σάς έχει αλλάξει ως άτομο; - Αν ναι, με ποιους τρόπους;	**Personal philosophy**	**2, 3**
12. Κάνετε σχέδια για το μέλλον; - Πώς επηρεάζει η τρέχουσα κατάστασή σας αυτά τα σχέδια;	**Personal philosophy**	**2, 3**
13. Ποιες είναι οι απόψεις σας σχετικά με τη φιλοσοφία που καθοδηγεί/ που διατρέχει το σύστημα υγείας; - Πιστεύετε ότι το περιβάλλον αποκατάστασης και η οργάνωσή του μπορεί να σας υποστηρίξει περαιτέρω; - Αν ναι, με ποιους τρόπους;	**Personal philosophy**	**4, 5**
14. Υπάρχει κάτι άλλο που θα θέλατε να προσθέσετε; - Υπάρχει κάτι άλλο που νομίζετε ότι είναι σημαντικό και δεν το συζητήσαμε;		

Appendix G

Poster-Invitation for Research Recruitment (in Greek)



Ανοιχτή Πρόσκληση
συμμετοχής σε έρευνα
του Πανεπιστημίου Ιωαννίνων
σε άτομα άνω των 65 ετών

Πανεπιστήμιο Ιωαννίνων

Θέλετε να μοιραστείτε τις εμπειρίες και τις απόψεις σας σχετικά με την αποκατάστασή σας και να βοηθήσετε στην έρευνα μας;

Προσκαλούμε

όλα τα άτομα άνω των 65 ετών, που έχουν ξεκινήσει την φυσική αποκατάστασή τους τουλάχιστον 1 μήνα πριν, να λάβουν μέρος στην έρευνά μας.

Σκοπός της έρευνας είναι να συμβάλει στην παραγωγή νέας γνώσης σχετικά με τους τρόπους με τους οποίους η υγειονομική φροντίδα για άτομα άνω των 65 ετών μπορεί να καταστεί πιο αξιοπρεπής, εξανθρωπισμένη και επικεντρωμένη στον χρήστη.

Τα άτομα θα κληθούν να μιλήσουν με συνεντεύξεις για τις προσωπικές εμπειρίες τους σχετικά με το πώς αντιλαμβάνονται την ευημερία τους και την παροχή φροντίδας σχετικά με την αποκατάστασή τους. Η συμμετοχή θα είναι εθελοντική και ανώνυμη και οι συμμετέχοντες θα μπορούν να αποσυρθούν από την έρευνα σε οποιοδήποτε σημείο θελήσουν χωρίς καμία συνέπεια.

Αν ενδιαφέρεστε να συμμετάσχετε μπορείτε να επικοινωνήσετε με την ερευνήτρια
Παναγιώτα Λαφιατόγλου
στο κινητό τηλέφωνο [redacted]
(από Δευτέρα έως Παρασκευή 09:00-17:00)
ή ενημερώστε έναν επαγγελματία υγείας.

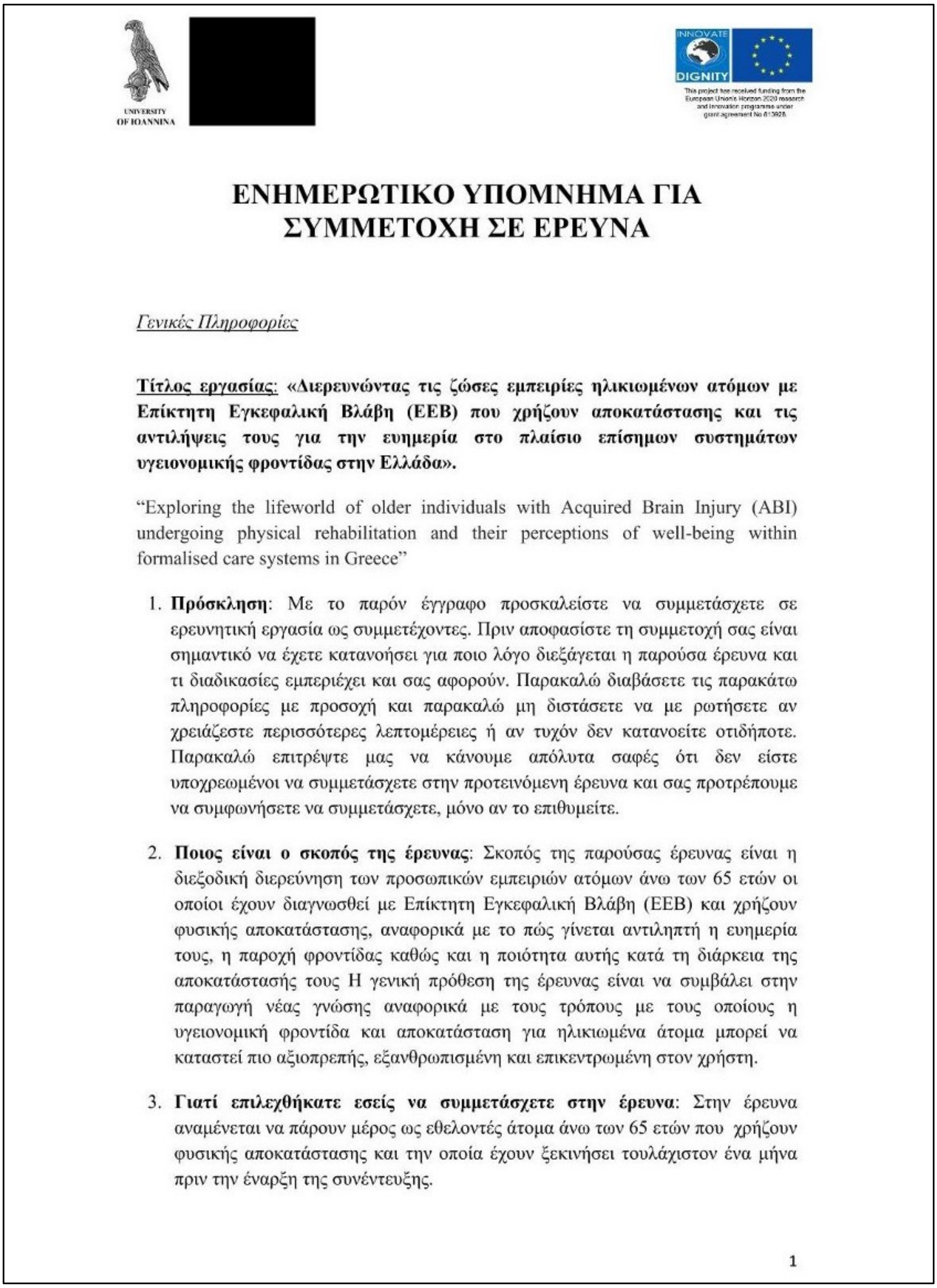
INNOVATE DIGNITY

INNOVATEDIGNITY
Training the next generation of leaders to deliver innovations in dignified sustainable care systems for older people

This project has received funding from the European Union's H2020 Research and Innovation Programme under the MSCA-ITN-2018 under grant agreement No 813928

Appendix H

H.1 Sample of the Information Sheet that was given to health professionals and participants (in Greek)



UNIVERSITY
OF IOANNINA

[redacted]

INNOVATE DIGNITY

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

ΕΝΗΜΕΡΩΤΙΚΟ ΥΠΟΜΝΗΜΑ ΓΙΑ ΣΥΜΜΕΤΟΧΗ ΣΕ ΕΡΕΥΝΑ

Γενικές Πληροφορίες

Τίτλος εργασίας: «Διερευνώντας τις ζώσες εμπειρίες ηλικιωμένων ατόμων με Επίκτητη Εγκεφαλική Βλάβη (ΕΕΒ) που χρήζουν αποκατάστασης και τις αντιλήψεις τους για την ευημερία στο πλαίσιο επίσημων συστημάτων υγειονομικής φροντίδας στην Ελλάδα».

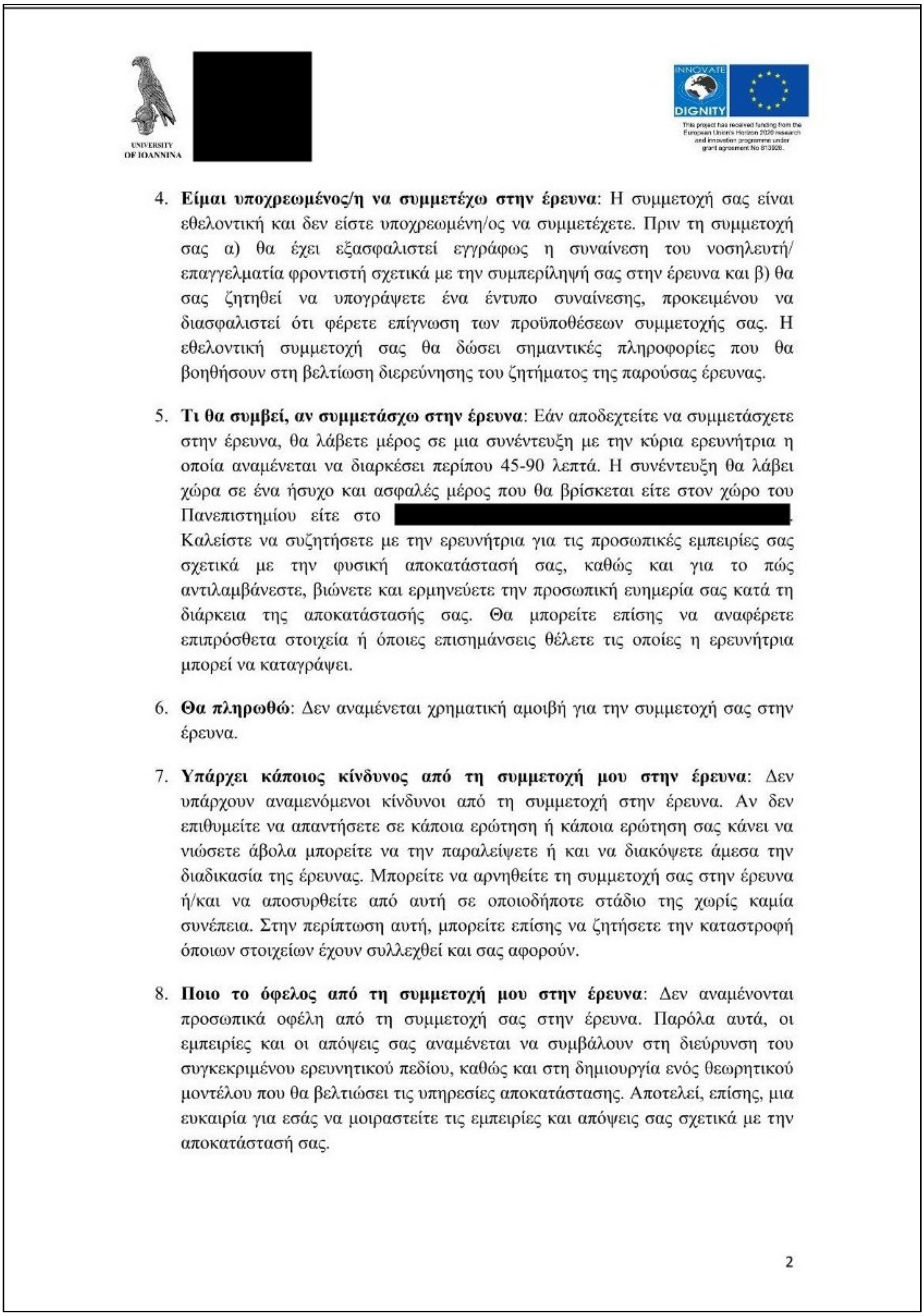
“Exploring the lifeworld of older individuals with Acquired Brain Injury (ABI) undergoing physical rehabilitation and their perceptions of well-being within formalised care systems in Greece”

1. **Πρόσκληση**: Με το παρόν έγγραφο προσκαλείστε να συμμετάσχετε σε ερευνητική εργασία ως συμμετέχοντες. Πριν αποφασίστε τη συμμετοχή σας είναι σημαντικό να έχετε κατανοήσει για ποιο λόγο διεξάγεται η παρούσα έρευνα και τι διαδικασίες εμπεριέχει και σας αφορούν. Παρακαλώ διαβάσετε τις παρακάτω πληροφορίες με προσοχή και παρακαλώ μη διστάσετε να με ρωτήσετε αν χρειάζεστε περισσότερες λεπτομέρειες ή αν τυχόν δεν κατανοείτε οτιδήποτε. Παρακαλώ επιτρέψτε μας να κάνουμε απόλυτα σαφές ότι δεν είστε υποχρεωμένοι να συμμετάσχετε στην προτεινόμενη έρευνα και σας προτρέπουμε να συμφωνήσετε να συμμετάσχετε, μόνο αν το επιθυμείτε.

2. **Ποιος είναι ο σκοπός της έρευνας**: Σκοπός της παρούσας έρευνας είναι η διεξοδική διερεύνηση των προσωπικών εμπειριών ατόμων άνω των 65 ετών οι οποίοι έχουν διαγνωσθεί με Επίκτητη Εγκεφαλική Βλάβη (ΕΕΒ) και χρήζουν φυσικής αποκατάστασης, αναφορικά με το πώς γίνεται αντιληπτή η ευημερία τους, η παροχή φροντίδας καθώς και η ποιότητα αυτής κατά τη διάρκεια της αποκατάστασής τους Η γενική πρόθεση της έρευνας είναι να συμβάλει στην παραγωγή νέας γνώσης αναφορικά με τους τρόπους με τους οποίους η υγειονομική φροντίδα και αποκατάσταση για ηλικιωμένα άτομα μπορεί να καταστεί πιο αξιοπρεπής, εξανθρωπισμένη και επικεντρωμένη στον χρήστη.

3. **Γιατί επιλεχθήκατε εσείς να συμμετάσχετε στην έρευνα**: Στην έρευνα αναμένεται να πάρουν μέρος ως εθελοντές άτομα άνω των 65 ετών που χρήζουν φυσικής αποκατάστασης και την οποία έχουν ξεκινήσει τουλάχιστον ένα μήνα πριν την έναρξη της συνέντευξης.

1



[redacted]

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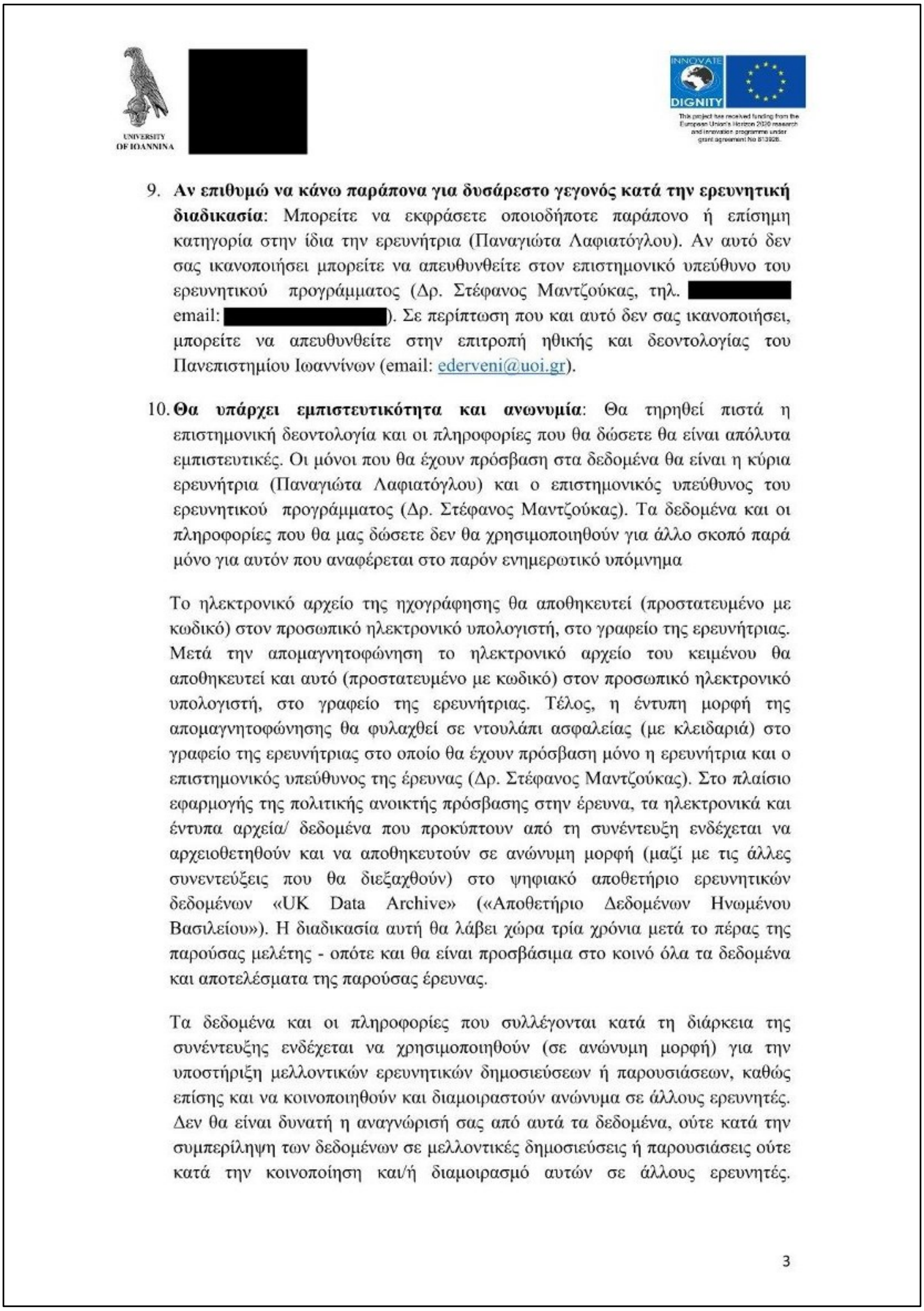
4. **Είμαι υποχρεωμένος/η να συμμετέχω στην έρευνα**: Η συμμετοχή σας είναι εθελοντική και δεν είστε υποχρεωμένη/ος να συμμετέχετε. Πριν τη συμμετοχή σας α) θα έχει εξασφαλιστεί εγγράφως η συναίνεση του νοσηλευτή/ επαγγελματία φροντιστή σχετικά με την συμπερίληψή σας στην έρευνα και β) θα σας ζητηθεί να υπογράψετε ένα έντυπο συναίνεσης, προκειμένου να διασφαλιστεί ότι φέρετε επίγνωση των προϋποθέσεων συμμετοχής σας. Η εθελοντική συμμετοχή σας θα δώσει σημαντικές πληροφορίες που θα βοηθήσουν στη βελτίωση διερεύνησης του ζητήματος της παρούσας έρευνας.

5. **Τι θα συμβεί, αν συμμετάσχω στην έρευνα**: Εάν αποδεχτείτε να συμμετάσχετε στην έρευνα, θα λάβετε μέρος σε μια συνέντευξη με την κύρια ερευνήτρια η οποία αναμένεται να διαρκέσει περίπου 45-90 λεπτά. Η συνέντευξη θα λάβει χώρα σε ένα ήσυχο και ασφαλές μέρος που θα βρίσκεται είτε στον χώρο του Πανεπιστημίου είτε στο [redacted].
Καλείστε να συζητήσετε με την ερευνήτρια για τις προσωπικές εμπειρίες σας σχετικά με την φυσική αποκατάστασή σας, καθώς και για το πώς αντιλαμβάνεστε, βιώνετε και ερμηνεύετε την προσωπική ευημερία σας κατά τη διάρκεια της αποκατάστασής σας. Θα μπορείτε επίσης να αναφέρετε επιπρόσθετα στοιχεία ή όποιες επισημάνσεις θέλετε τις οποίες η ερευνήτρια μπορεί να καταγράψει.

6. **Θα πληρωθώ**: Δεν αναμένεται χρηματική αμοιβή για την συμμετοχή σας στην έρευνα.

7. **Υπάρχει κάποιος κίνδυνος από τη συμμετοχή μου στην έρευνα**: Δεν υπάρχουν αναμενόμενοι κίνδυνοι από τη συμμετοχή στην έρευνα. Αν δεν επιθυμείτε να απαντήσετε σε κάποια ερώτηση ή κάποια ερώτηση σας κάνει να νιώσετε άβολα μπορείτε να την παραλείψετε ή και να διακόψετε άμεσα την διαδικασία της έρευνας. Μπορείτε να αρνηθείτε τη συμμετοχή σας στην έρευνα ή/και να αποσυρθείτε από αυτή σε οποιοδήποτε στάδιο της χωρίς καμία συνέπεια. Στην περίπτωση αυτή, μπορείτε επίσης να ζητήσετε την καταστροφή όποιων στοιχείων έχουν συλλεχθεί και σας αφορούν.

8. **Ποιο το όφελος από τη συμμετοχή μου στην έρευνα**: Δεν αναμένονται προσωπικά οφέλη από τη συμμετοχή σας στην έρευνα. Παρόλα αυτά, οι εμπειρίες και οι απόψεις σας αναμένεται να συμβάλουν στη διεύρυνση του συγκεκριμένου ερευνητικού πεδίου, καθώς και στη δημιουργία ενός θεωρητικού μοντέλου που θα βελτιώσει τις υπηρεσίες αποκατάστασης. Αποτελεί, επίσης, μια ευκαιρία για εσάς να μοιραστείτε τις εμπειρίες και απόψεις σας σχετικά με την αποκατάστασή σας.



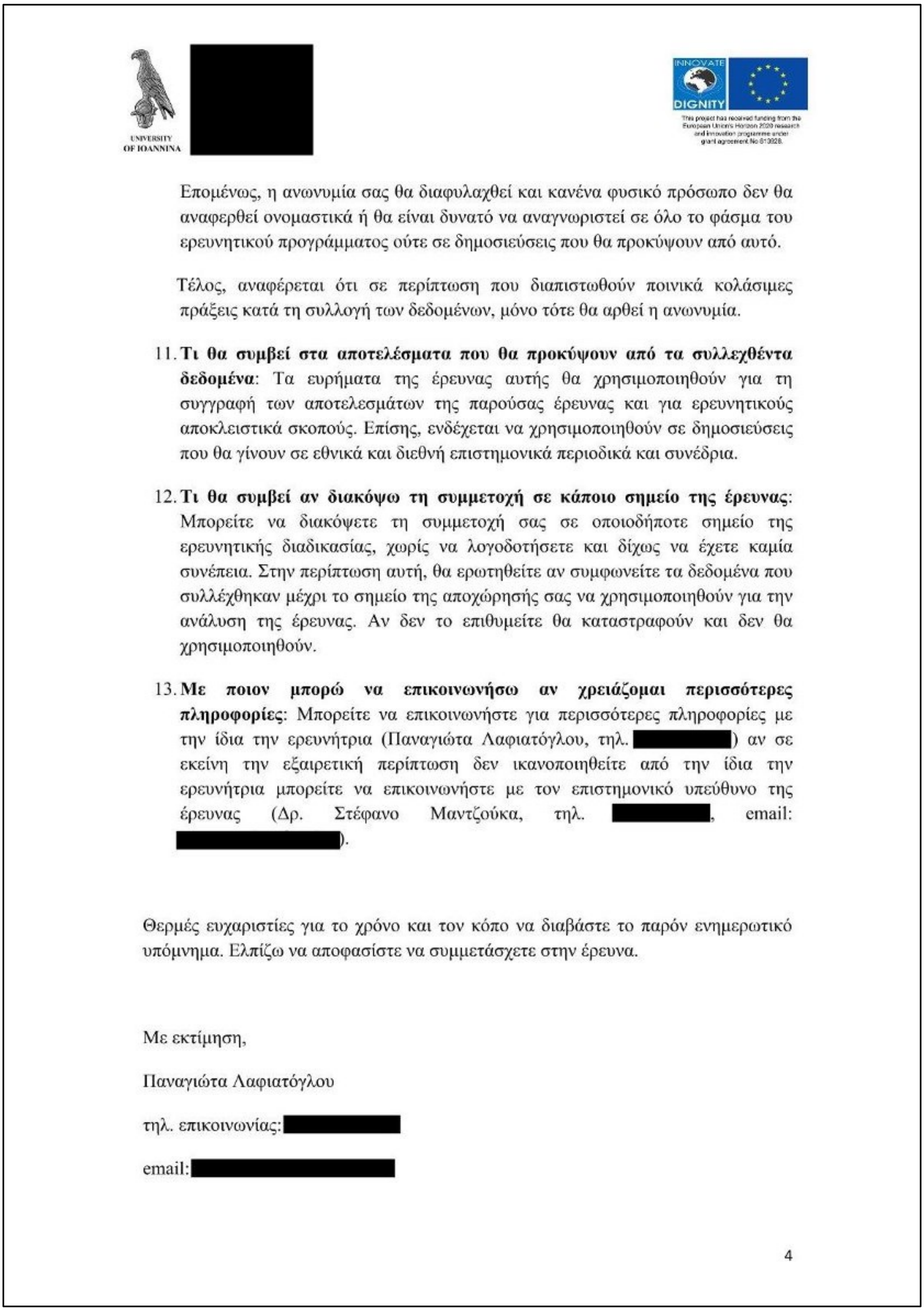
This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813926.

9. **Αν επιθυμώ να κάνω παράπονα για δυσάρεστο γεγονός κατά την ερευνητική διαδικασία**: Μπορείτε να εκφράσετε οποιοδήποτε παράπονο ή επίσημη κατηγορία στην ίδια την ερευνήτρια (Παναγιώτα Λαφιατόγλου). Αν αυτό δεν σας ικανοποιήσει μπορείτε να απευθυνθείτε στον επιστημονικό υπεύθυνο του ερευνητικού προγράμματος (Δρ. Στέφανος Μαντζούκας, τηλ. [redacted] email: [redacted]). Σε περίπτωση που και αυτό δεν σας ικανοποιήσει, μπορείτε να απευθυνθείτε στην επιτροπή ηθικής και δεοντολογίας του Πανεπιστημίου Ιωαννίνων (email: ederveni@uoi.gr).

10. **Θα υπάρχει εμπιστευτικότητα και ανωνυμία**: Θα τηρηθεί πιστά η επιστημονική δεοντολογία και οι πληροφορίες που θα δώσετε θα είναι απόλυτα εμπιστευτικές. Οι μόνοι που θα έχουν πρόσβαση στα δεδομένα θα είναι η κύρια ερευνήτρια (Παναγιώτα Λαφιατόγλου) και ο επιστημονικός υπεύθυνος του ερευνητικού προγράμματος (Δρ. Στέφανος Μαντζούκας). Τα δεδομένα και οι πληροφορίες που θα μας δώσετε δεν θα χρησιμοποιηθούν για άλλο σκοπό παρά μόνο για αυτόν που αναφέρεται στο παρόν ενημερωτικό υπόμνημα

Το ηλεκτρονικό αρχείο της ηχογράφησης θα αποθηκευτεί (προστατευμένο με κωδικό) στον προσωπικό ηλεκτρονικό υπολογιστή, στο γραφείο της ερευνήτριας. Μετά την απομαγνητοφώνηση το ηλεκτρονικό αρχείο του κειμένου θα αποθηκευτεί και αυτό (προστατευμένο με κωδικό) στον προσωπικό ηλεκτρονικό υπολογιστή, στο γραφείο της ερευνήτριας. Τέλος, η έντυπη μορφή της απομαγνητοφώνησης θα φυλαχθεί σε ντουλάπι ασφαλείας (με κλειδαριά) στο γραφείο της ερευνήτριας στο οποίο θα έχουν πρόσβαση μόνο η ερευνήτρια και ο επιστημονικός υπεύθυνος της έρευνας (Δρ. Στέφανος Μαντζούκας). Στο πλαίσιο εφαρμογής της πολιτικής ανοικτής πρόσβασης στην έρευνα, τα ηλεκτρονικά και έντυπα αρχεία/ δεδομένα που προκύπτουν από τη συνέντευξη ενδέχεται να αρχειοθετηθούν και να αποθηκευτούν σε ανώνυμη μορφή (μαζί με τις άλλες συνεντεύξεις που θα διεξαχθούν) στο ψηφιακό αποθετήριο ερευνητικών δεδομένων «UK Data Archive» («Αποθετήριο Δεδομένων Ηνωμένου Βασιλείου»). Η διαδικασία αυτή θα λάβει χώρα τρία χρόνια μετά το πέρας της παρούσας μελέτης - οπότε και θα είναι προσβάσιμα στο κοινό όλα τα δεδομένα και αποτελέσματα της παρούσας έρευνας.

Τα δεδομένα και οι πληροφορίες που συλλέγονται κατά τη διάρκεια της συνέντευξης ενδέχεται να χρησιμοποιηθούν (σε ανώνυμη μορφή) για την υποστήριξη μελλοντικών ερευνητικών δημοσιεύσεων ή παρουσιάσεων, καθώς επίσης και να κοινοποιηθούν και διαμοιραστούν ανώνυμα σε άλλους ερευνητές. Δεν θα είναι δυνατή η αναγνώρισή σας από αυτά τα δεδομένα, ούτε κατά την συμπερίληψη των δεδομένων σε μελλοντικές δημοσιεύσεις ή παρουσιάσεις ούτε κατά την κοινοποίηση και/ή διαμοιρασμό αυτών σε άλλους ερευνητές.



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[redacted]

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Επομένως, η ανωνυμία σας θα διαφυλαχθεί και κανένα φυσικό πρόσωπο δεν θα αναφερθεί ονομαστικά ή θα είναι δυνατό να αναγνωριστεί σε όλο το φάσμα του ερευνητικού προγράμματος ούτε σε δημοσιεύσεις που θα προκύψουν από αυτό.

Τέλος, αναφέρεται ότι σε περίπτωση που διαπιστωθούν ποινικά κολάσιμες πράξεις κατά τη συλλογή των δεδομένων, μόνο τότε θα αρθεί η ανωνυμία.

11. **Τι θα συμβεί στα αποτελέσματα που θα προκύψουν από τα συλλεχθέντα δεδομένα**: Τα ευρήματα της έρευνας αυτής θα χρησιμοποιηθούν για τη συγγραφή των αποτελεσμάτων της παρούσας έρευνας και για ερευνητικούς αποκλειστικά σκοπούς. Επίσης, ενδέχεται να χρησιμοποιηθούν σε δημοσιεύσεις που θα γίνουν σε εθνικά και διεθνή επιστημονικά περιοδικά και συνέδρια.

12. **Τι θα συμβεί αν διακόψω τη συμμετοχή σε κάποιο σημείο της έρευνας**: Μπορείτε να διακόψετε τη συμμετοχή σας σε οποιοδήποτε σημείο της ερευνητικής διαδικασίας, χωρίς να λογοδοτήσετε και δίχως να έχετε καμία συνέπεια. Στην περίπτωση αυτή, θα ερωτηθείτε αν συμφωνείτε τα δεδομένα που συλλέχθηκαν μέχρι το σημείο της αποχώρησής σας να χρησιμοποιηθούν για την ανάλυση της έρευνας. Αν δεν το επιθυμείτε θα καταστραφούν και δεν θα χρησιμοποιηθούν.

13. **Με ποιον μπορώ να επικοινωνήσω αν χρειάζομαι περισσότερες πληροφορίες**: Μπορείτε να επικοινωνήστε για περισσότερες πληροφορίες με την ίδια την ερευνήτρια (Παναγιώτα Λαφιατόγλου, τηλ. [redacted]) αν σε εκείνη την εξαιρετική περίπτωση δεν ικανοποιηθείτε από την ίδια την ερευνήτρια μπορείτε να επικοινωνήστε με τον επιστημονικό υπεύθυνο της έρευνας (Δρ. Στέφανο Μαντζούκα, τηλ. [redacted], email: [redacted]).

Θερμές ευχαριστίες για το χρόνο και τον κόπο να διαβάστε το παρόν ενημερωτικό υπόμνημα. Ελπίζω να αποφασίστε να συμμετάσχετε στην έρευνα.

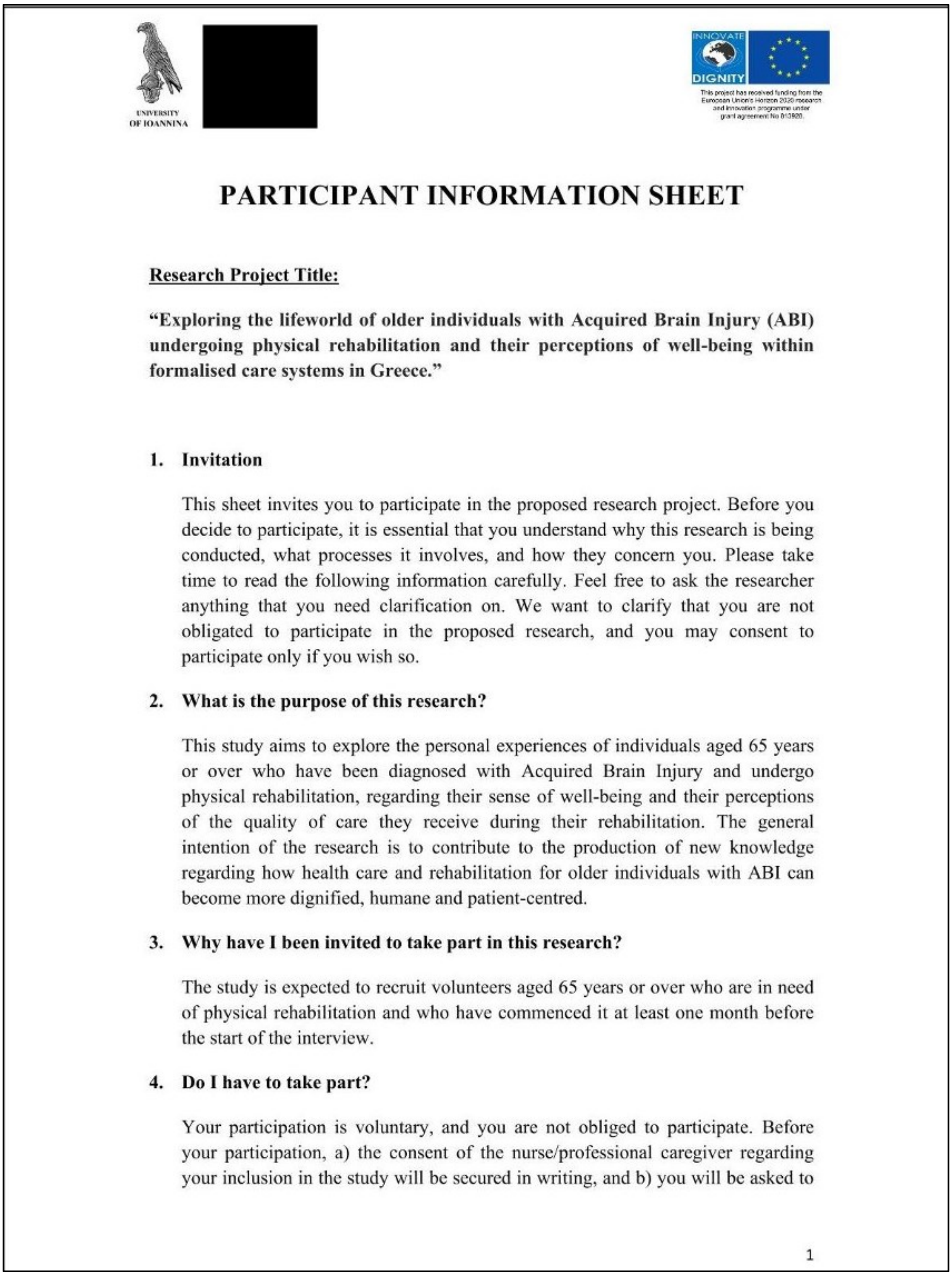
Με εκτίμηση,

Παναγιώτα Λαφιατόγλου

τηλ. επικοινωνίας: [redacted]

email: [redacted]

H.2 Sample of the Information Sheet that was given to health professionals and participants (translated in English)



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PARTICIPANT INFORMATION SHEET

Research Project Title:

"Exploring the lifeworld of older individuals with Acquired Brain Injury (ABI) undergoing physical rehabilitation and their perceptions of well-being within formalised care systems in Greece."

1. Invitation

This sheet invites you to participate in the proposed research project. Before you decide to participate, it is essential that you understand why this research is being conducted, what processes it involves, and how they concern you. Please take time to read the following information carefully. Feel free to ask the researcher anything that you need clarification on. We want to clarify that you are not obligated to participate in the proposed research, and you may consent to participate only if you wish so.

2. What is the purpose of this research?

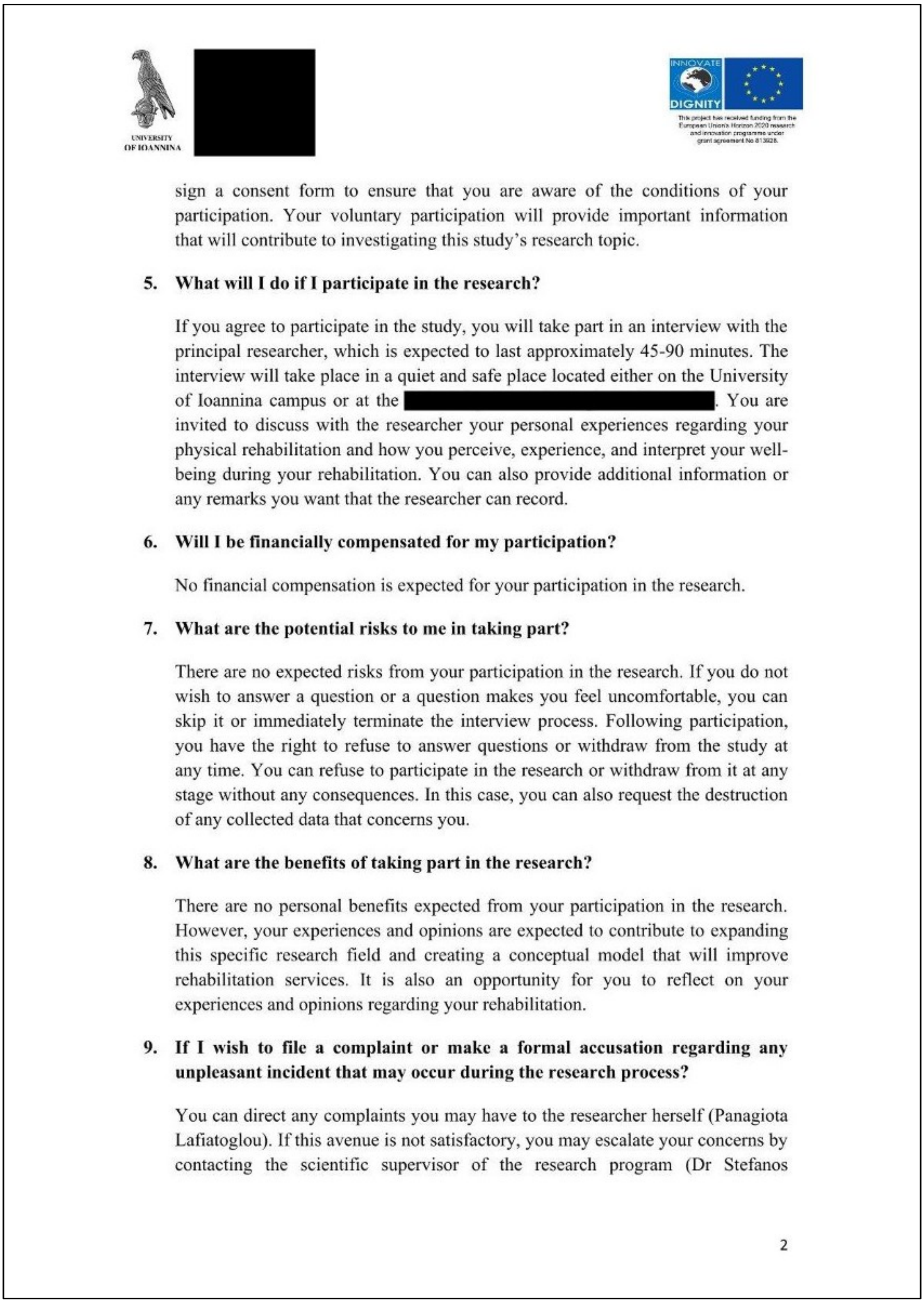
This study aims to explore the personal experiences of individuals aged 65 years or over who have been diagnosed with Acquired Brain Injury and undergo physical rehabilitation, regarding their sense of well-being and their perceptions of the quality of care they receive during their rehabilitation. The general intention of the research is to contribute to the production of new knowledge regarding how health care and rehabilitation for older individuals with ABI can become more dignified, humane and patient-centred.

3. Why have I been invited to take part in this research?

The study is expected to recruit volunteers aged 65 years or over who are in need of physical rehabilitation and who have commenced it at least one month before the start of the interview.

4. Do I have to take part?

Your participation is voluntary, and you are not obliged to participate. Before your participation, a) the consent of the nurse/professional caregiver regarding your inclusion in the study will be secured in writing, and b) you will be asked to



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sign a consent form to ensure that you are aware of the conditions of your participation. Your voluntary participation will provide important information that will contribute to investigating this study's research topic.

5. **What will I do if I participate in the research?**

   If you agree to participate in the study, you will take part in an interview with the principal researcher, which is expected to last approximately 45-90 minutes. The interview will take place in a quiet and safe place located either on the University of Ioannina campus or at the [redacted]. You are invited to discuss with the researcher your personal experiences regarding your physical rehabilitation and how you perceive, experience, and interpret your well-being during your rehabilitation. You can also provide additional information or any remarks you want that the researcher can record.

6. **Will I be financially compensated for my participation?**

   No financial compensation is expected for your participation in the research.

7. **What are the potential risks to me in taking part?**

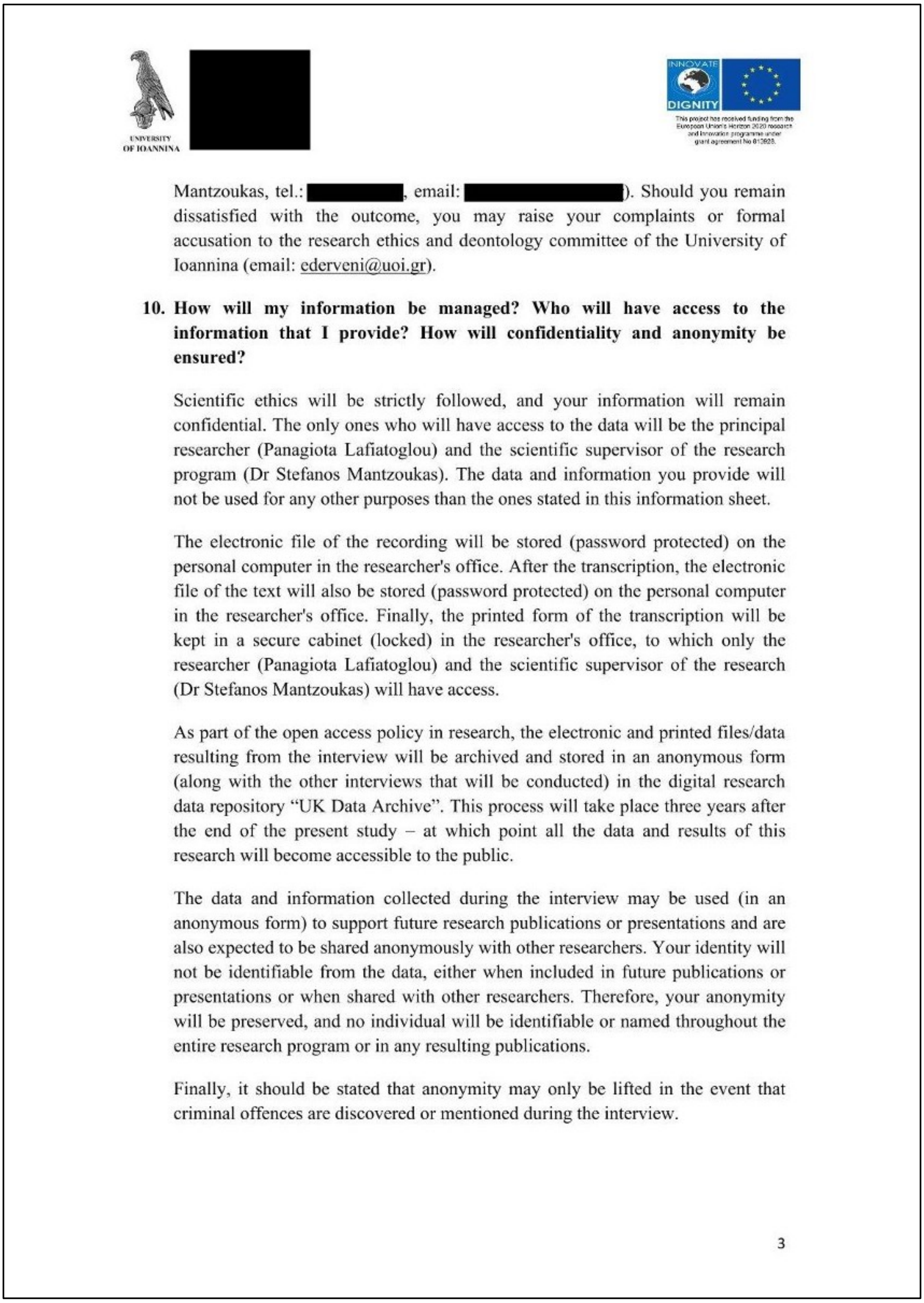
   There are no expected risks from your participation in the research. If you do not wish to answer a question or a question makes you feel uncomfortable, you can skip it or immediately terminate the interview process. Following participation, you have the right to refuse to answer questions or withdraw from the study at any time. You can refuse to participate in the research or withdraw from it at any stage without any consequences. In this case, you can also request the destruction of any collected data that concerns you.

8. **What are the benefits of taking part in the research?**

   There are no personal benefits expected from your participation in the research. However, your experiences and opinions are expected to contribute to expanding this specific research field and creating a conceptual model that will improve rehabilitation services. It is also an opportunity for you to reflect on your experiences and opinions regarding your rehabilitation.

9. **If I wish to file a complaint or make a formal accusation regarding any unpleasant incident that may occur during the research process?**

   You can direct any complaints you may have to the researcher herself (Panagiota Lafiatoglou). If this avenue is not satisfactory, you may escalate your concerns by contacting the scientific supervisor of the research program (Dr Stefanos



Mantzoukas, tel.: [redacted], email: [redacted]). Should you remain dissatisfied with the outcome, you may raise your complaints or formal accusation to the research ethics and deontology committee of the University of Ioannina (email: ederveni@uoi.gr).

10. How will my information be managed? Who will have access to the information that I provide? How will confidentiality and anonymity be ensured?

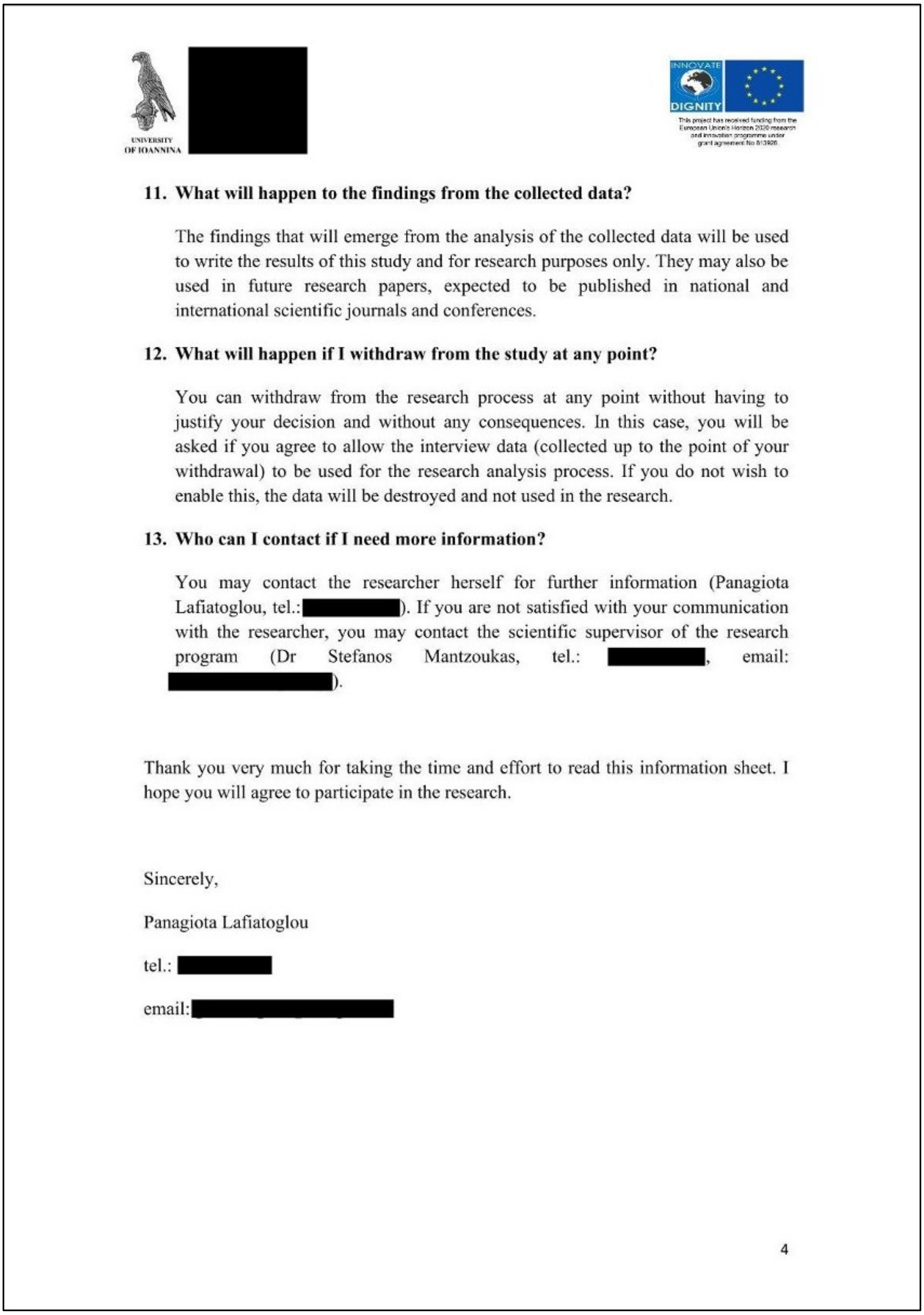
Scientific ethics will be strictly followed, and your information will remain confidential. The only ones who will have access to the data will be the principal researcher (Panagiota Lafiatoglou) and the scientific supervisor of the research program (Dr Stefanos Mantzoukas). The data and information you provide will not be used for any other purposes than the ones stated in this information sheet.

The electronic file of the recording will be stored (password protected) on the personal computer in the researcher's office. After the transcription, the electronic file of the text will also be stored (password protected) on the personal computer in the researcher's office. Finally, the printed form of the transcription will be kept in a secure cabinet (locked) in the researcher's office, to which only the researcher (Panagiota Lafiatoglou) and the scientific supervisor of the research (Dr Stefanos Mantzoukas) will have access.

As part of the open access policy in research, the electronic and printed files/data resulting from the interview will be archived and stored in an anonymous form (along with the other interviews that will be conducted) in the digital research data repository “UK Data Archive”. This process will take place three years after the end of the present study – at which point all the data and results of this research will become accessible to the public.

The data and information collected during the interview may be used (in an anonymous form) to support future research publications or presentations and are also expected to be shared anonymously with other researchers. Your identity will not be identifiable from the data, either when included in future publications or presentations or when shared with other researchers. Therefore, your anonymity will be preserved, and no individual will be identifiable or named throughout the entire research program or in any resulting publications.

Finally, it should be stated that anonymity may only be lifted in the event that criminal offences are discovered or mentioned during the interview.



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11. What will happen to the findings from the collected data?

The findings that will emerge from the analysis of the collected data will be used to write the results of this study and for research purposes only. They may also be used in future research papers, expected to be published in national and international scientific journals and conferences.

12. What will happen if I withdraw from the study at any point?

You can withdraw from the research process at any point without having to justify your decision and without any consequences. In this case, you will be asked if you agree to allow the interview data (collected up to the point of your withdrawal) to be used for the research analysis process. If you do not wish to enable this, the data will be destroyed and not used in the research.

13. Who can I contact if I need more information?

You may contact the researcher herself for further information (Panagiota Lafiatoglou, tel.:[redacted]). If you are not satisfied with your communication with the researcher, you may contact the scientific supervisor of the research program (Dr Stefanos Mantzoukas, tel.: [redacted], email: [redacted]).

Thank you very much for taking the time and effort to read this information sheet. I hope you will agree to participate in the research.

Sincerely,

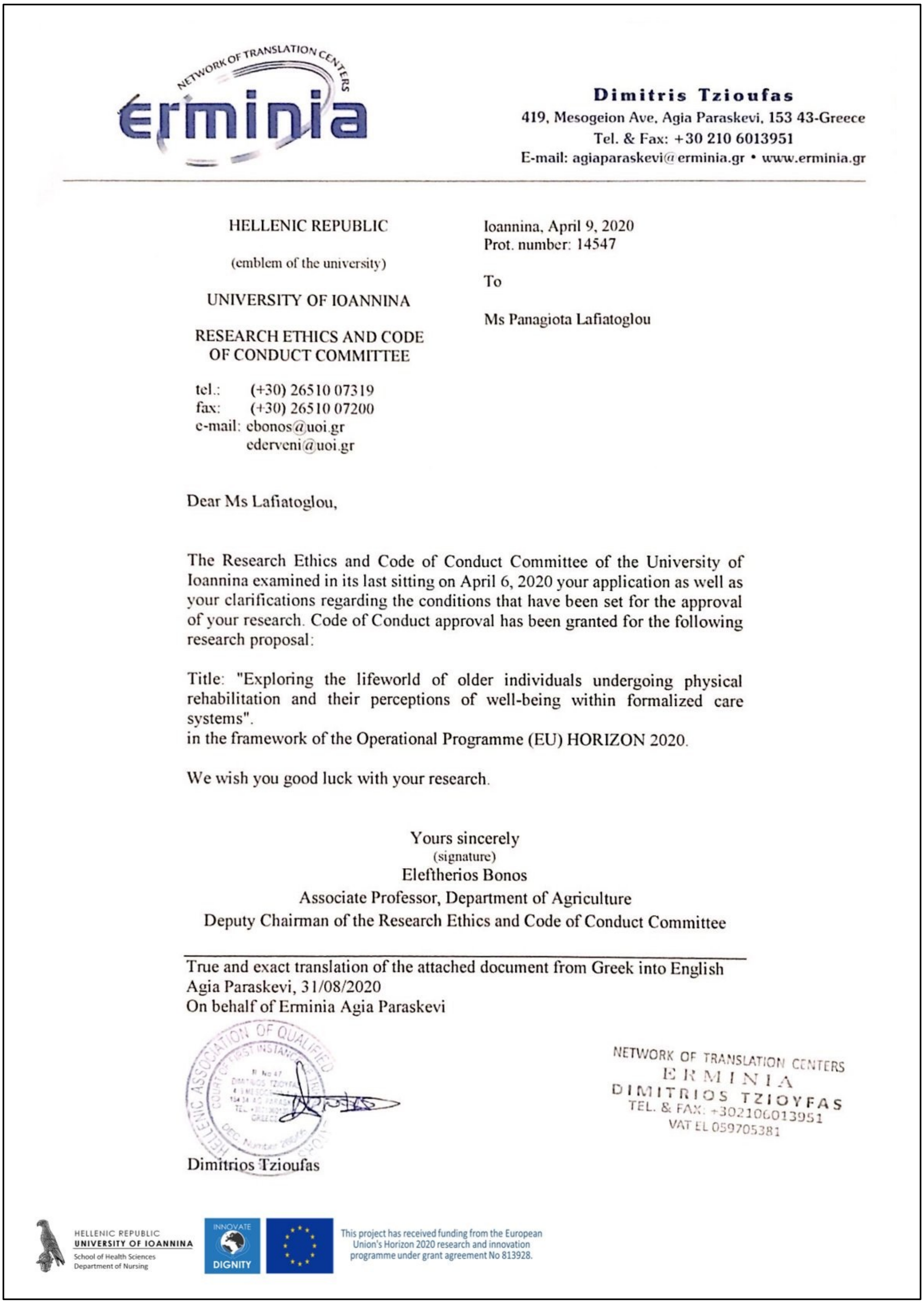
Panagiota Lafiatoglou

tel.: [redacted]

email:[redacted]

Appendix I

I.1 Ethics Approval by the University of Ioannina, Greece.



NETWORK OF TRANSLATION CENTERS
erminia

Dimitris Tzioufas
419, Mesogeion Ave, Agia Paraskevi, 153 43-Greece
Tel. & Fax: +30 210 6013951
E-mail: agiaparaskevi@erminia.gr • www.erminia.gr

HELLENIC REPUBLIC

(emblem of the university)

UNIVERSITY OF IOANNINA

RESEARCH ETHICS AND CODE OF CONDUCT COMMITTEE

tel.: (+30) 26510 07319
fax: (+30) 26510 07200
e-mail: ebonos@uoi.gr
ederveni@uoi.gr

Ioannina, April 9, 2020
Prot. number: 14547

To

Ms Panagiota Lafiatoglou

Dear Ms Lafiatoglou,

The Research Ethics and Code of Conduct Committee of the University of Ioannina examined in its last sitting on April 6, 2020 your application as well as your clarifications regarding the conditions that have been set for the approval of your research. Code of Conduct approval has been granted for the following research proposal:

Title: "Exploring the lifeworld of older individuals undergoing physical rehabilitation and their perceptions of well-being within formalized care systems".
in the framework of the Operational Programme (EU) HORIZON 2020.

We wish you good luck with your research.

Yours sincerely
(signature)
Eleftherios Bonos
Associate Professor, Department of Agriculture
Deputy Chairman of the Research Ethics and Code of Conduct Committee

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True and exact translation of the attached document from Greek into English
Agia Paraskevi, 31/08/2020
On behalf of Erminia Agia Paraskevi

Dimitrios Tzioufas

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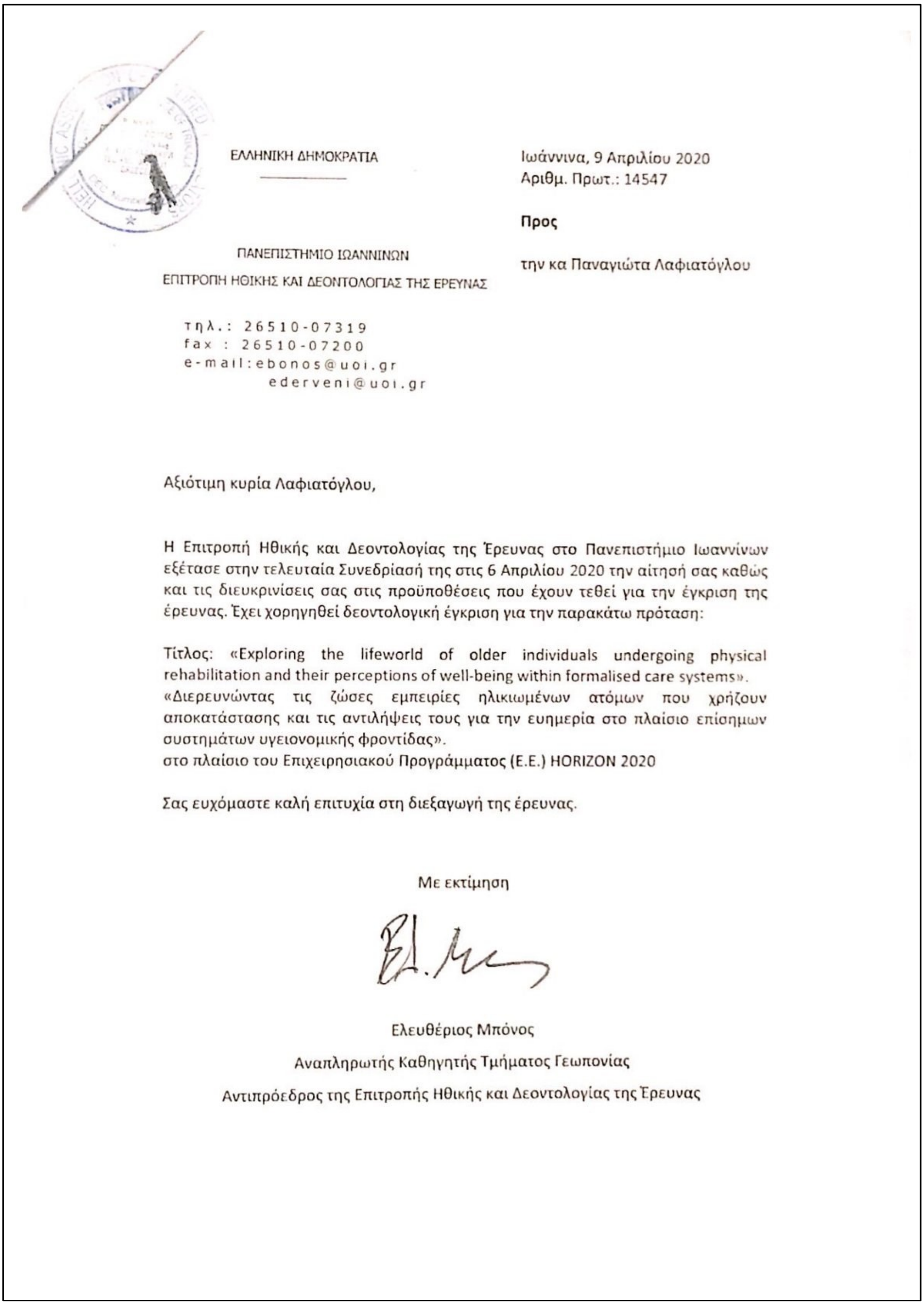
School of Health Sciences
Department of Nursing

INNOVATE DIGNITY

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.



ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ

ΠΑΝΕΠΙΣΤΗΜΙΟ ΙΩΑΝΝΙΝΩΝ
ΕΠΙΤΡΟΠΗ ΗΘΙΚΗΣ ΚΑΙ ΔΕΟΝΤΟΛΟΓΙΑΣ ΤΗΣ ΕΡΕΥΝΑΣ

τηλ.: 26510-07319
fax : 26510-07200
e-mail:ebonos@uoi.gr
ederveni@uoi.gr

Ιωάννινα, 9 Απριλίου 2020
Αριθμ. Πρωτ.: 14547

Προς

την κα Παναγιώτα Λαφιατόγλου

Αξιότιμη κυρία Λαφιατόγλου,

Η Επιτροπή Ηθικής και Δεοντολογίας της Έρευνας στο Πανεπιστήμιο Ιωαννίνων εξέτασε στην τελευταία Συνεδρίασή της στις 6 Απριλίου 2020 την αίτησή σας καθώς και τις διευκρινίσεις σας στις προϋποθέσεις που έχουν τεθεί για την έγκριση της έρευνας. Έχει χορηγηθεί δεοντολογική έγκριση για την παρακάτω πρόταση:

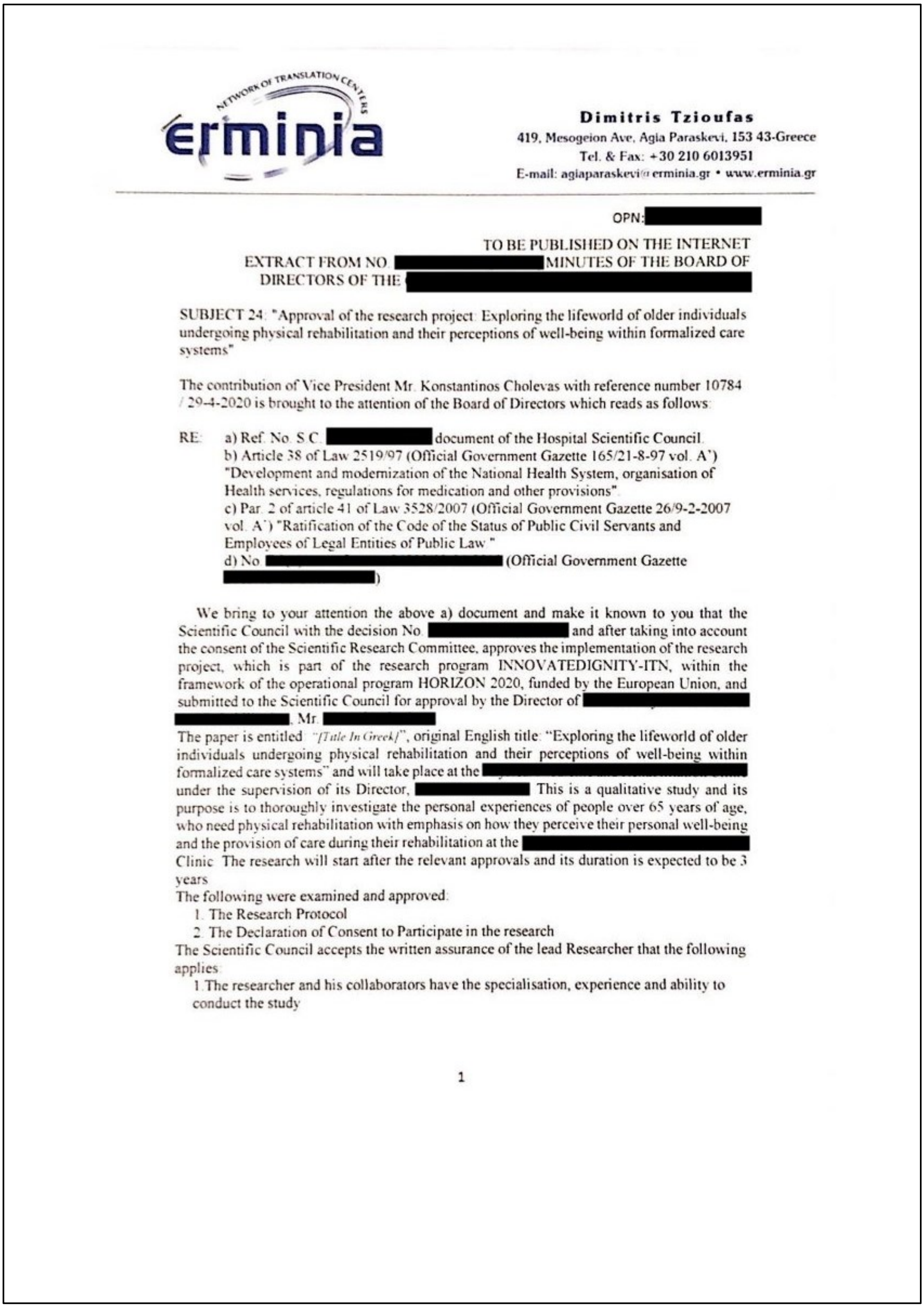
Τίτλος: «Exploring the lifeworld of older individuals undergoing physical rehabilitation and their perceptions of well-being within formalised care systems».
«Διερευνώντας τις ζώσες εμπειρίες ηλικιωμένων ατόμων που χρήζουν αποκατάστασης και τις αντιλήψεις τους για την ευημερία στο πλαίσιο επίσημων συστημάτων υγειονομικής φροντίδας».
στο πλαίσιο του Επιχειρησιακού Προγράμματος (Ε.Ε.) HORIZON 2020

Σας ευχόμαστε καλή επιτυχία στη διεξαγωγή της έρευνας.

Με εκτίμηση

Ελευθέριος Μπόνος
Αναπληρωτής Καθηγητής Τμήματος Γεωπονίας
Αντιπρόεδρος της Επιτροπής Ηθικής και Δεοντολογίας της Έρευνας

I.2 Ethics Approval by the healthcare clinic



erminia
NETWORK OF TRANSLATION CENTERS

Dimitris Tzioufas
419, Mesogeion Ave, Agia Paraskevi, 153 43-Greece
Tel. & Fax: +30 210 6013951
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OPN: [redacted]

TO BE PUBLISHED ON THE INTERNET
EXTRACT FROM NO. [redacted] MINUTES OF THE BOARD OF
DIRECTORS OF THE [redacted]

SUBJECT 24: "Approval of the research project: Exploring the lifeworld of older individuals undergoing physical rehabilitation and their perceptions of well-being within formalized care systems"

The contribution of Vice President Mr. Konstantinos Cholevas with reference number 10784 / 29-4-2020 is brought to the attention of the Board of Directors which reads as follows:

RE: a) Ref. No. S.C. [redacted] document of the Hospital Scientific Council.
b) Article 38 of Law 2519/97 (Official Government Gazette 165/21-8-97 vol. A') "Development and modernization of the National Health System, organisation of Health services, regulations for medication and other provisions".
c) Par. 2 of article 41 of Law 3528/2007 (Official Government Gazette 26/9-2-2007 vol. A') "Ratification of the Code of the Status of Public Civil Servants and Employees of Legal Entities of Public Law."
d) No. [redacted] (Official Government Gazette [redacted])

We bring to your attention the above a) document and make it known to you that the Scientific Council with the decision No. [redacted] and after taking into account the consent of the Scientific Research Committee, approves the implementation of the research project, which is part of the research program INNOVATEDIGNITY-ITN, within the framework of the operational program HORIZON 2020, funded by the European Union, and submitted to the Scientific Council for approval by the Director of [redacted], Mr. [redacted]

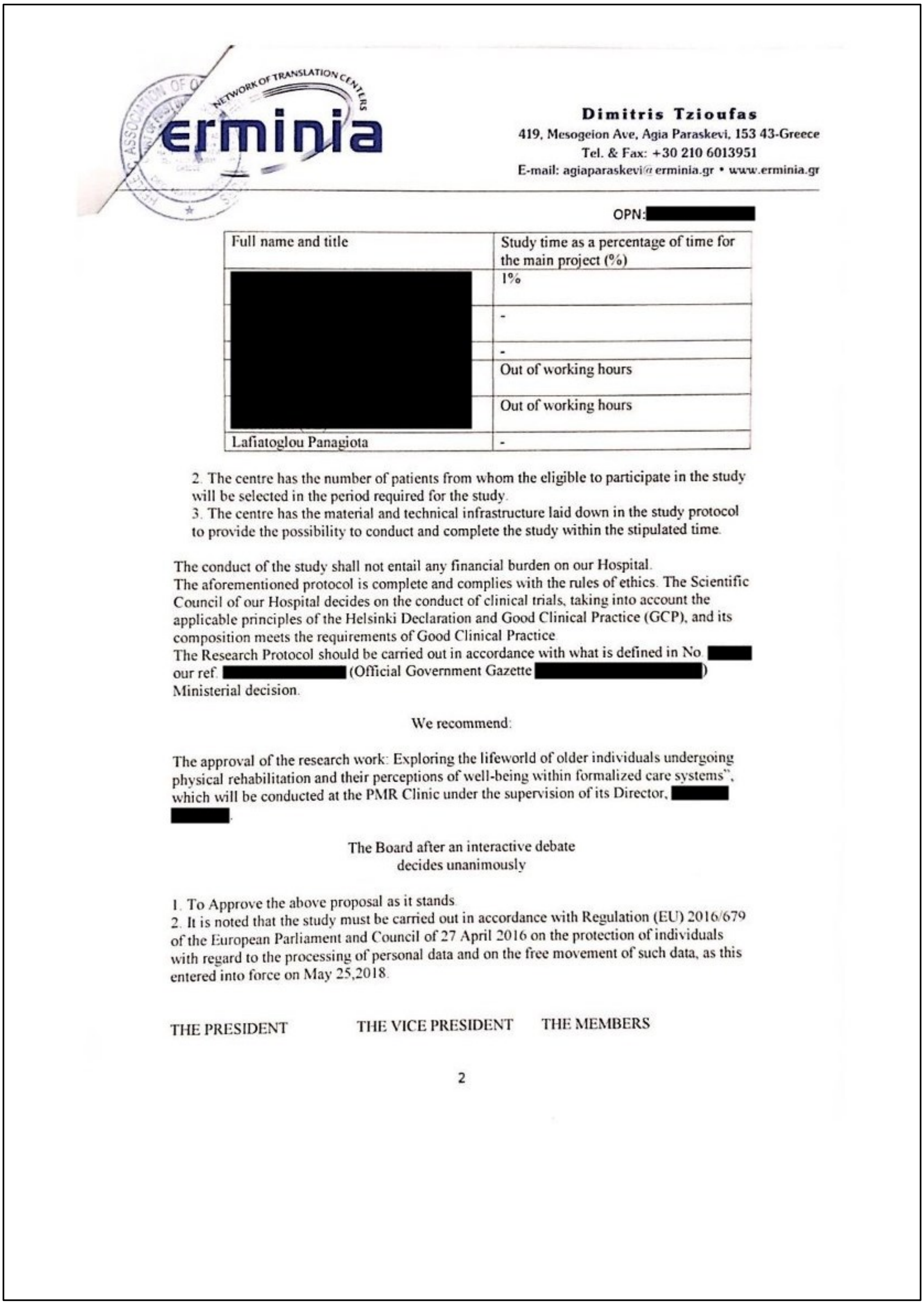
The paper is entitled: *"[Title In Greek]"*, original English title: "Exploring the lifeworld of older individuals undergoing physical rehabilitation and their perceptions of well-being within formalized care systems" and will take place at the [redacted] under the supervision of its Director, [redacted] This is a qualitative study and its purpose is to thoroughly investigate the personal experiences of people over 65 years of age, who need physical rehabilitation with emphasis on how they perceive their personal well-being and the provision of care during their rehabilitation at the [redacted] Clinic. The research will start after the relevant approvals and its duration is expected to be 3 years.

The following were examined and approved:

1. The Research Protocol
2. The Declaration of Consent to Participate in the research

The Scientific Council accepts the written assurance of the lead Researcher that the following applies:

1. The researcher and his collaborators have the specialisation, experience and ability to conduct the study



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OPN: [redacted]

Full name and title	Study time as a percentage of time for the main project (%)
[redacted]	1%
[redacted]	-
[redacted]	-
[redacted]	Out of working hours
[redacted]	Out of working hours
Lafiatoglou Panagiota	-

2. The centre has the number of patients from whom the eligible to participate in the study will be selected in the period required for the study.
3. The centre has the material and technical infrastructure laid down in the study protocol to provide the possibility to conduct and complete the study within the stipulated time.

The conduct of the study shall not entail any financial burden on our Hospital.
The aforementioned protocol is complete and complies with the rules of ethics. The Scientific Council of our Hospital decides on the conduct of clinical trials, taking into account the applicable principles of the Helsinki Declaration and Good Clinical Practice (GCP), and its composition meets the requirements of Good Clinical Practice.
The Research Protocol should be carried out in accordance with what is defined in No [redacted] our ref. [redacted] (Official Government Gazette [redacted]) Ministerial decision.

We recommend:

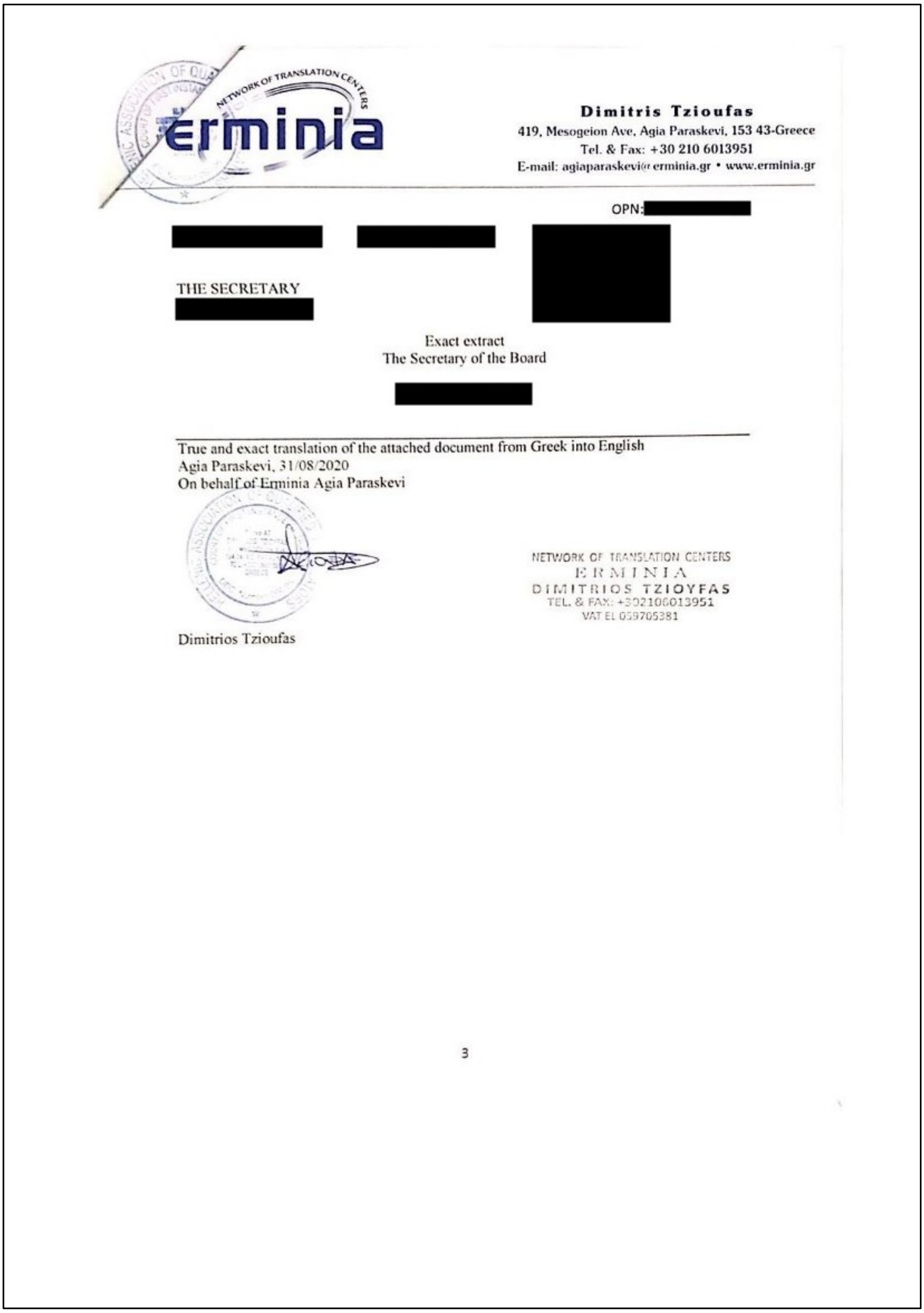
The approval of the research work: Exploring the lifeworld of older individuals undergoing physical rehabilitation and their perceptions of well-being within formalized care systems", which will be conducted at the PMR Clinic under the supervision of its Director, [redacted].

The Board after an interactive debate
decides unanimously

1. To Approve the above proposal as it stands.
2. It is noted that the study must be carried out in accordance with Regulation (EU) 2016/679 of the European Parliament and Council of 27 April 2016 on the protection of individuals with regard to the processing of personal data and on the free movement of such data, as this entered into force on May 25,2018.

THE PRESIDENT THE VICE PRESIDENT THE MEMBERS

2



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OPN: [redacted]

[redacted] [redacted] [redacted]

THE SECRETARY
[redacted]

Exact extract
The Secretary of the Board

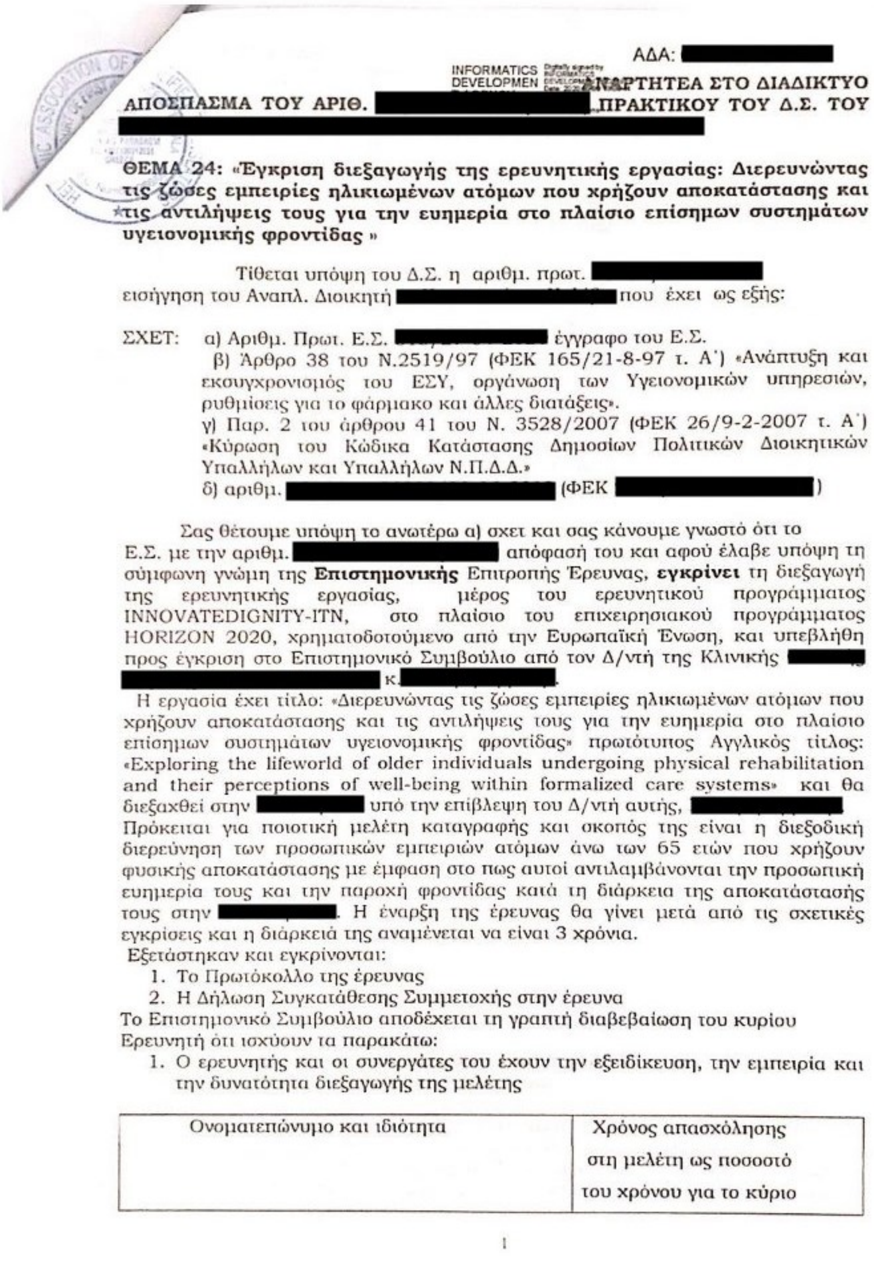
[redacted]

True and exact translation of the attached document from Greek into English
Agia Paraskevi, 31/08/2020
On behalf of Erminia Agia Paraskevi

NETWORK OF TRANSLATION CENTERS
ERMINIA
DIMITRIOS TZIOYFAS
TEL. & FAX: +302106013951
VAT EL 059705381

Dimitrios Tzioufas

3



ΑΔΑ: [redacted]

INFORMATICS DEVELOPMEN

ΑΝΑΡΤΗΤΕΑ ΣΤΟ ΔΙΑΔΙΚΤΥΟ

ΑΠΟΣΠΑΣΜΑ ΤΟΥ ΑΡΙΘ. [redacted] ΠΡΑΚΤΙΚΟΥ ΤΟΥ Δ.Σ. ΤΟΥ [redacted]

ΘΕΜΑ 24: «Έγκριση διεξαγωγής της ερευνητικής εργασίας: Διερευνώντας τις ζώσες εμπειρίες ηλικιωμένων ατόμων που χρήζουν αποκατάστασης και τις αντιλήψεις τους για την ευημερία στο πλαίσιο επίσημων συστημάτων υγειονομικής φροντίδας »

Τίθεται υπόψη του Δ.Σ. η αριθμ. πρωτ. [redacted] εισήγηση του Αναπλ. Διοικητή [redacted] που έχει ως εξής:

ΣΧΕΤ: α) Αριθμ. Πρωτ. Ε.Σ. [redacted] έγγραφο του Ε.Σ.
β) Άρθρο 38 του Ν.2519/97 (ΦΕΚ 165/21-8-97 τ. Α') «Ανάπτυξη και εκσυγχρονισμός του ΕΣΥ, οργάνωση των Υγειονομικών υπηρεσιών, ρυθμίσεις για το φάρμακο και άλλες διατάξεις».
γ) Παρ. 2 του άρθρου 41 του Ν. 3528/2007 (ΦΕΚ 26/9-2-2007 τ. Α') «Κύρωση του Κώδικα Κατάστασης Δημοσίων Πολιτικών Διοικητικών Υπαλλήλων και Υπαλλήλων Ν.Π.Δ.Δ.»
δ) αριθμ. [redacted] (ΦΕΚ [redacted])

Σας θέτουμε υπόψη το ανωτέρω α) σχετ και σας κάνουμε γνωστό ότι το Ε.Σ. με την αριθμ. [redacted] απόφασή του και αφού έλαβε υπόψη τη σύμφωνη γνώμη της **Επιστημονικής** Επιτροπής Έρευνας, **εγκρίνει** τη διεξαγωγή της ερευνητικής εργασίας, μέρος του ερευνητικού προγράμματος INNOVATEDIGNITY-ITN, στο πλαίσιο του επιχειρησιακού προγράμματος HORIZON 2020, χρηματοδοτούμενο από την Ευρωπαϊκή Ένωση, και υπεβλήθη προς έγκριση στο Επιστημονικό Συμβούλιο από τον Δ/ντή της Κλινικής [redacted] κ. [redacted].

Η εργασία έχει τίτλο: «Διερευνώντας τις ζώσες εμπειρίες ηλικιωμένων ατόμων που χρήζουν αποκατάστασης και τις αντιλήψεις τους για την ευημερία στο πλαίσιο επίσημων συστημάτων υγειονομικής φροντίδας» πρωτότυπος Αγγλικός τίτλος: «Exploring the lifeworld of older individuals undergoing physical rehabilitation and their perceptions of well-being within formalized care systems» και θα διεξαχθεί στην [redacted] υπό την επίβλεψη του Δ/ντή αυτής, [redacted]. Πρόκειται για ποιοτική μελέτη καταγραφής και σκοπός της είναι η διεξοδική διερεύνηση των προσωπικών εμπειριών ατόμων άνω των 65 ετών που χρήζουν φυσικής αποκατάστασης με έμφαση στο πως αυτοί αντιλαμβάνονται την προσωπική ευημερία τους και την παροχή φροντίδας κατά τη διάρκεια της αποκατάστασής τους στην [redacted]. Η έναρξη της έρευνας θα γίνει μετά από τις σχετικές εγκρίσεις και η διάρκειά της αναμένεται να είναι 3 χρόνια.

Εξετάστηκαν και εγκρίνονται:

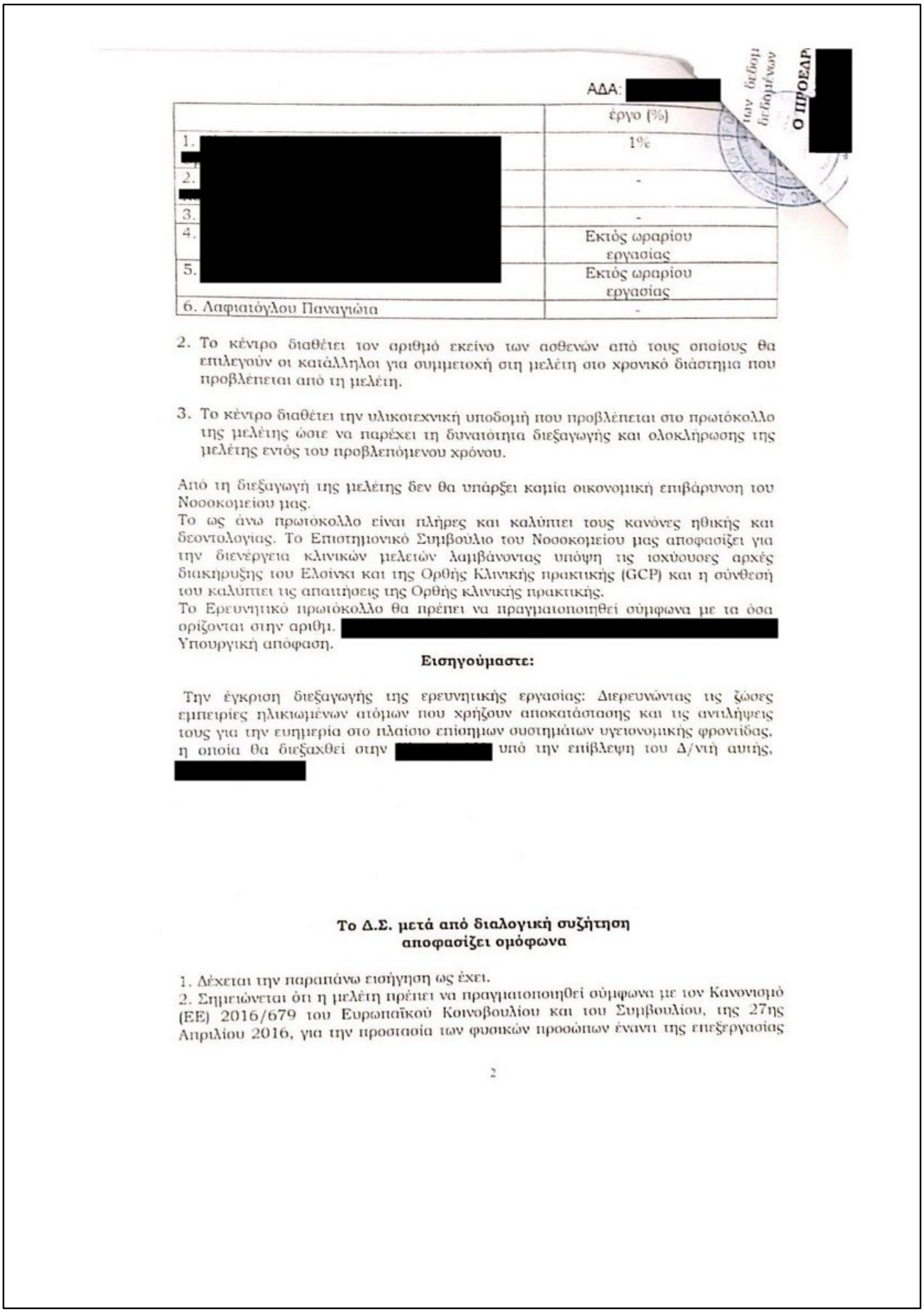
1. Το Πρωτόκολλο της έρευνας
2. Η Δήλωση Συγκατάθεσης Συμμετοχής στην έρευνα

Το Επιστημονικό Συμβούλιο αποδέχεται τη γραπτή διαβεβαίωση του κυρίου Ερευνητή ότι ισχύουν τα παρακάτω:

1. Ο ερευνητής και οι συνεργάτες του έχουν την εξειδίκευση, την εμπειρία και την δυνατότητα διεξαγωγής της μελέτης

Ονοματεπώνυμο και ιδιότητα	Χρόνος απασχόλησης στη μελέτη ως ποσοστό του χρόνου για το κύριο

1



ΑΔΑ: [redacted]

	έργο (%)
1. [redacted]	1%
2. [redacted]	-
3. [redacted]	-
4. [redacted]	Εκτός ωραρίου εργασίας
5. [redacted]	Εκτός ωραρίου εργασίας
6. Λαφιατόγλου Παναγιώτα	-

2. Το κέντρο διαθέτει τον αριθμό εκείνο των ασθενών από τους οποίους θα επιλεγούν οι κατάλληλοι για συμμετοχή στη μελέτη στο χρονικό διάστημα που προβλέπεται από τη μελέτη.

3. Το κέντρο διαθέτει την υλικοτεχνική υποδομή που προβλέπεται στο πρωτόκολλο της μελέτης ώστε να παρέχει τη δυνατότητα διεξαγωγής και ολοκλήρωσης της μελέτης εντός του προβλεπόμενου χρόνου.

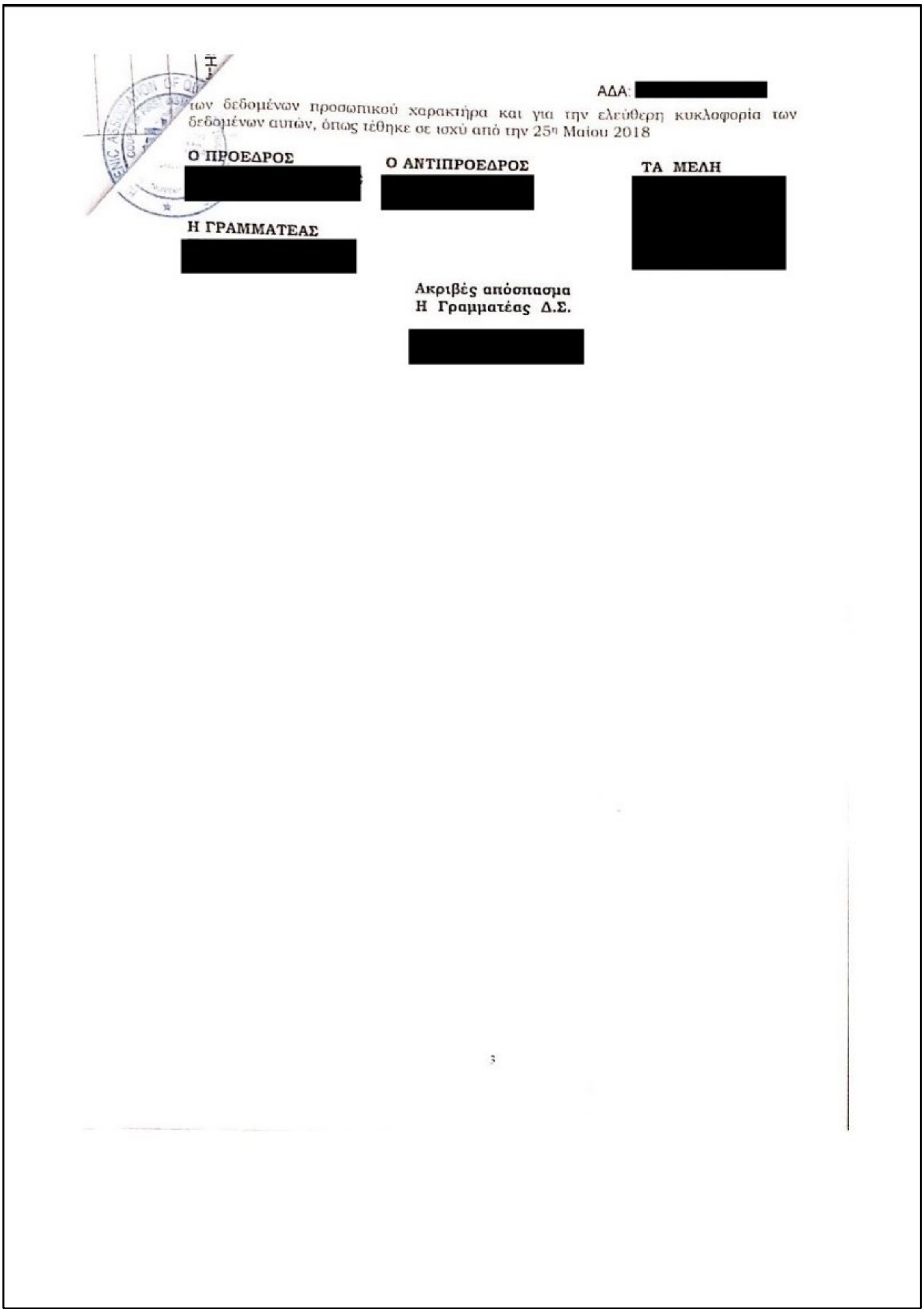
Από τη διεξαγωγή της μελέτης δεν θα υπάρξει καμία οικονομική επιβάρυνση του Νοσοκομείου μας.
Το ως άνω πρωτόκολλο είναι πλήρες και καλύπτει τους κανόνες ηθικής και δεοντολογίας. Το Επιστημονικό Συμβούλιο του Νοσοκομείου μας αποφασίζει για την διενέργεια κλινικών μελετών λαμβάνοντας υπόψη τις ισχύουσες αρχές διακήρυξης του Ελσίνκι και της Ορθής Κλινικής πρακτικής (GCP) και η σύνθεσή του καλύπτει τις απαιτήσεις της Ορθής κλινικής πρακτικής.
Το Ερευνητικό πρωτόκολλο θα πρέπει να πραγματοποιηθεί σύμφωνα με τα όσα ορίζονται στην αριθμ. [redacted]
Υπουργική απόφαση.

Εισηγούμαστε:

Την έγκριση διεξαγωγής της ερευνητικής εργασίας: Διερευνώντας τις ζώσες εμπειρίες ηλικιωμένων ατόμων που χρήζουν αποκατάστασης και τις αντιλήψεις τους για την ευημερία στο πλαίσιο επίσημων συστημάτων υγειονομικής φροντίδας, η οποία θα διεξαχθεί στην [redacted] υπό την επίβλεψη του Δ/ντή αυτής, [redacted]

Το Δ.Σ. μετά από διαλογική συζήτηση
αποφασίζει ομόφωνα

1. Δέχεται την παραπάνω εισήγηση ως έχει.
2. Σημειώνεται ότι η μελέτη πρέπει να πραγματοποιηθεί σύμφωνα με τον Κανονισμό (ΕΕ) 2016/679 του Ευρωπαϊκού Κοινοβουλίου και του Συμβουλίου, της 27ης Απριλίου 2016, για την προστασία των φυσικών προσώπων έναντι της επεξεργασίας



ΑΔΑ: [redacted]

των δεδομένων προσωπικού χαρακτήρα και για την ελεύθερη κυκλοφορία των δεδομένων αυτών, όπως τέθηκε σε ισχύ από την 25η Μαίου 2018

Ο ΠΡΟΕΔΡΟΣ
[redacted]

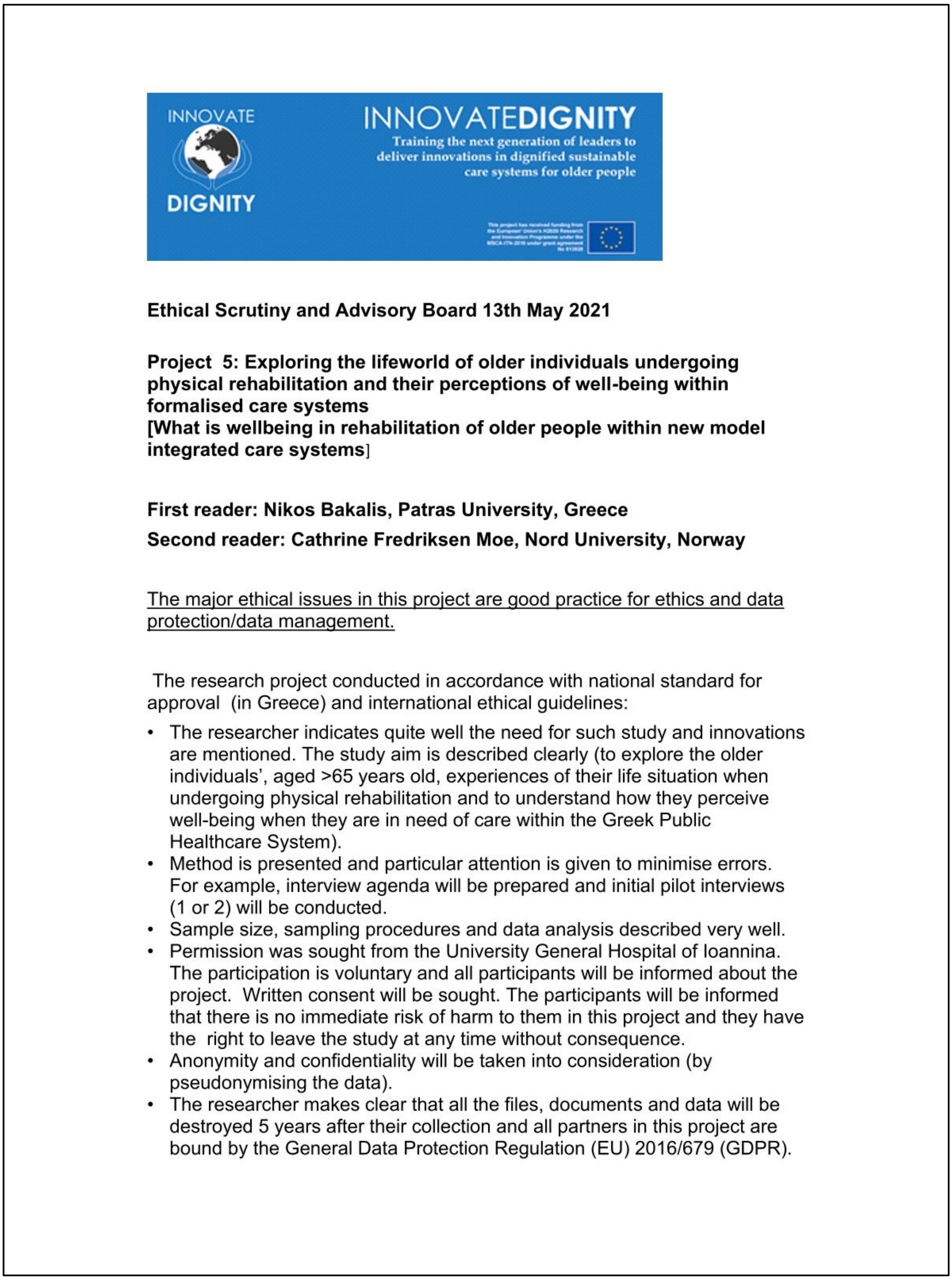
Ο ΑΝΤΙΠΡΟΕΔΡΟΣ
[redacted]

ΤΑ ΜΕΛΗ
[redacted]

Η ΓΡΑΜΜΑΤΕΑΣ
[redacted]

Ακριβές απόσπασμα
Η Γραμματέας Δ.Σ.
[redacted]

I.3 Ethics Approval by the Ethical Scrutiny and Advisory Board of the INNOVATEDIGNITY project



INNOVATE DIGNITY

INNOVATEDIGNITY
Training the next generation of leaders to
deliver innovations in dignified sustainable
care systems for older people

Ethical Scrutiny and Advisory Board 13th May 2021

Project 5: Exploring the lifeworld of older individuals undergoing physical rehabilitation and their perceptions of well-being within formalised care systems
[What is wellbeing in rehabilitation of older people within new model integrated care systems]

First reader: Nikos Bakalis, Patras University, Greece

Second reader: Cathrine Fredriksen Moe, Nord University, Norway

The major ethical issues in this project are good practice for ethics and data protection/data management.

The research project conducted in accordance with national standard for approval (in Greece) and international ethical guidelines:

- The researcher indicates quite well the need for such study and innovations are mentioned. The study aim is described clearly (to explore the older individuals', aged >65 years old, experiences of their life situation when undergoing physical rehabilitation and to understand how they perceive well-being when they are in need of care within the Greek Public Healthcare System).
- Method is presented and particular attention is given to minimise errors. For example, interview agenda will be prepared and initial pilot interviews (1 or 2) will be conducted.
- Sample size, sampling procedures and data analysis described very well.
- Permission was sought from the University General Hospital of Ioannina. The participation is voluntary and all participants will be informed about the project. Written consent will be sought. The participants will be informed that there is no immediate risk of harm to them in this project and they have the right to leave the study at any time without consequence.
- Anonymity and confidentiality will be taken into consideration (by pseudonymising the data).
- The researcher makes clear that all the files, documents and data will be destroyed 5 years after their collection and all partners in this project are bound by the General Data Protection Regulation (EU) 2016/679 (GDPR).

- The research findings will be used only for research purposes and will be disseminated through articles published in national or international journals and presented at national and international scientific conferences.

  - Second reader contributes to confirmation of consistency in data management plan following INNOVATEDIGNITY programme plans for open access data management pilot.

The second reader subsequently read a requested data management plan following the INNOVATEDIGNITY template, but data management is thoroughly described in the study protocol (only document available in English) and supplementary documents were also provided in English:

The purpose of the data collection is clearly stated (to thoroughly explore the older individuals' (aged >65 years old) experiences of their life situation when undergoing physical rehabilitation and to understand how they perceive well-being when they are in need of care within the Greek Public Healthcare System) . Also there is a clear relation between data collection (face-to- face semi-structured interviews with older individuals,) and the objectives of the project.

The researcher will conduct 25 interviews with older individuals. The estimated duration of each interview will be 45- 90 minutes. Before the start of each interview, the participant's name, age and type of rehabilitation / reason for hospitalization will be collected. The interviews will be recorded and the researcher will take handwritten notes of the discussions. The digital audio files of the interviews will be stored (password protected) on the personal computer of the researcher in her office. After the transcription the electronic file of the text will also be stored (password protected) on the personal computer of the researcher in her office. Finally, the paper files of the transcriptions will be kept in a locker in the researcher's office, accessible only to the researcher and the project director. All the files, documents and data will be destroyed 5 years after their collection. All partners in this project are bound by the General Data Protection Regulation (EU) 2016/679 (GDPR) on the protection of natural persons with regard to the processing of personal data, for ensuring the anonymity of all participants and the confidentiality of their personal information during the processing and editing of all data, as well as during the publication of the research findings.

Researcher provides useful and clear information related to informed consent and sampling procedures.

During the analysis of the data the researcher will ensure that all participants will be
anonymised and no information regarding the identity and personal details of the participants will be able to be identified in the entire range of the proposed research nor in any publication resulting from it. Further measures to protect participants' anonymity and confidentiality will be taken in case their answers include identifiable information (e.g. by pseudonymising the
data).

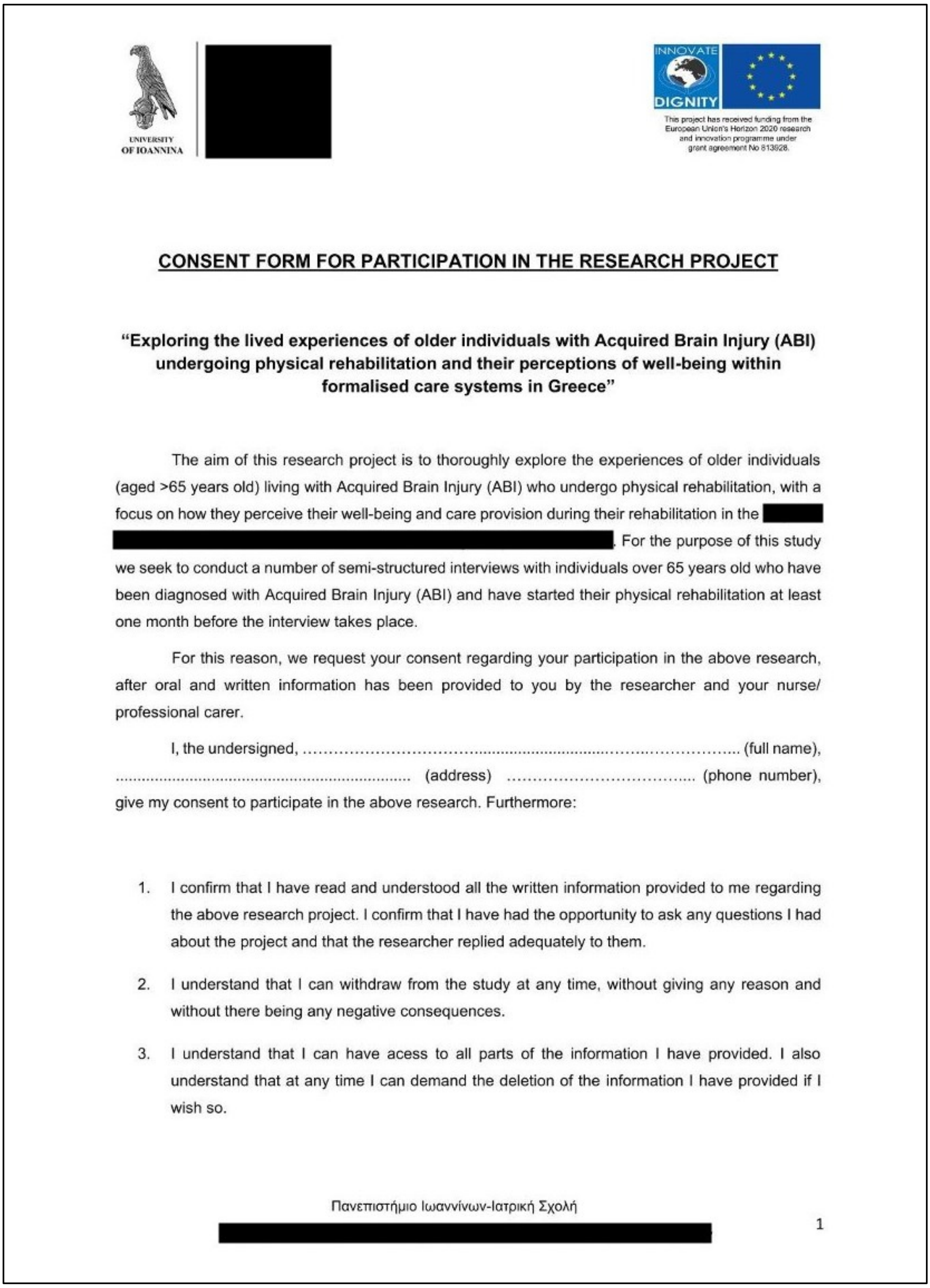
Data management addresses the requirements of the open access mandate of INNOVATEDIGNITY. However, all data cannot be destroyed at the five year period but must be archived in a suitable repository in keeping with data open access.

We confirm ethical issues and data management issues are appropriately addressed but need confirmation from the researcher regarding adjustment to the participant information sheets to make clear to participans the process for archiving anonymised data three years after the end of the study.

First Reviewer Nikos Bakalis Nikos	Second Reviewer Cathrine Fredriksen Moe Cathrine Fredriksen Moe

Appendix J

J.1 Sample of the Consent Form that was given to the participants (in English).



UNIVERSITY
OF IOANNINA

[redacted]

INNOVATE
DIGNITY

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

CONSENT FORM FOR PARTICIPATION IN THE RESEARCH PROJECT

"Exploring the lived experiences of older individuals with Acquired Brain Injury (ABI) undergoing physical rehabilitation and their perceptions of well-being within formalised care systems in Greece"

The aim of this research project is to thoroughly explore the experiences of older individuals (aged >65 years old) living with Acquired Brain Injury (ABI) who undergo physical rehabilitation, with a focus on how they perceive their well-being and care provision during their rehabilitation in the [redacted]. For the purpose of this study we seek to conduct a number of semi-structured interviews with individuals over 65 years old who have been diagnosed with Acquired Brain Injury (ABI) and have started their physical rehabilitation at least one month before the interview takes place.

For this reason, we request your consent regarding your participation in the above research, after oral and written information has been provided to you by the researcher and your nurse/ professional carer.

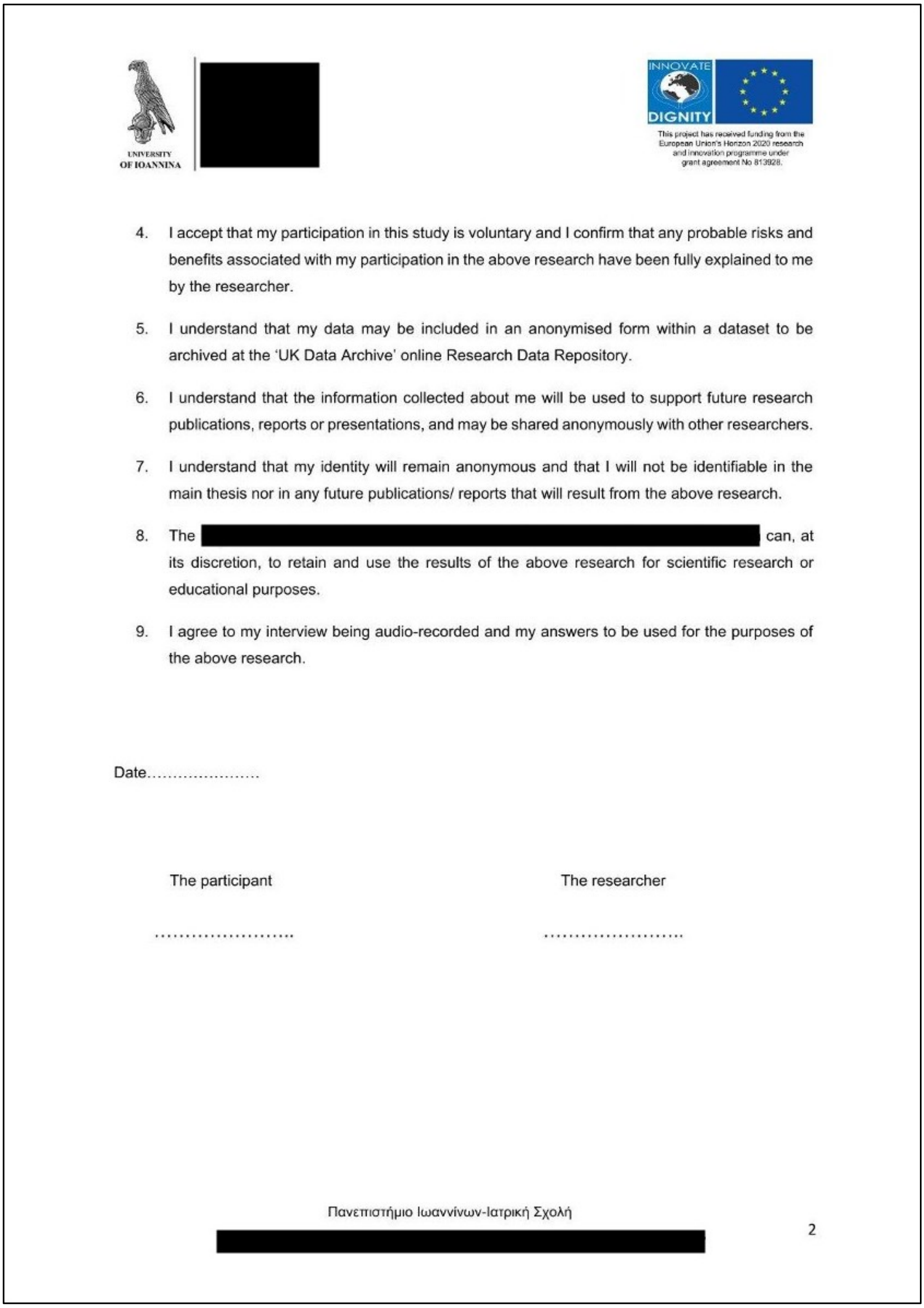
I, the undersigned, ………………………………………………………………………… (full name), …………………………………………………… (address) ……………………………… (phone number), give my consent to participate in the above research. Furthermore:

1. I confirm that I have read and understood all the written information provided to me regarding the above research project. I confirm that I have had the opportunity to ask any questions I had about the project and that the researcher replied adequately to them.
2. I understand that I can withdraw from the study at any time, without giving any reason and without there being any negative consequences.
3. I understand that I can have acess to all parts of the information I have provided. I also understand that at any time I can demand the deletion of the information I have provided if I wish so.

Πανεπιστήμιο Ιωαννίνων-Ιατρική Σχολή

[redacted]

1



UNIVERSITY
OF IOANNINA

[redacted]

INNOVATE DIGNITY

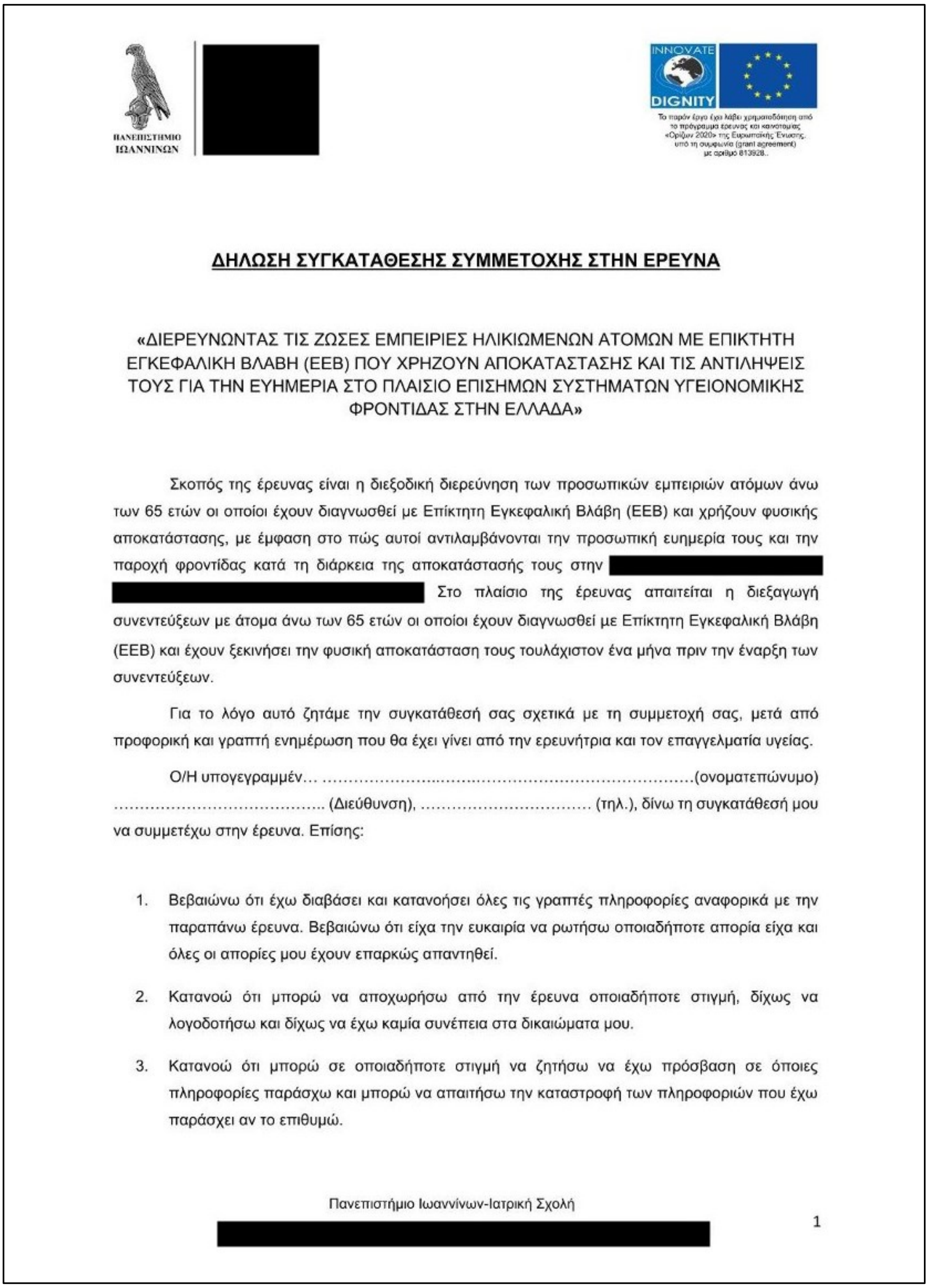
This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

4. I accept that my participation in this study is voluntary and I confirm that any probable risks and benefits associated with my participation in the above research have been fully explained to me by the researcher.
5. I understand that my data may be included in an anonymised form within a dataset to be archived at the 'UK Data Archive' online Research Data Repository.
6. I understand that the information collected about me will be used to support future research publications, reports or presentations, and may be shared anonymously with other researchers.
7. I understand that my identity will remain anonymous and that I will not be identifiable in the main thesis nor in any future publications/ reports that will result from the above research.
8. The [redacted] can, at its discretion, to retain and use the results of the above research for scientific research or educational purposes.
9. I agree to my interview being audio-recorded and my answers to be used for the purposes of the above research.

Date………………….

The participant	The researcher
……………………..	……………………..

J.2 Sample of the Consent Form that was given to the participants (in Greek).



ΠΑΝΕΠΙΣΤΗΜΙΟ
ΙΩΑΝΝΙΝΩΝ

[redacted]

Το παρόν έργο έχει λάβει χρηματοδότηση από το πρόγραμμα έρευνας και καινοτομίας «Ορίζων 2020» της Ευρωπαϊκής Ένωσης, υπό τη συμφωνία (grant agreement) με αριθμό 813928..

ΔΗΛΩΣΗ ΣΥΓΚΑΤΑΘΕΣΗΣ ΣΥΜΜΕΤΟΧΗΣ ΣΤΗΝ ΕΡΕΥΝΑ

«ΔΙΕΡΕΥΝΩΝΤΑΣ ΤΙΣ ΖΩΣΕΣ ΕΜΠΕΙΡΙΕΣ ΗΛΙΚΙΩΜΕΝΩΝ ΑΤΟΜΩΝ ΜΕ ΕΠΙΚΤΗΤΗ ΕΓΚΕΦΑΛΙΚΗ ΒΛΑΒΗ (ΕΕΒ) ΠΟΥ ΧΡΗΖΟΥΝ ΑΠΟΚΑΤΑΣΤΑΣΗΣ ΚΑΙ ΤΙΣ ΑΝΤΙΛΗΨΕΙΣ ΤΟΥΣ ΓΙΑ ΤΗΝ ΕΥΗΜΕΡΙΑ ΣΤΟ ΠΛΑΙΣΙΟ ΕΠΙΣΗΜΩΝ ΣΥΣΤΗΜΑΤΩΝ ΥΓΕΙΟΝΟΜΙΚΗΣ ΦΡΟΝΤΙΔΑΣ ΣΤΗΝ ΕΛΛΑΔΑ»

Σκοπός της έρευνας είναι η διεξοδική διερεύνηση των προσωπικών εμπειριών ατόμων άνω των 65 ετών οι οποίοι έχουν διαγνωσθεί με Επίκτητη Εγκεφαλική Βλάβη (ΕΕΒ) και χρήζουν φυσικής αποκατάστασης, με έμφαση στο πώς αυτοί αντιλαμβάνονται την προσωπική ευημερία τους και την παροχή φροντίδας κατά τη διάρκεια της αποκατάστασής τους στην [redacted] Στο πλαίσιο της έρευνας απαιτείται η διεξαγωγή συνεντεύξεων με άτομα άνω των 65 ετών οι οποίοι έχουν διαγνωσθεί με Επίκτητη Εγκεφαλική Βλάβη (ΕΕΒ) και έχουν ξεκινήσει την φυσική αποκατάσταση τους τουλάχιστον ένα μήνα πριν την έναρξη των συνεντεύξεων.

Για το λόγο αυτό ζητάμε την συγκατάθεσή σας σχετικά με τη συμμετοχή σας, μετά από προφορική και γραπτή ενημέρωση που θα έχει γίνει από την ερευνήτρια και τον επαγγελματία υγείας.

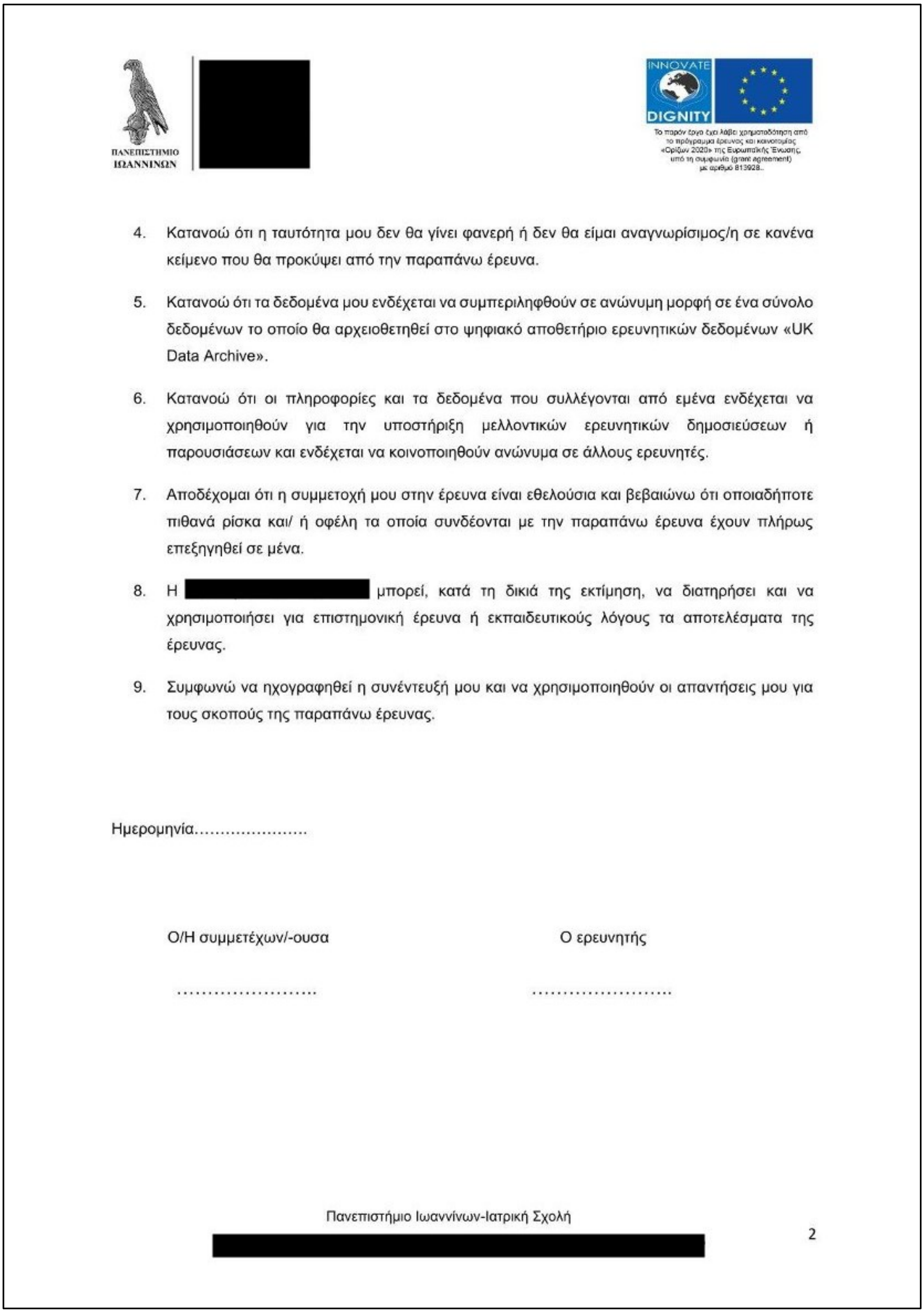
Ο/Η υπογεγραμμέν… …………………..………………………………………(ονοματεπώνυμο) ………………………………….. (Διεύθυνση), …………………………… (τηλ.), δίνω τη συγκατάθεσή μου να συμμετέχω στην έρευνα. Επίσης:

1. Βεβαιώνω ότι έχω διαβάσει και κατανοήσει όλες τις γραπτές πληροφορίες αναφορικά με την παραπάνω έρευνα. Βεβαιώνω ότι είχα την ευκαιρία να ρωτήσω οποιαδήποτε απορία είχα και όλες οι απορίες μου έχουν επαρκώς απαντηθεί.
2. Κατανοώ ότι μπορώ να αποχωρήσω από την έρευνα οποιαδήποτε στιγμή, δίχως να λογοδοτήσω και δίχως να έχω καμία συνέπεια στα δικαιώματα μου.
3. Κατανοώ ότι μπορώ σε οποιαδήποτε στιγμή να ζητήσω να έχω πρόσβαση σε όποιες πληροφορίες παράσχω και μπορώ να απαιτήσω την καταστροφή των πληροφοριών που έχω παράσχει αν το επιθυμώ.

Πανεπιστήμιο Ιωαννίνων-Ιατρική Σχολή

[redacted]

1



ΠΑΝΕΠΙΣΤΗΜΙΟ
ΙΩΑΝΝΙΝΩΝ

[redacted]

Το παρόν έργο έχει λάβει χρηματοδότηση από το πρόγραμμα έρευνας και καινοτομίας «Ορίζων 2020» της Ευρωπαϊκής Ένωσης, υπό τη συμφωνία (grant agreement) με αριθμό 813928..

4. Κατανοώ ότι η ταυτότητα μου δεν θα γίνει φανερή ή δεν θα είμαι αναγνωρίσιμος/η σε κανένα κείμενο που θα προκύψει από την παραπάνω έρευνα.

5. Κατανοώ ότι τα δεδομένα μου ενδέχεται να συμπεριληφθούν σε ανώνυμη μορφή σε ένα σύνολο δεδομένων το οποίο θα αρχειοθετηθεί στο ψηφιακό αποθετήριο ερευνητικών δεδομένων «UK Data Archive».

6. Κατανοώ ότι οι πληροφορίες και τα δεδομένα που συλλέγονται από εμένα ενδέχεται να χρησιμοποιηθούν για την υποστήριξη μελλοντικών ερευνητικών δημοσιεύσεων ή παρουσιάσεων και ενδέχεται να κοινοποιηθούν ανώνυμα σε άλλους ερευνητές.

7. Αποδέχομαι ότι η συμμετοχή μου στην έρευνα είναι εθελούσια και βεβαιώνω ότι οποιαδήποτε πιθανά ρίσκα και/ ή οφέλη τα οποία συνδέονται με την παραπάνω έρευνα έχουν πλήρως επεξηγηθεί σε μένα.

8. Η [redacted] μπορεί, κατά τη δικιά της εκτίμηση, να διατηρήσει και να χρησιμοποιήσει για επιστημονική έρευνα ή εκπαιδευτικούς λόγους τα αποτελέσματα της έρευνας.

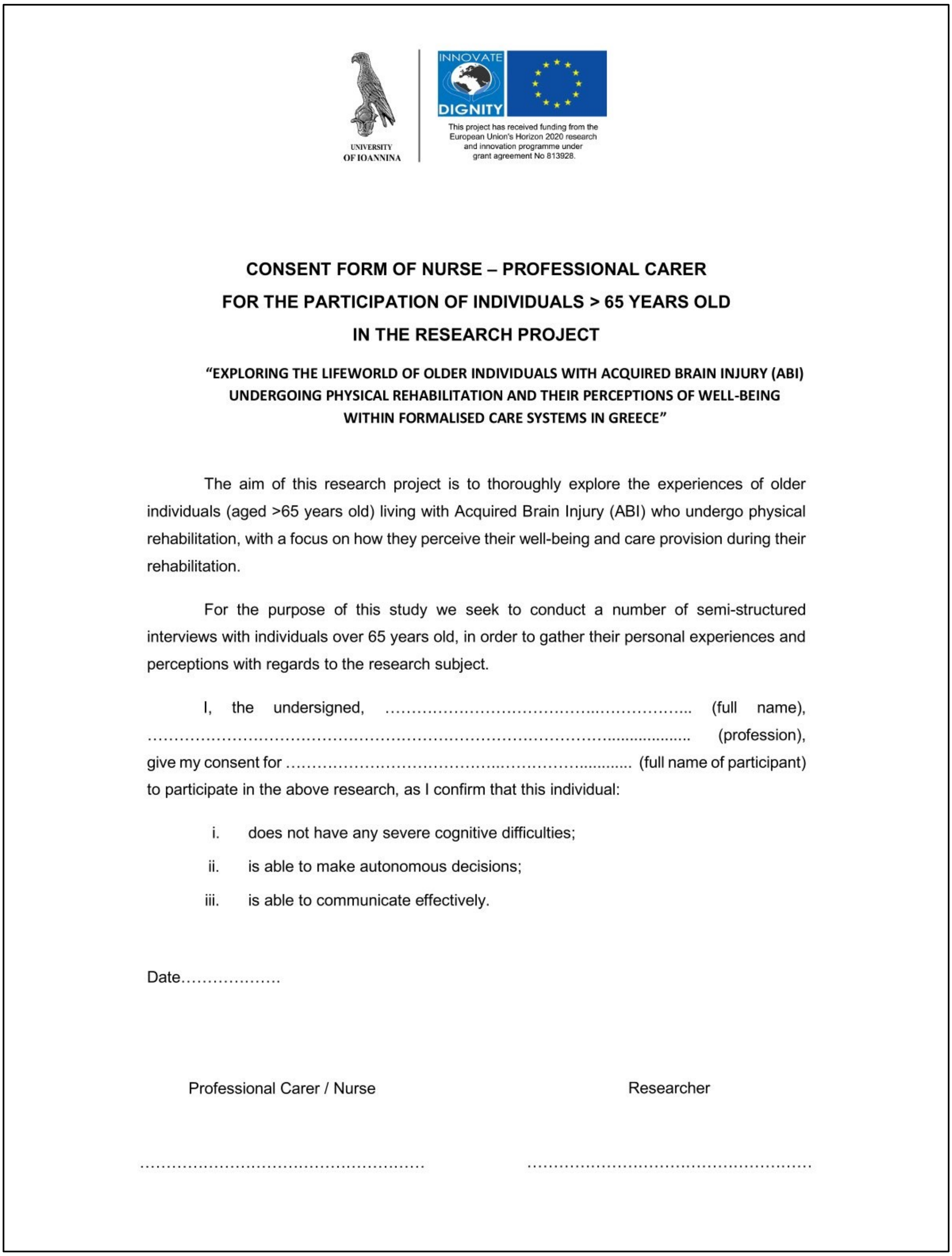
9. Συμφωνώ να ηχογραφηθεί η συνέντευξή μου και να χρησιμοποιηθούν οι απαντήσεις μου για τους σκοπούς της παραπάνω έρευνας.

Ημερομηνία…………………

Ο/Η συμμετέχων/-ουσα	Ο ερευνητής
…………………..	…………………..

Appendix K

K.1 Sample of the Consent Form that was given to the head of the healthcare unit (in English).



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INNOVATE
DIGNITY

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

CONSENT FORM OF NURSE – PROFESSIONAL CARER
FOR THE PARTICIPATION OF INDIVIDUALS > 65 YEARS OLD
IN THE RESEARCH PROJECT

“EXPLORING THE LIFEWORLD OF OLDER INDIVIDUALS WITH ACQUIRED BRAIN INJURY (ABI) UNDERGOING PHYSICAL REHABILITATION AND THEIR PERCEPTIONS OF WELL-BEING WITHIN FORMALISED CARE SYSTEMS IN GREECE”

The aim of this research project is to thoroughly explore the experiences of older individuals (aged >65 years old) living with Acquired Brain Injury (ABI) who undergo physical rehabilitation, with a focus on how they perceive their well-being and care provision during their rehabilitation.

For the purpose of this study we seek to conduct a number of semi-structured interviews with individuals over 65 years old, in order to gather their personal experiences and perceptions with regards to the research subject.

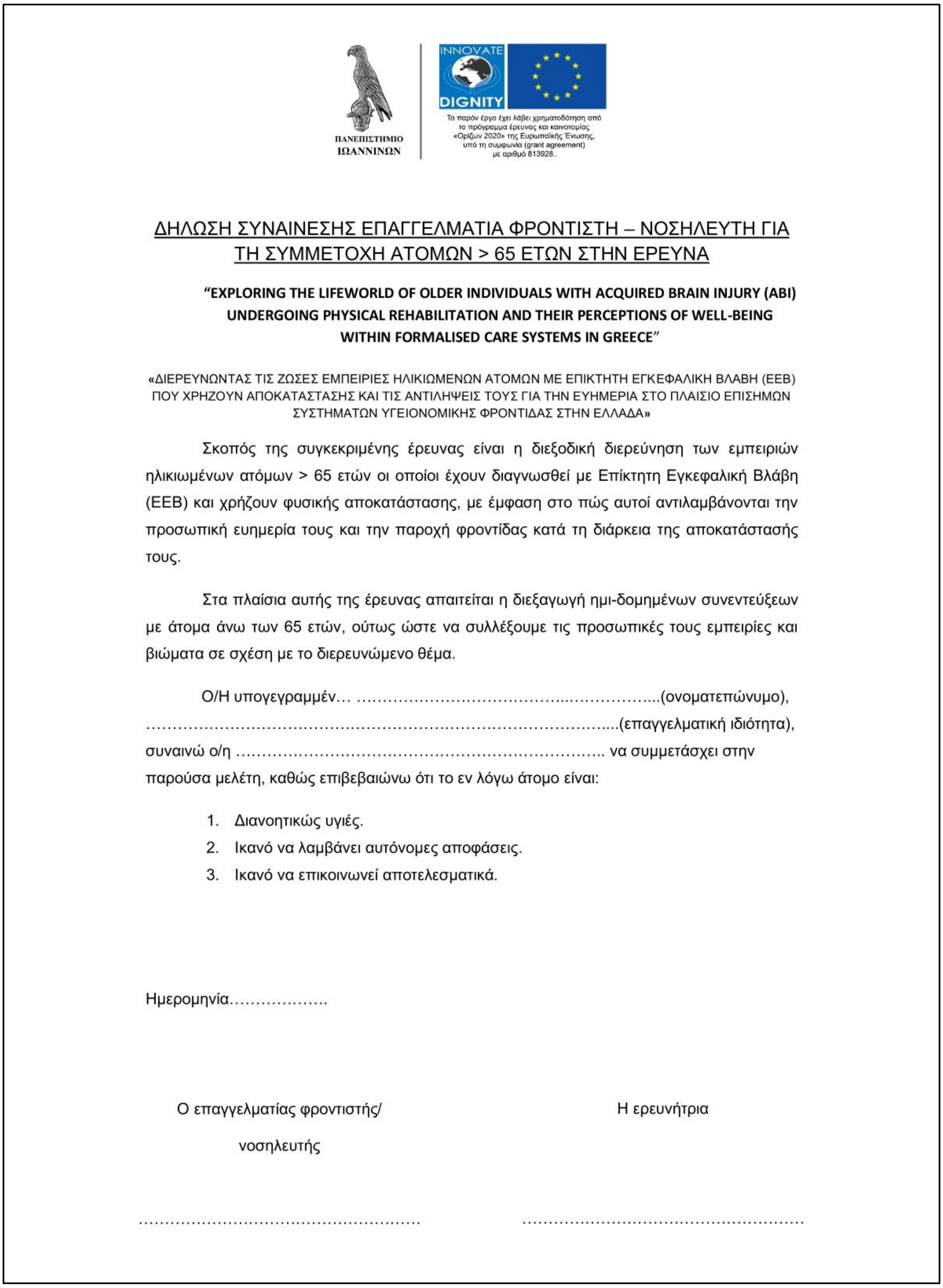
I, the undersigned, ……………………………………..……………….. (full name), ………………………………………………………….…………………………................... (profession), give my consent for ………………………………….……………….......... (full name of participant) to participate in the above research, as I confirm that this individual:

i. does not have any severe cognitive difficulties;
ii. is able to make autonomous decisions;
iii. is able to communicate effectively.

Date……………….

Professional Carer / Nurse	Researcher
………………………………………………	………………………………………………

K.2 Sample of the Consent Form that was given to the head of the healthcare unit (in Greek).



ΠΑΝΕΠΙΣΤΗΜΙΟ
ΙΩΑΝΝΙΝΩΝ

Το παρόν έργο έχει λάβει χρηματοδότηση από
το πρόγραμμα έρευνας και καινοτομίας
«Ορίζων 2020» της Ευρωπαϊκής Ένωσης,
υπό τη συμφωνία (grant agreement)
με αριθμό 813928..

ΔΗΛΩΣΗ ΣΥΝΑΙΝΕΣΗΣ ΕΠΑΓΓΕΛΜΑΤΙΑ ΦΡΟΝΤΙΣΤΗ – ΝΟΣΗΛΕΥΤΗ ΓΙΑ ΤΗ ΣΥΜΜΕΤΟΧΗ ΑΤΟΜΩΝ > 65 ΕΤΩΝ ΣΤΗΝ ΕΡΕΥΝΑ

"EXPLORING THE LIFEWORLD OF OLDER INDIVIDUALS WITH ACQUIRED BRAIN INJURY (ABI) UNDERGOING PHYSICAL REHABILITATION AND THEIR PERCEPTIONS OF WELL-BEING WITHIN FORMALISED CARE SYSTEMS IN GREECE"

«ΔΙΕΡΕΥΝΩΝΤΑΣ ΤΙΣ ΖΩΣΕΣ ΕΜΠΕΙΡΙΕΣ ΗΛΙΚΙΩΜΕΝΩΝ ΑΤΟΜΩΝ ΜΕ ΕΠΙΚΤΗΤΗ ΕΓΚΕΦΑΛΙΚΗ ΒΛΑΒΗ (ΕΕΒ) ΠΟΥ ΧΡΗΖΟΥΝ ΑΠΟΚΑΤΑΣΤΑΣΗΣ ΚΑΙ ΤΙΣ ΑΝΤΙΛΗΨΕΙΣ ΤΟΥΣ ΓΙΑ ΤΗΝ ΕΥΗΜΕΡΙΑ ΣΤΟ ΠΛΑΙΣΙΟ ΕΠΙΣΗΜΩΝ ΣΥΣΤΗΜΑΤΩΝ ΥΓΕΙΟΝΟΜΙΚΗΣ ΦΡΟΝΤΙΔΑΣ ΣΤΗΝ ΕΛΛΑΔΑ»

Σκοπός της συγκεκριμένης έρευνας είναι η διεξοδική διερεύνηση των εμπειριών ηλικιωμένων ατόμων > 65 ετών οι οποίοι έχουν διαγνωσθεί με Επίκτητη Εγκεφαλική Βλάβη (ΕΕΒ) και χρήζουν φυσικής αποκατάστασης, με έμφαση στο πώς αυτοί αντιλαμβάνονται την προσωπική ευημερία τους και την παροχή φροντίδας κατά τη διάρκεια της αποκατάστασής τους.

Στα πλαίσια αυτής της έρευνας απαιτείται η διεξαγωγή ημι-δομημένων συνεντεύξεων με άτομα άνω των 65 ετών, ούτως ώστε να συλλέξουμε τις προσωπικές τους εμπειρίες και βιώματα σε σχέση με το διερευνώμενο θέμα.

Ο/Η υπογεγραμμέν… …………………………………..……………...(ονοματεπώνυμο),
……………………………………………………………………………....(επαγγελματική ιδιότητα),
συναινώ ο/η ……………………………………………………………. να συμμετάσχει στην
παρούσα μελέτη, καθώς επιβεβαιώνω ότι το εν λόγω άτομο είναι:

1. Διανοητικώς υγιές.
2. Ικανό να λαμβάνει αυτόνομες αποφάσεις.
3. Ικανό να επικοινωνεί αποτελεσματικά.

Ημερομηνία……………….

Ο επαγγελματίας φροντιστής/ νοσηλευτής	Η ερευνήτρια
………………………………………………	………………………………………………

Appendix L

Themes, Categories & Codes

CODES	Code Identifier	CATEGORIES	THEMES
1. Never asked more from the healthcare staff as she felt pessimistic for her situation	**Part.B-24-i**	*Processing of emotional struggles and existential concerns*	**Theme 1: Challenges of new life situation**
2. Satisfied with the care received by the healthcare staff but all these are meaningless due to his bad health condition	**Part.E-20-i**		
3. First days at the hospital was in shock/ difficult to adapt	**Part.M-6-i**		
4. First moments in the hospital he was in shock	**Part.H-2-i**		
5. The first shocking moments arriving at hospital stayed in his memory	**Part.G-35-ii**		
6. In the first days at hospital he was at shock	**Part.G-7-i**		
7. Bad memory from the incident day/ she was in shock	**Part.B-14-ii**		
8. Initial reaction on the incident: calmness/ participant has not realised what happened yet	**Part.B-1-i**		
9. Unclear memories after the incident as an in-patient	**Part.C-16-i**		
10. Participant does not care for herself but only for her children/ Cannot find any reaon to live except of her family	**Part.B-2-ii**		
11. She would prefer to die in order to not be a burden for the family	**Part.L-47-i**		
12. She believes she is their burden and she prefers to die	**Part.B-26-iii**		
13. Thinking about death	**Part.K-24-i**		
14. So difficult period of his life that he has thought about dying	**Part.M-12-ii**		
15. Gaining a new perspective in life/ Health is the most important thing	**Part.D-22-ii**		
16. Life has ended/ meaningless life	**Part.I-35-i**		
17. Loosing meaning in doing things	**Part.J-17-i**		
18. New way of thinking about life	**Part.B-32-ii**		
19. Not enjoying the life anymore because of the disease	**Part.K-21-i**		
20. Trying to find a meaning in her life	**Part.B-7-i**		
21. Feeling bad for his wife that for so long time she was assisting him with everything	**Part.C-37-ii**		
22. Feeling guilty that he makes tired his wife	**Part.E-11-i**		
23. Feeling guilty that her family has to take care of her	**Part.B-27-i**		
24. Feeling guilty that now her family has to take care of her	**Part.A-4-ii**		
25. Feels sad about his wife's fatigue	**Part.G-35-i**		
26. Feels she is a problem for her family	**Part.L-122-i**		
27. Feels that he was a burden for the family	**Part.J-36-i**		
28. He perceives his family as being stressed	**Part.N-18-i**		
29. Patient believes that his family's well-being has been negative affected by his health condition	**Part.H-17-i**		

30. Patient believes that his wife's well-being has been negative affected by his health condition	**Part.H-18-i**	*Processing of emotional struggles and existential concerns*	**Theme 1: Challenges of new life situation**
31. Signs of sorrow due to family's exhaustion	**Part.L-44-i**		
32. The only things that matters is now his family's wellness	**Part.G-44-ii**		
33. The psychological part is the most difficult issue for the family	**Part.N-20-i**		
34. When the patient suffers, family suffers too	**Part.K-24-ii**		
35. Worried about her children	**Part.D-16-i**		
36. When in rehabilitation for long time he felt pressure and stressed from his wife as she was caring for him too much	**Part.C-32-i**		
37. Feels pressured by family to continue the physiotherapy	**Part.K-16-i**		
38. Intense emotions	**Part.F-28-i**		
39. Feeling very upset due to his mobility problems	**Part.M-6-i**		
40. Depressed/ A desire to walk again, to feel active	**Part.L-58-i**		
41. New situation makes him feel upset easily	**Part.M-34-i**		
42. Desperate about his future	**Part.C-45-iii**	*Temporal distribution of past and future life*	
43. Fear for the future	**Part.A-1-iii**		
44. He does not find any meaning to plan his life after his incident/ afraid of making plans	**Part.H-28-i**		
45. Life is short so no sense to make any plans for the future	**Part.A-15-ii**		
46. Making plans for the future makes him feel more human/ giving him life, hope	**Part.N-33-i**		
47. Meaningless to do plans for the future in this health situation	**Part.F-29-i**		
48. Negative thoughts about his future/ Feeling useless	**Part.J-28-i**		
49. No hope and no need for plans for the future	**Part.B-33-i**		
50. No need to do make big plans for the future	**Part.C-48-i**		
51. Pessimistic about the future/ about the recovery	**Part.B-19-i**		
52. Plans for the future are pointless	**Part.G-44-i**		
53. She only cares for others/ not making personal plans	**Part.D-23-i**		
54. The combination of the age and illness hampers her of making plans for the future	**Part.L-79-i**		
55. Uncertainty for her future	**Part.A-15-i**		
56. Signs of fatigue/ ready to give up	**Part.K-17-i**		
57. Stroke made her calm - "What worse can happen?"	**Part.D-22-i**		
58. Feels tired to continue the physiotherapy	**Part.K-16-ii**		
59. Low expectations for recovery	**Part.B-16-ii**		
60. Positive attitude about his recovery/ optimistic	**Part.G-1-i**		
61. The only thing that matters to him is his recovery/ perseverance	**Part.J-12-i**		
62. Disappointed that he cannot work as in the past	**Part.C-11-ii**		
63. Feeling nostalgic about his old life/ his capabilities	**Part.J-10-i**		
64. Feeling nostalgic about things she used to do at house	**Part.B-12-i**		
65. Feeling nostalgic for the days he could offer through his work	**Part.C-12-ii**		
66. Misses his old life when he was more capable	**Part.H-21-i**		

67. Unable to do the things he used to do in the past	**Part.N-30-i**	*Temporal distribution of past and future life*	**Theme 1: Challenges of new life situation**
68. Life was totally different before stroke	**Part.G-41-ii**		
69. Totally different everyday life before the incident	**Part.G-8-ii**		
70. Not the same capabilities as in the past/ weak	**Part.N-3-i**		
71. Not the same person as before	**Part.I-33-i**		
72. Not the same person as before/ missed everyday simple things	**Part.B-32-i**		
73. She cannot do any personal activities like in the past – pleasant activities	**Part.D-4-i**		
74. Reconsidering all the simple things in life after the incident/ Thoughts about the past and what matters now most – the little things	**Part.A-14-i**		
75. Enthusiasm for returning home	**Part.N-23-i**	*Emotional variations on returning home*	
76. Feeling more secure to continue the rehabilitation exercises at home	**Part.L-31-i**		
77. He missed the “home” feeling	**Part.N-24-i**		
78. Home creates positive feelings despite the difficulty of the situation	**Part.A-10-i**		
79. Home feels better than hospital	**Part.I-8-i**		
80. Home is a safe place – Hospital as an unpleasant environment	**Part.A-2-iv**		
81. Home is always a safe place	**Part.A-3-iii**		
82. Home is your place/ feeling better at home	**Part.M-52-i**		
83. Home reminds him he is still alive	**Part.F-31-ii**		
84. Home setting is more comfortable than the hospital setting	**Part.G-47-i**		
85. Initial feeling of returning home is relief and happiness	**Part.E-37-i**		
86. Relief when he was back at home/ Home is always home	**Part.F-31-i**		
87. Ambivalence towards his health condition when returning home/ scared	**Part.H-10-i**		
88. At home he is not the same person as before	**Part.E-38-i**		
89. Delusions of being the same person when returning home	**Part.K-6-i**		
90. Difficult first period at home	**Part.N-25-i**		
91. Difficult to adjust to new realty/ feeling disappointed	**Part.M-41-i**		
92. Feeling sad that home is not the same place as before	**Part.M-8-ii**		
93. He prefers to be more active (to leave the house) as this makes him more human being/ more capable/ more active	**Part.H-24-i**		
94. Homecoming had unpleasant effects/ not feeling comfortable at home	**Part.K-11-i**		
95. The pleasant feeling of getting home turning into realization of the difficult situation	**Part.A-13-i**		
96. When returned home made him think what has changed compared to the past	**Part.G-48-i**		
97. Day passes slow when returning home	**Part.E-2-i**		
98. Feeling useless to his home and to the society/ He has lost his old life	**Part.F-27-i**		
99. Powerless/ unable to help at home	**Part.H-7-i**		
100. Realization of the new reality at home	**Part.J-54-i**		
101. Doing some works at home made him feel useful	**Part.H-20-iii**		

102. A simple smile from someone could raise his morale/ motivation	**Part.C-1-ii**	*Strengthening the sense of belonging through social interactions*	**Theme 2:** **Seeking emotional and practical support through social interaction**
103. Feeling nice that he had a good relationship/ communication with the doctor (when other patients did not)	**Part.M-17-ii**		
104. Feeling very comfortable with his doctor and this gives him more confidence	**Part.G-19-i**		
105. Good relationship with doctors after hospitalization	**Part.C-41-i**		
106. Impersonal relationships between doctor – patient	**Part.M-28-i**		
107. Nursing staff ease/ soften the loneliness that the patient feels when hospitalized	**Part.D-12-i**		
108. Patient-doctor communication is effective for the well-being	**Part.J-10-ii**		
109. Poor communication about health provision between patient and healthcare staff	**Part.B-1-ii**		
110. Sign of familiarity with staff	**Part.H-12-ii**		
111. Meaningless discussions with other patients/ in need of more social activities/ more interaction	**Part.C-3-i**		
112. Family's involvement in in-patient recovery plan	**Part.A-8-ii**		
113. It is important when you suffer a stroke and you are in rehabilitation not to stay alone	**Part.D-15-i**		
114. The only thing that keeps her alive is the love that she receives from her family	**Part.B-29-i**		
115. Well-being means to feel comfort and secure – to always have someone on your side	**Part.C-40-i**		
116. Interaction with other patients made him feel that he was not alone	**Part.C-18-ii**		
117. Loneliness and sadness during hospitalization	**Part.B-20-i**		
118. A need for social interaction	**Part.C-44-i**		
119. A need for social interaction	**Part.L-59-i**		
120. A need for social interaction/ To be part of the society	**Part.G-3-ii**		
121. A need to feel more human being though social interaction	**Part.N-32-ii**		
122. Feel human again through interaction	**Part.K-20-i**		
123. Need to interact with others	**Part.K-18-i**		
124. There is a need to keep a contact with friends/ a need for social interaction	**Part.D-4-iii**		
125. He misses the social interaction and this saddens him	**Part.H-28-ii**		
126. He needs to keep a contact with the outside world/ social interaction	**Part.F-2-i**		
127. Feeling like he could not communicate with anybody/ Feeling invisible	**Part.F-10-i**		
128. Rehabilitation at home needs courage from the family and from the patient	**Part.M-35-i**	*Emotional support and encouragement by family*	
129. Could not believe in himself – his wife was always his anchor	**Part.C-40-ii**		
130. Family made her feel that she is not alone	**Part.B-26-ii**		
131. Feeling happy when his children think about him	**Part.C-34-i**		
132. Feeling relief that his wife supports him in his hardest times	**Part.M-34-ii**		
133. In his most difficult period of his life he realised the love from his family	**Part.G-29-i**		
134. Stroke can alter lives but family will always be a part of this new life	**Part.D-18-i**		
135. Thankful for his family	**Part.C-29-i**		
136. His children is his strength	**Part.E-29-i**		
137. It gives you strength when your people believe in you	**Part.M-36-i**		
138. Care at home becomes difficult for family members/ family needs additional support	**Part.A-11-ii**		

139. Carers are strangers/ family takes care of you in a more human way	**Part.M-37-i**	*Emotional support and encouragement by family*	**Theme 2:** **Seeking emotional and practical support through social interaction**
140. Family cannot treat her but only to give her love	**Part.B-26-i**		
141. Family gives hope and power	**Part.B-2-i**		
142. Family involved in his rehabilitation	**Part.G-36-i**		
143. Family is important when someone needs care	**Part.C-21-i**		
144. Family offers a feeling of not being alone	**Part.D-14-iii**		
145. Family offers practical help in the everyday life	**Part.H-20-ii**		
146. Family played a crucial role in the care	**Part.D-14-ii**		
147. Family plays a crucial role in the rehabilitation	**Part.J-2-v**		
148. Family plays a crucial role in the rehabilitation process	**Part.A-18-iii**		
149. Family support increases well-being	**Part.K-15-i**		
150. Family support increases well-being	**Part.N-28-i**		
151. Family's love and support is the best medicine and the best therapy	**Part.G-36-ii**		
152. He could not cope without family's support	**Part.C-30-ii**		
153. He could not make it without his wife/ Thankful for this	**Part.G-26-i**		
154. He felt support from his family, and this had a positive effect to his well-being	**Part.H-15-i**		
155. His wife was the most significant person who helped him to recover	**Part.C-46-iii**		
156. In general, not all the family members can be supportive to patients	**Part.H-20-i**		
157. It is hard for her family to take care of her	**Part.A-4-iii**		
158. Mental and physical support from family is invaluable	**Part.C-30-i**		
159. Motivated to continue his rehabilitation due to the support of his family	**Part.H-16-i**		
160. Nurses were health professionals caring for him, but nothing is like family	**Part.G-24-i**		
161. Overprotection by family leads to pressure	**Part.H-5-i**		
162. Practical and physical help from family	**Part.E-23-i**		
163. Practical assistance received from family	**Part.J-28-ii**		
164. Satisfied and thankful for the support received by the family	**Part.E-33-i**		
165. She takes it for granted that the family helps during the rehabilitation	**Part.A-4-i**		
166. Strong positive feelings for the family support	**Part.A-11-i**		
167. Supportive family	**Part.E-25-i**		
168. The love received from his family gave him courage and confidence	**Part.G-32-i**		
169. Without the help of his family we could not make it/ Family is everything	**Part.F-24-i**		
170. Wife's support enhances his well-being	**Part.F-20-i**		
171. Wife's support positively impacts on his well-being	**Part.F-21-i**		

172. She could never say a bad thing for the staff who took care of her	**Part.L-33-i**	*Adopting the role of "good patient" as a coping mechanism*	**Theme 2:** **Seeking emotional and practical support through social interaction**
173. Family tries to keep a good relationship with healthcare staff	**Part.K-13-i**		
174. Patient had a specific perception regarding the way he should behave towards health professionals/ with respect and empathy	**Part.H-14-ii**		
175. There is a tendency to conceal any complaints from the healthcare staff	**Part.D-2-i**		
176. She may have some complaints but she never felt the need to express them	**Part.B-22-i**		
177. A complaint about a late appointment that she never felt secure to do	**Part.B-37-ii**		
178. Avoid to clearly say about what information she was provided with/ Poor information was given	**Part.B-16-i**		
179. Did not want to bother the nurses all the time/ embarrassed to bother the nurses	**Part.D-2-ii**		
180. He buried his disappointment as he did not feel comfortable to make complaints about the food	**Part.C-56-i**		
181. He did not feel comfortable to make any complaints to the staff	**Part.C-54-i**		
182. He did not have the opportunity to make any complaints/ unfamiliar hospital setting	**Part.C-53-ii**		
183. Healthcare staff are human beings as well who have a heavy workload to deal with	**Part.H-14-i**		
184. Patients shouldn't tire healthcare staff / perception of keeping a decent behavior towards them	**Part.K-10-i**		
185. Perception of always saying good things for the staff who takes care of you	**Part.L-34-i**		
186. She recognises the high doctors' workload and the work-life balance	**Part.D-26-ii**		
187. Thought being quiet in the clinic would be appropriate/ that would be better treated by the healthcare staff	**Part.D-3-ii**		
188. More information about his condition is now meaningless	**Part.C-18-i**	*Identifying structural issues in relation to care provision*	**Theme 3: Identifying contextual processes of rehabilitation**
189. No need for more information regarding his rehabilitation	**Part.N-5-i**		
190. A pleasant and happy nurse can motivate him and make him feel good in this difficult situation	**Part.C-36-i**		
191. Appreciate the doctors who helped him to recover	**Part.C-46-ii**		
192. Feeling trust with the healthcare professionals	**Part.B-25-i**		
193. He was trusting the doctors/ Doctors were nice with him	**Part.C-7-i**		
194. Making fun with staff makes him forgets his pain	**Part.M-15-ii**		
195. Motivated to continue his rehabilitation exercises by the doctor	**Part.C-49-ii**		
196. Not all the relatives had good relationship with the staff	**Part.L-36-i**		
197. No reservations to express his feelings with the healthcare staff	**Part.H-12-i**		
198. Pleasant memories from the nursing staff	**Part.N-1-ii**		
199. Positive and pleasant health staff improves patients' well-being	**Part.I-21-i**		
200. Psychological support from nursing staff was not enough	**Part.A-9-i**		
201. Relationship with doctors is not always great	**Part.N-1-i**		
202. Satisfied with healthcare staff	**Part.A-17-ii**		
203. Satisfied with the care received by the nurses	**Part.G-23-i**		
204. Satisfied with the staff	**Part.A-1-ii**		
205. Satisfied with the staff	**Part.A-2-vi**		
206. She trusts the healthcare professionals	**Part.D-7-i**		
207. The majority of the nursing staff was always very polite and friendly	**Part.N-12-i**		

208. The positive attitude of nurses contributed to his well-being	**Part.C-28-i**	*Identifying structural issues in relation to care provision*	**Theme 3: Identifying contextual processes of rehabilitation**
209. The support from the healthcare staff affects the well-being and the recovery	**Part.D-1-iv**		
210. Unprofessional behaviour by nurse reduces the sense of well-being	**Part.M-44-i**		
211. Happy when he hears from a professional that he has an improvement	**Part.E-18-i**		
212. He needs the reassurance of the experts	**Part.J-18-i**		
213. Participant needs professional advice to feel reassurance/ encouragement	**Part.A-3-ii**		
214. Effective physiotherapy	**Part.H-4-i**		
215. Feeling satisfied with the medical care received	**Part.C-26-i**		
216. Felt satisfied with the overall care received	**Part.B-37-i**		
217. Good quality of care and humanising care	**Part.H-32-ii**		
218. Happy with the rehabilitation programme	**Part.B-35-i**		
219. No trust to the recovery plan	**Part.J-2-iii**		
220. Pleasant feelings for the rehabilitation department	**Part.G-16-i**		
221. Positive experience of in-patient rehabilitation system	**Part.A-17-i**		
222. Situational difficulties lead to limited memories	**Part.F-1-ii**		
223. Some medical practices lead to stressful situations for the patient	**Part.C-8-ii**		
224. Very satisfied with the rehabilitation clinic	**Part.M-17-i**		
225. Family shares the rehabilitation duties with a (in) formal carer	**Part.K-15-ii**		
226. Day was passing very slow during in-patient rehabilitation	**Part.E-1-i**		
227. Feeling good and secure when a doctor was visiting her in the room	**Part.B-20-ii**		
228. Not so good memory/ hospitalization was a difficult time for him	**Part.C-17-i**		
229. Signs of boredom/ loosing hope during hospitalization	**Part.J-52-i**		
230. As the rehabilitation programme was progressing, he was feeling more and more confident about his recovery	**Part.G-7-ii**		
231. Satisfied of the care received	**Part.L-9-i**		
232. Bad news hinder her rehabilitation progress	**Part.A-16-ii**		
233. Causal relationship between the treatment received and patient's feelings	**Part.K-12-i**		
234. Disappointed because of the bad rehabilitation progress	**Part.B-8-i**		
235. He wants/ needs to hear a confirmation of his good condition	**Part.C-44-ii**		
236. His good rehabilitation progress is related to his well-being	**Part.C-49-iii**		
237. Waiting times in the physical therapies lead to patients' fatigue	**Part.E-45-ii**		
238. Pleasant memories from the hospitalization	**Part.C-1-i**		
239. Home rehabilitation is unaffordable	**Part.C-23-i**		
240. Distressed by his wife suffering due to doctor's unprofessional behaviour	**Part.C-54-iv**		
241. Feeling sad/ worried that a doctor made his wife stressed about his situation	**Part.C-53-iii**		
242. In general not all the doctors are good	**Part.D-10-i**		
243. Family was needing help from nursing staff when she was hospitalized	**Part.B-36-ii**		
244. Feeling surprised by the attention that the doctors gave him	**Part.C-26-ii**		

245. A need for integrated healthcare services	**Part.D-5-ii**	*Identifying structural issues in relation to care provision*	**Theme 3: Identifying contextual processes of rehabilitation**
246. Criticizing the healthcare system in Greece	**Part.C-21-ii**		
247. Does not believe that the healthcare system in Greece can improve	**Part.E-42-i**		
248. Expensive care for people with disabilities	**Part.L-122-ii**		
249. Expensive private rehabilitation care	**Part.M-22-i**		
250. Feeling lucky - Not all the doctors give so much attention to patients	**Part.C-25-i**		
251. Feeling lucky his doctors are good and pay attention to him	**Part.C-42-ii**		
252. Feels lucky he went to this rehabilitation department because there are other low quality rehabilitation centres	**Part.H-32-i**		
253. Felt lucky she met good doctors caring about her	**Part.D-10-ii**		
254. Financial difficulties due to disability – impact on well-being	**Part.J-34-i**		
255. Health organisation deficiencies and corruption – lack of transparency	**Part.C-54-ii**		
256. Health organisational difficulties and inequalities	**Part.A-18-i**		
257. Healthcare organisation corruption (pay extra for good care)	**Part.N-38-i**		
258. Healthcare system needs a more qualified and responsible staff	**Part.C-51-ii**		
259. Healthcare system needs full reorganization – difficult to be achieved	**Part.K-26-i**		
260. Healthcare system needs improvement	**Part.C-51-i**		
261. Insufficient communication between hospital departments	**Part.D-5-i**		
262. Issues of corruption in disability assessment creates mistrust to the healthcare system	**Part.J-32-i**		
263. It is difficult for the healthcare in Greece to be ameliorated as the system needs radical changes	**Part.E-43-i**		
264. It is well-known (for him) that the healthcare system in Greece is not great	**Part.F-30-i**		
265. Lack of motivation for the nursing staff	**Part.J-24-i**		
266. Misconceptions about proper professional care	**Part.A-3-i**		
267. Not all the healthcare professionals receive brown envelopes/ patients' preconceptions play into the perpetuation and consolidation of this phenomenon	**Part.H-31-i**		
268. Not all the patients have good experience with their rehabilitation	**Part.K-27-i**		
269. Not enough help from the nursing staff/ short staffed	**Part.E-34-i**		
270. Organisational corruption	**Part.M-51-i**		
271. Organisational deficiencies and different experiences across departments	**Part.A-2-i**		
272. Organisational difficulties negatively impact on well-being	**Part.J-41-i**		
273. Organisational difficulties were faced in the hospitalization	**Part.E-44-i**		
274. Organisational factors need improvement	**Part.I-38-i**		
275. Organizational deficiencies/ Waiting times	**Part.L-86-i**		
276. Private sector offers better care experiences than the public sector	**Part.M-24-i**		
277. Qualified healthcare staff which truly cares for patients	**Part.D-24-i**		
278. Rehabilitation after hospitalization costs a lot	**Part.K-9-i**		
279. Rehabilitation becomes unaffordable for pensioners who get low income	**Part.A-18-ii**		
280. Rehabilitation is unaffordable for patients and families	**Part.K-26-ii**		

281. Short number of staff	**Part.B-35-ii**	*Identifying structural issues in relation to care provision*	**Theme 3: Identifying contextual processes of rehabilitation**
282. Short number of staff/ feeling guilty that his wife was feeling tired	**Part.C-19-i**		
283. Short number of staff/ no nursing staff responsible for the hygiene needs	**Part.B-36-i**		
284. Short staffed	**Part.E-45-i**		
285. Short staffed department	**Part.G-27-i**		
286. Short-staffed/ Family's fatigue	**Part.L-99-i**		
287. State's inefficiency to provide better healthcare services	**Part.D-26-iii**		
288. Structural and organisational deficiencies	**Part.J-47-i**		
289. The healthcare system needs to be audited more effectively/ there must be a check on corruption	**Part.H-30-i**		
290. There are also trustful doctors – exception	**Part.C-54-iii**		
291. There are doctors who ignore patients/low medical attention	**Part.C-42-i**		
292. Unaffordable rehabilitation services in the private sector	**Part.K-28-i**		
293. More rehabilitation needed but COVID-19 interrupted this	**Part.L-109-i**		
294. If someone does not have family to take care of him, he has to pay a carer	**Part.C-21-ii**		
295. If there is no family a patient can suffer a lot	**Part.B-38-i**		
296. The family will treat you with more respect than the healthcare staff	**Part.C-38-i**		
297. The main assistance provided by family (not by the staff)	**Part.L-11-i**		
298. Without his wife in the hospital situation would be much more difficult	**Part.E-34-ii**		
299. Staff always willing to help but wife was always caring for his hygiene	**Part.N-12-ii**		
300. Healthcare staff's reactions should be more attentive in front of patient	**Part.J-51-i**		
301. Nursing staff did not meet his expectations	**Part.C-38-ii**		
302. The citizens are also responsible for the good quality/ operation of the healthcare system	**Part.G-45-i**		
303. Feeling annoyed that the nurses could not help his wife with his hygiene needs	**Part.C-20-i**		
304. Situational barriers lead to minimum communication	**Part.F-11-i**		
305. Feeling familiar with the healthcare staff	**Part.M-11-ii**	*Impact of clinical environment on rehabilitation process*	
306. Healthcare staff create a familiar hospital environment for the patients	**Part.D-11-i**		
307. Medical staff makes him feel very familiar and pleasant	**Part.M-15-i**		
308. Friendly and familiar hospital environment	**Part.D-14-iv**		
309. Noisy hospital environment	**Part.D-3-iii**		
310. Noisy hospital environment	**Part.L-35-i**		
311. Not attractive hospital/ rehabilitation environment	**Part.J-14-i**		
312. Not very pleased with the rehabilitation setting organization	**Part.C-53-i**		
313. Pleased with the rehabilitation clinic/ Clinic offered a family environment	**Part.D-25-i**		
314. Rehabilitation department felt very organised but again it was an unfamiliar environment/ home is always home	**Part.G-23-ii**		
315. Situational and environmental limitations / Unpleasant factors	**Part.A-1-i**		
316. Funny and pleasant memories from hospitalization	**Part.M-11-i**		

317. Hospital environment made him feel less human/ inactive	**Part.J-14-ii**	*Impact of clinical environment on rehabilitation process*	**Theme 3: Identifying contextual processes of rehabilitation**
318. Hospital offers safety in contrast to home	**Part.M-52-ii**		
319. Hospital setting feels unfamiliar	**Part.A-3-iv**		
320. Hospital was felt as a safe place	**Part.D-1-ii**		
321. It took time to get used the hospital setting	**Part.G-2-ii**		
322. The hospital is a place that he would never wish to go back	**Part.C-31-i**		
323. Time passes hard in the hospital	**Part.C-2-i**		
324. Time seems to move slowly at hospital	**Part.I-4-i**		
325. Time was passing difficult in the hospital/ not many things to do	**Part.G-2-i**		
326. When he was in-patient, he was missing the life out of hospital	**Part.C-29-iii**		
327. Unfamiliar hospital setting	**Part.F-31-iii**		
328. Healthcare staff provided confidence and love	**Part.D-1-iii**		
329. Rehabilitation department and its staff felt like family	**Part.G-47-ii**		
330. Painful memories from hospitalizing	**Part.K-1-i**		
331. Feeling deserted - Not involved in his rehabilitation programme	**Part.H-9-i**	*Passivity and sense of dependency*	**Theme 4: The felt sense of self in the aftermath of ABI**
332. Inadequate information about recovery process and rehabilitation	**Part.A-5-i**		
333. Poor information given to patient regarding his health condition	**Part.E-15-i**		
334. Poor information provided by the healthcare staff in the acute phase	**Part.B-14-i**		
335. She was not involved in the planning and options of her recovery programme	**Part.D-5-iii**		
336. Passive recipient of care	**Part.I-2-i**		
337. Passive recipient of care/ All that matters is the recovery	**Part.J-22-i**		
338. Inadequate communication between healthcare staff and patient about the discharge process	**Part.B-18-i**		
339. Basic daily things that she cannot do for herself/ feeling bad to depend for such things to others	**Part.B-11-i**		
340. Depending on other people leads to sadness and feelings of being incapable	**Part.A-13-ii**		
341. Embarrassed about her health situation/ depending on her husband and what the others will think of that	**Part.B-31-ii**		
342. Embarrassed to depend to someone else for her hygiene needs	**Part.D-2-iii**		
343. Feeling disappointed that she is not independent	**Part.L-65-i**		
344. Feeling upset he cannot do things by himself	**Part.M-12-i**		
345. Feeling vulnerable because she depends on a family member for her hygiene needs	**Part.B-4-i**		
346. Feeling vulnerable/ Depending on family for the basic needs	**Part.L-46-i**		
347. Her new health situation affected her independence	**Part.B-13-i**		
348. Not an autonomous person the first days at home	**Part.N-22-i**		
349. Realising he depends on others	**Part.M-8-i**		
350. Unable to take care of himself makes him sad and weak	**Part.E-9-ii**		
351. Depending on his daughter makes him feel embarrassed	**Part.M-32-i**		
352. He could not take care of himself/ Depending on his wife	**Part.F-1-i**		
353. The fact that she needs someone to help her makes her upset and sad	**Part.D-21-i**		

354. He needs all the family members by his side	**Part.H-26-i**	*Passivity and sense of dependency*	**Theme 4: The felt sense of self in the aftermath of ABI**
355. His wife assists him in his social interaction	**Part.F-3-i**		
356. Incapable of self-care	**Part.K-4-ii**		
357. He would like more information to be given to him in his admission	**Part.F-9-i**	*Self-reliance and involvement as a means for independence*	
358. He would like to receive some information for his rehabilitation programme	**Part.M-13-i**		
359. Involvement in in-patient recovery plan	**Part.A-8-i**		
360. Need more comprehensive information from healthcare staff	**Part.A-6-i**		
361. Received full update/ information regarding his health condition	**Part.G-10-i**		
362. She was informed about the type of rehabilitation she would follow	**Part.D-6-i**		
363. Willing to know more about the continuation of her rehabilitation	**Part.D-26-i**		
364. He has been informed about the home rehabilitation	**Part.G-14-i**		
365. Positive experience for information received	**Part.A-7-i**		
366. A desire to be independent	**Part.E-12-i**		
367. Felt independent and more human when he realised that he does not need help to walk	**Part.C-8-i**		
368. Independence led to satisfaction and relief	**Part.A-2-v**		
369. Need to feel independent in his daily life	**Part.C-9-ii**		
370. She tries to be independent and to take care of herself	**Part.D-3-i**		
371. There is a need to feel independent again	**Part.C-32-ii**		
372. There is a need to feel independent/ to walk without any assistance from his wife	**Part.C-24-i**		
373. Trying to find ways to feel more independent	**Part.B-4-ii**		
374. Feeling autonomous person	**Part.D-17-i**		
375. Aware of the severity of his health condition	**Part.G-21-i**	*Making sense of the new identity*	
376. Being aware of his serious situation	**Part.C-12-i**		
377. Come to terms with the new reality/ acceptance of the new reality	**Part.A-13-iii**		
378. Difficult new reality	**Part.M-1-i**		
379. Feeling disappointed he has lost his abilities	**Part.N-36-i**		
380. Feeling embarrassed that she can no longer do the household	**Part.B-12-ii**		
381. Feeling incapable	**Part.L-4-i**		
382. Feeling sad for the new reality	**Part.N-32-i**		
383. Feeling useless/ Unable to do things she used to do in the past	**Part.L-18-i**		
384. Feels that going back to his hometown things will be better as before stroke	**Part.E-12-ii**		
385. Hard to adapt to the new situation	**Part.I-25-i**		
386. He suffers with his health condition and he wants to his old life back	**Part.E-30-i**		
387. Impatient to return to his old habits	**Part.C-41-ii**		
388. It is so difficult to adapt to a new reality	**Part.H-1-i**		
389. Need to keep doing the things he used to do before stroke to feel more alive	**Part.C-9-i**		
390. Patient avoids moments of tension at home	**Part.D-14-i**		

391. Realisation of new life habits/ feeling disappointed	**Part.M-44-ii**	*Making sense of the new identity*	**Theme 4: The felt sense of self in the aftermath of ABI**
392. Realising the new reality – signs of sorrow	**Part.K-4-i**		
393. Realization of his current feelings (new reality)	**Part.C-43-i**		
394. Realization of the new reality/ new situation	**Part.B-10-i**		
395. Realizing he has not the same capabilities/abilities in his daily life as before the incident	**Part.H-6-i**		
396. Realizing his new life makes him sad/ wants his old life (work) back	**Part.F-7-i**		
397. Staying inside drowns him/ prefers/likes to stay in the garden	**Part.F-4-i**		
398. Unable to live as before – this affects his well-being	**Part.E-36-i**		
399. He misses going to work/ He realises the new reality	**Part.E-7-i**		
400. New reality has made her more susceptible to bad news	**Part.A-18-iv**		
401. New reality/ feeling a different person than before	**Part.B-9-i**		
402. Realizing that she is not the same person as before made her feel sad	**Part.L-118-i**		
403. A desire to get his life back but he realises this is not possible	**Part.F-29-ii**		
404. Lost his job due to the new reality	**Part.G-8-i**		
405. He needs to feel useful for his family/ unable to help them	**Part.E-32-i**		
406. He wants to look strong for his daughter but there are signs of sorrow when she leaves	**Part.H-26-ii**		
407. Unable to offer his assistance to his wife/ feeling useless	**Part.F-15-i**		
408. Being sensitive when he is speaking for his children	**Part.E-24-i**		
409. Cannot offer what she would like to her beloved ones anymore	**Part.B-7-ii**		
410. He feels incapable to financially help his children and this makes him sad	**Part.E-9-i**		
411. Cannot deal with his new life and this affects well-being	**Part.M-48-i**		
412. Not able to handle this situation on his own	**Part.H-8-i**		
413. Not the same person as before but she tries to do many things on her own	**Part.D-19-ii**		
414. Relieved that he can now be dressed by himself	**Part.C-37-i**		
415. Self-reliance gave him more confidence	**Part.G-7-iii**		
416. A need to feel human/ normal again	**Part.J-2-ii**		
417. A need to feel the same person/ human as before the incident	**Part.J-54-i**		
418. Acceptance of his new personality/ accepts he is weaker than before	**Part.H-25-i**		
419. Although he seems emotionally strong there are some emotionally charged times	**Part.J-2-iv**		
420. Despite the difficulties he was confident	**Part.G-1-ii**		
421. Different person with no capacities to do any work	**Part.K-1-i**		
422. Disease has made her more sensitive	**Part.A-16-i**		
423. Emotions change and become more intense after stroke	**Part.A-4-iv**		
424. Feeling afraid to get back to work	**Part.C-45-ii**		
425. Feeling different person due to memories issues	**Part.L-68-i**		
426. Feeling lucky he is still alive after his incident	**Part.C-46-i**		
427. Feeling more sensitive/ He cannot manage the new reality	**Part.E-40-i**		

428. Feeling tired of his new life	**Part.C-43-ii**	*Making sense of the new identity*	**Theme 4: The felt sense of self in the aftermath of ABI**
429. Feeling weak to work again	**Part.C-45-i**		
430. Feeling weaker due to his health condition	**Part.E-39-i**		
431. Getting emotional more easily	**Part.I-34-i**		
432. Getting more emotional because of the disease	**Part.K-22-i**		
433. Getting very emotional when remembering the days at hospital	**Part.C-29-ii**		
434. Going through a hard time	**Part.I-10-i**		
435. He has accepted his new health condition and lives with this	**Part.F-16-i**		
436. In need of hope	**Part.A-2-ii**		
437. More emotional after the incident	**Part.H-23-ii**		
438. Personality has been altered	**Part.J-17-ii**		
439. Personality has been changed/ calmness	**Part.J-2-i**		
440. Positive thinking despite the difficult situation	**Part.D-19-i**		
441. Recognition of new feelings emerged after the incident	**Part.J-54-ii**		
442. Scared – participant does not believe in herself	**Part.A-2-iii**		
443. She enjoys the little things	**Part.D-20-i**		
444. Signs of sorrow	**Part.I-33-ii**		
445. Still hope for getting better	**Part.C-48-ii**		
446. Stroke altered her life	**Part.D-1-i**		
447. The disease has totally changed her life	**Part.L-82-i**		
448. Sad feelings because of the disease	**Part.A-9-ii**		
449. A new perception about little things that give hope and creates pleasant feelings	**Part.B-5-i**		
450. He has perceived his poor well-being	**Part.F-26-i**		
451. He thinks that his well-being has not been affected at all	**Part.H-23-i**		
452. His health condition affected his well-being	**Part.G-41-i**		
453. Thinking about happy memories makes him fragile	**Part.E-12-iii**		
454. Well-being is related to pleasant feelings	**Part.A-12-i**		
455. A desire to return to his old work	**Part.C-11-i**		
456. Trying to find ways to feel more human like before stroke	**Part.B-6-i**		
457. Finding ways to escape from the new reality (through his work)/ this improved his well-being	**Part.G-3-i**		
458. Finding ways to overcome the sadness (such as a walk to the garden reminds her the sense of being alive)	**Part.B-38-ii**		
459. He tries to do things that satisfy him	**Part.H-23-iii**		
460. Return to work made her feel more human/ to feel as she used to be before the stroke	**Part.D-4-ii**		
461. Little things in life make her feel the joy	**Part.B-31-i**		
462. He tries to convince himself that he will return back to his old habits	**Part.E-41-i**		
463. Need to feel useful again through his work	**Part.C-49-i**		
464. Aware of the severity of his health condition but still keeping a positive attitude	**Part.G-21-i**		